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University of Kent
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The I in fibromyalgia:
The construction of academic identity under the influence of fibromyalgia

by Nicole Brown
in partial fulfilment for the degree of Doctor of Philosophy
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I certify that this thesis is my own work based on my own research.
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Nicole Brown

Abstract

Fibromyalgia is a condition that is characterised by chronic, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, often described as "brain fog" or "fibro fog", increased sensitivity and psychological disorders. As there are currently no unique identifiers or biomarkers to diagnose fibromyalgia and symptoms are very changeable, the condition is contested amongst the general public but also amongst medical professionals. Despite increasing interest in socio-cultural factors interacting with the sociomatic qualities of fibromyalgia there is as of yet no exploration of fibromyalgia within the context of the contemporary, neoliberal higher education sector. This research investigates the interrelationship of fibromyalgia symptoms, the precarious working conditions in academia and academic identity. At the same time, the study examines the impact of metaphors, creative and arts-based approaches on understanding individuals' experiences.

The research was designed as an interpretivist study that emphasised the bodily, sensory and embodied. To this end, identity boxes were introduced as a new field instrument to gather data in two out of the study's four phases. Across the four phases of the study 16 non-academic participants and 28 academic participants were recruited. Data collection was seen as a process of interactions between researcher and participants. Consequently, during data collection participants were encouraged to deploy their preferred methods of reflection and communication in addition to more traditional interviews. As a result, data sets are varied and very personal, which allowed for flexibility also where illness fluctuations were concerned. The difficulty with researching fibromyalgia was the changeability of the illness and trying to capture all variations holistically. The focus on developing appropriate research methods was therefore key to unlocking the doctoral research. The use of metaphors and materials alongside the many forms of expressions provided insight into the fibromyalgia experience in unprecedented ways.

Findings show that for the non-academic participants, fibromyalgia represents the loss of a previous self, of employment and in some instances of relationships, whilst also representing gains, as individuals felt more tolerant, empathetic, patient and compassionate. Fibromyalgia in this sense is equated with personal growth. For the academic participants, however, there was no silver lining to be found in and with fibromyalgia. Consequently, academics' narratives were narratives of resistance against the condition and the associated stigmatisation and marginalisation. These narratives were also evident in how academic individuals engaged in active bodywork in order to cope with fibromyalgia symptoms but also to consciously control their public academic identity. Against the backdrop of the precarious working conditions and highly pressurised environment in academia fibromyalgia emerged in its somatic quality as a physical manifestation of tensions academics experience. At the same time, academics exhibited perfectionist tendencies, which made them more prone to developing fibromyalgia symptoms. And yet, for academics the academic lifestyle and work in academia were so internalised and ingrained in their personalities, that they did not see any alternatives to being academics.

Drawing on the data presented, this thesis argues that academics in the neoliberal university feel trapped between their personal values and norms, their own character traits and the need to comply with external forces such as rules and regulations, practices and policies forever demanding higher levels of efficiency, excellence and productivity. The problem with contemporary academia in this context is that it appears to offer flexibility and autonomy, but in reality, works with and through pressurising individuals into compliance in return for the prospect of potential job security, for example. This setting then does not allow academics to appear weak or ill, so that individuals feel they cannot be open and honest about their personal health. On a personal level academics struggle with the fibromyalgia diagnosis and its meaning as a stigmatising condition and therefore academics actively employ mechanisms and strategies in order to resist marginalisation processes and discourses. The management of fibromyalgia and its bodily symptoms is therefore a private and strongly controlled affair that invariably but involuntarily spills over into the academic's public life.

To the chronically ill in academia.

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When I started writing up my thesis, this was the section I dreaded most to write. It goes without saying that a doctoral thesis does not develop in a vacuum, but is shaped by many conversations and encounters. I have been lucky to have been part of an amazing postgraduate research community at the University of Kent, where acquaintances, peers, colleagues, and supervisors continuously inspired me to push myself that little further.

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Table of Contents

List of Figures

1. Introduction

Imagine.

Imagine you have the flu,
but on top of that you get sunburned,
you fall down a flight of stairs,
you haven't slept for thirty-six hours,
your brain feels like it's packed in cotton,
you forget simple sequences,
like putting toothpaste on the toothbrush before you
brush your teeth,
but your work requires you to be coherent, functional,
brainy

Now imagine
that nobody sees any of that.

For those diagnosed with fibromyalgia, this is the reality of life. Fibromyalgia is not a disease or an illness; it is a syndrome, a collection of symptoms that can only be diagnosed by excluding other conditions. Fibromyalgia is characterised by chronic, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, often described as "brain fog" or "fibro fog", increased sensitivity and psychological disorders (White and Harth, 2001) and it is associated with a wide range of somatic symptoms (Wolfe et al., 2010). The range of symptoms on its own makes the condition difficult to grasp. However, typically, fibromyalgia symptoms wax and wane, change and move. These shifts of kinds of symptoms, their distribution and their severity happen over the space of longer periods such as months and weeks, but often occur within days or even within hours. A person with fibromyalgia may get up early in the morning struggling to move for the pain, but then several hours later may be well enough to engage in exercise programmes, work routines or other everyday activities, only for the body to then crash under the strain to the point where the person will experience debilitating fatigue and pain; sometimes for several days before getting better again. Therein lies the main problem for individuals diagnosed with fibromyalgia. The lack of a definite process for diagnosis and the variability of the condition make it a doubtful and contested condition within the medical professions, too (Ehrlich, 2003; Wolfe, 2009; Mengshoel et al., 2018; Häuser and Fitzcharles, 2018). However, the phenomenon fibromyalgia is more complex and problematic still.

For the remainder of this chapter, I provide analytical threads that introduce my thesis and explain the complexity in and around fibromyalgia. In the first section "The problem of fibromyalgia" I identify the historical and aetiological roots of fibromyalgia, whilst highlighting critiques of fibromyalgia as a diagnostic entity that sits on the cusp of the physiological, psychological and somatic. The great variety and range of symptoms and severity coupled with a predominantly (bio)medical view has led to fibromyalgia being widely contested and debated. Medical disciplines dealing with fibromyalgia include rheumatology, virology, immunology alongside psychologists with each disciplinary perspective lending a particular focus to fibromyalgia research. Consequently, fibromyalgia in its entire illness experience is secondary to considerations of individual aspects of and within fibromyalgia. In "Fibromyalgia and higher education" I outline how I drew on anecdotal evidence and personal experiences to follow my "hunch" that fibromyalgia in higher education would be a topic worth pursuing further. I explain how an initial review of literature confirmed that conditions related to fibromyalgia are more common amongst the medical and educational professions, and that individuals with personality traits like perfectionism or over-activity which are often associated with academics and academic lifestyle are more likely to develop fibromyalgia. I show how this initial hunch developed further into a research topic and research questions, and how my background as an educationalist has shaped the development of this sociological exploration of the fibromyalgia illness experience. "The line of argument" then emphasises the four main areas of interest of the thesis: (a) aetiology and meaning of fibromyalgia, (b) issues of methodology, (c) significance of the higher education context and (d) experience of living with fibromyalgia. The concern of this section and the thesis as a whole relates to the actual experience of and with fibromyalgia within higher education. I show that academics are aware that a diagnosis of a contested condition like fibromyalgia triggers processes of stigmatisation and marginalisation and that as a consequence, they consciously employ resistance strategies whilst also engaging in active bodywork in order to manage the bodily symptoms as well as their personal and public identity and image. I argue that the context of the contemporary, neoliberal academy with its high levels of precarity compounds the academics' personal resistance discourses but also has a negative impact on the condition. I conclude this section with an outline of how I further methodological debates with my thesis in that I tend to the embodied and sensory.

This leads into the section "The value of this thesis", where I provide a summary of my original contribution to knowledge in the form of (1) a new field of investigation, (2) the development of a new field instrument, (3) the new application of existing frameworks, and (4) the reconceptualization of existing frameworks. This thesis consistently draws on and refers to my publications in peer-reviewed journals and edited collections, which demonstrates and evidences the significance of the work on hand. In the final section in this introduction "The structure of this thesis" I offer a summary of each chapter, which links more openly the thesis argument with the research questions and the chapter contents.

The problem of fibromyalgia

(Bio)medical research into fibromyalgia seeks to understand the condition in its aetiology in order to develop effective treatment options. However, the story of fibromyalgia is not a simple one. Mentions of symptoms reflecting today's descriptions of fibromyalgia are said to date back centuries (Wallace and Hallegua, 2001; White and Harth, 2001; FitzGibbons, 2007), although the terminology used to categorise the symptoms varied greatly. In the 18th century, for example, the term febricula was introduced to describe a fever condition with additional symptoms of pain and cognitive dysfunctions (Manningham, n.d.). In the 19th century the term fibrositis was coined as the symptoms were thought to stem from the inflammation of muscle fibres (Gowers, 1904). With better medical technology it was possible to prove that patients did not have inflamed muscle fibres (Stockman, 1904). The physical cause of an inflammation underlying the condition was formally refuted and the term fibrositis disappeared again from the medical textbooks. However, the condition itself continued to be observed and recorded in conditions such as neurasthenia (Beard, 1878; Ware and Kleinman, 1992), chronic fatigue syndrome and myalgic encephalomyelitis (Wessely, 1994).

Over the decades, there have been many attempts to understand the physiological causes of the symptoms of pain, cognitive dysfunctions, psychological disorders and sleep disturbances. The problem of fibromyalgia is that despite all the advances in virology, immunology and rheumatology it is still evasive. Increased understanding of the human psyche has led to some recognition that a link between physical symptoms and psychological disorders such as depression and stress may play a role in the development of fibromyalgia. Nowadays there are largely two opposing camps amongst the medical professionals where fibromyalgia is concerned: those who believe that there is an organic and physiological cause to the condition and who therefore continue to search for underlying triggers or biomarkers (e.g. Goldenberg, 1999; Wolfe et al., 2010) and those who see fibromyalgia as a psychogenic, psychosomatic or behavioural condition (Yunus, 1994, 2008, 2009). This categorisation between fibromyalgia as an organic, physiological, physical illness versus the condition as psychological, psychosomatic results in further issues within the medical profession, as individual medical disciplines are ill-equipped to deal with and treat fibromyalgia (Barker, 2005). The proponents of the physiological explanation within rheumatology find themselves challenged due to the relevance of psychosomatics in relation to the aggravation of symptoms. Medical professionals supporting the psychogenic, psychosomatic and behavioural model face the challenge that all mental health disorders bring: stigmatisation, fear of stigmatisation and resulting resistance strategies. For individuals with fibromyalgia this dispute leads to uncertainty about the diagnosis, whereby a purely (bio)medical approach masks the fact that illness is not merely a physiological condition but a socially constructed event.

Historically, fibromyalgia and neurasthenia were socially constructed as conditions of women (Manningham, n.d.; Beard, 1878; Abbey and Garfinkel, 1991; Luthra and Wessely, 2004), of people with a more highly-developed and therefore more sensitive nervous system (Manningham, n.d.; Beard, 1878; Berger, 1973; Sicherman, 1977, Wessely, 1990) and of people whose lifestyles are associated with intense thoughts, overwork and grief (Manningham, n.d.; Sicherman, 1977; Abbey and Garfinkel, 1991). Fibromyalgia prevalence studies confirm a male to female ratio of 1:9 (Grodman et al., 2011), with the large majority of women diagnosed with fibromyalgia aged from 30 to 40 years and older. Research also shows that students, teachers, medical staff and doctors are overrepresented amongst the patient groups for conditions related to fibromyalgia such as chronic fatigue syndrome or myalgic encephalomyelitis (Wessely, 1990, 1994). Studies like these corroborate the historical development of the fibromyalgia categorisation as a female condition of those with higher levels of education and of higher socio-economic classes.

However, this is only part of the story. There is ample evidence for women to engage in more health-seeking behaviours and to pursue diagnosis more fervently than men, who are known to withdraw into addiction, alcoholism and develop anger management issues instead of seeking help with doctors (Wolfe et al., 2013). In addition, some medical research suggests that there may be a link between fibromyalgia and fibromyalgia-like symptoms and hormone levels in the human body, which would indeed result in more women being diagnosed with the condition (Jenner, 2011). Nonetheless, the role of hormones in fibromyalgia and in diseases in general remains under-explored. As critics highlight, medical research considers sex/gender as an "irritant variable" (Barker, 2005:62), and so continually fails to account for the specificities of the female body. Yet, differences in gender cannot solely be explained biologically (Lockshin, 2006) and therefore require a more social constructionist view that would consider individuals' social environment (Bird and Rieker, 1999) and the impact of individuals' social environment on gender and health behaviours as well as coping mechanisms (Rieker et al., 2010). The genderisation of the condition and the entire medical field combined with the lack of specific research considering the female body by comparison to the male body is one of the major criticisms of contemporary fibromyalgia research. On the one hand, (bio)medical perspectives emphasise that women show more increased somatic tendencies than men; on the other hand, the entire process to identify symptomology and develop classifications for the fibromyalgia diagnosis started with the determination of tender points, which are more pronounced in women due to their heightened somatic tendencies. In this sense, the fibromyalgia diagnosis represents an attempt to fit women's distress and somaticism into a neat (bio)medical order instead of a distinct, uncontested and uncontextualized diagnostic unit (Barker, 2005).

Similarly, debates around the prevalence relationship between socio-economic class and fibromyalgia, need to be seen critically. Just as women are more likely to engage in health-seeking behaviours, particular population groups, such as students, teachers, medical staff and doctors are more likely to have access to medical support and therefore to be diagnosed with fibromyalgia (Wessely, 1990, 1994). However, the data is still distorted. Those people from more stable, higher socio-economic backgrounds and who are educated to higher levels have more financial resources available to obtain diagnosis, but are also more likely to have better coping mechanisms, again due to their financial resources, so that they may not necessarily be recorded as fibromyalgia patients (Hagen et al., 2005). Overall, the prevalence among the general public is reported to range somewhere between 0.66% and 10.5% (Assumpção et al., 2009) as per the diagnostic criteria for the condition from 1990 (Wolfe et al., 1990). Under the driving force of Wolfe et al. (2010) the American College of Rheumatology revised these initial criteria in order to better account for the condition's heterogeneity (Häuser et al., 2015), which has led to the rise of fibromyalgia diagnoses by up to 25% (Salaffi and Sarzi-Puttini, 2012).

The issue of prevalence is complicated further if seen in relation to the insecurity of the medical profession (Barker, 2005) where fibromyalgia is concerned. The fibromyalgia diagnosis typically involves general practitioners, rheumatologists, gynaecologists, immunologists and virologists as well as psychologists, with each professional coming at the problem of fibromyalgia from a particular angle focussing on particular aspects of the condition in the process. Overall prevalence figures must therefore be seen as inconclusive or skewed, as some professionals emphasise the psychological disorders whilst others focus on pain aspects of the condition (e.g. Picavet and Schouten, 2003).

This disciplinary focus is also reflected in the way fibromyalgia research is carried out. Within medical research scholars try to find the physiological causes and so focus on discovering unique identifiers (e.g. Giacomelli et al., 2013; Menzies et al., 2013; Feng et al., 2013) or on treatment options that may improve the experience of patients with fibromyalgia (e.g. Jones et al., 2012; Lami et al., 2013; Cording et al., 2015). These kinds of studies focus on particular aspects of fibromyalgia, such as the pain experience (e.g. Giacomelli et al., 2013; Rossi et al., 2015; Vincent et al., 2016) or the relationship between dietary choices and the bowel symptoms associated with fibromyalgia (e.g. Tovoli et al., 2012). As such, research considers the relationship between fibromyalgia and quality of life (Pagano et al., 2004; Arnold et al., 2008; Wuytack and Miller, 2011; Fletcher et al., 2015), status of health, employment and disability (Henriksson and Liedberg, 2000; Henriksson et al., 2005; Verbunt et al., 2008), emotional experiences of those diagnosed with fibromyalgia (Kashikar-Zuck et al., 2002; Cunningham and Jillings, 2006), experiences of relationships (Arnold et al., 2008; Wuytack and Miller, 2011; Armentor, 2017) and the impact of exercise (Sanz-Baños et al., 2016; Russell et al., 2018). Most of these and similar research projects hone in on particular experiences of fibromyalgia symptoms and rely predominantly on interviews, surveys, Likert scales or pain measures like the McGill pain questionnaire (Melzack, 1975, 1987). Focussing on pain experiences through the pain questionnaires and Likert scales for example allows researchers to extrapolate ways forward for medical interventions programmes and potential treatments. At the same time, the above-mentioned fibromyalgia researches overlook sociocultural dimensions of and related to fibromyalgia. These approaches therefore miss out on developing an adequately elaborated, holistic understanding of fibromyalgia as an illness experience in all its facets and including the sensory and bodily, in particular in view of the changeability of symptoms and symptom severity that is so typical. McMahon et al. (2012a) have highlighted this lack of holistic understanding of fibromyalgia and the general disregard of the bodily and sensory within fibromyalgia research and in answer to this particular research issue they recommend the introduction of narrative analysis within fibromyalgia. The narrative approach does provide a holistic view in relation to the "temporal and social understanding of FM" (McMahon et al., 2012a:1128), which in turn may improve healthcare provision as the focus is no longer on the here and now, but on the overall illness experience.

Illness experiences, illness narratives and the impact of illness on identities have been the focus of sociological research for decades (e.g. Good, 1992, 1994; Kleinman, 1986, 1988; Bury, 1982; Charmaz, 1983, 1990, 1994, 1995, 1997; Frank, 2013) and have provided the foundation for our understanding of the impact of chronic illness on individuals. However, within the context of fibromyalgia the few studies employing elements of narrative approaches and analyses rely on interviews and language. It has long been acknowledged within pain research that language and words are often inadequate in describing sensations (Scarry, 1985; Sontag, 2003; Eccleston, 2016), especially, if they include embodied and bodily experiences. Also, human understanding and experiences are not linguistic, but meta-linguistic, embodied (Finlay, 2015), which results in human communication being metaphorical (Lakoff and Johnson, 2003) to account for this embodiedness in our experience. It is therefore counterproductive to employ research approaches that do not account for the sensory and embodied, but solely rely on verbalisation of emotions and experiences, as for example in interviews. Researchers exploring illness experiences comment on the complexity of asking research participants to communicate their experiences and put thoughts and emotions around illness into words (e.g. Charmaz, 1997; McMahon et al., 2012a; Bates, 2019) and specifically demand for more interest in and attention to embodiment (Ellingson, 2017; Pink, 2013, 2015).

In sum, the problem of fibromyalgia has many facets: There are debates and disputes around the diagnostic process and categorisation of symptoms, which makes fibromyalgia a condition that is at best difficult to understand and at worst contested for individuals, the wider public and within the medical profession. Related to this first issue, prevalence of fibromyalgia is difficult to ascertain due to the differing diagnostic criteria, but also due to differences in health-seeking behaviours and access to health care based on financial resources. Additionally, much fibromyalgia research is bound up with disciplinary conventions and research aims that result in particular types of knowledge and understanding. Where there is research that seeks to break out of these conventions, for example where illness narratives are concerned, the sensory and the embodied experiences linked to the variability of fibromyalgia symptoms are not accounted for. But, why focus on higher education and the relationship between fibromyalgia and academic identity?

Fibromyalgia and higher education

Existing fibromyalgia research has focused on socio-economic factors (Queiroz, 2013) and levels of education (Hagen et al., 2005) or country-specific circumstances (Picavet and Schouten, 2003), for example, but has not taken into account higher education. When I started my doctoral journey, I had already been a lecturer in academia for seven years and had formally been diagnosed with fibromyalgia for more than a decade. From my personal experience of working in academia and being involved in fibromyalgia support groups, I had gained anecdotal evidence that fibromyalgia in academia was more prevalent than may have been acknowledged formally. Additionally, I had come across studies highlighting that students, teachers, medical staff and doctors were overrepresented amongst the patient groups for chronic fatigue syndrome or myalgic encephalomyelitis (Wessely, 1990, 1994).

My initial literature review in relation to fibromyalgia uncovered that irrespective of individuals' socio-economic backgrounds there is a link between fibromyalgia and personality traits. Although there is no typical fibromyalgia personality as such (Malin and Littlejohn, 2012), fibromyalgia is more likely amongst people who are action-prone and tend to over-exert themselves (Van Houdenhove et al., 2001), amongst people who show high levels of neuroticism-anxiety and low sociability (Albiol et al., 2014), amongst people who display high levels of harm avoidance, persistence and self-transcendence combined with low levels of self-directedness (Lundberg et al., 2009; Glazer et al., 2010), amongst people with high levels of neuroticism and psychoticism (Montoro and del Paso, 2015), and amongst type D personalities, who experience negative emotions but do not express those to avoid disapproval or rejection (van Middendorp et al., 2016). Ultimately, research publications confirmed my observations: that fibromyalgia is common enough in academia to warrant closer exploration.

Research into chronic illness demonstrates that illness is conceived as disruption to existing identities (Bury, 1982) and that individuals need to make sense of their new beings to maintain identity continuity (Wolfenden and Grace, 2012; Llewellyn et al., 2014) or to reach a state of normalisation (Sanderson et al., 2011, 2015). One symptom of fibromyalgia is the cognitive dysfunction that sets in as brain fog unannounced at any time. What was particularly interesting to me therefore was how individuals reconcile their cognitive academic work with the risks of the fibromyalgia body intruding on their work and potentially impacting their identity as academics. Within higher education research academic identity is seen as provisional and multidimensional (Henkel, 2002), and can therefore not be determined simply. Indeed, there is a close link and very fine line between academic work, the roles one assumes in academia and academic identity (Clegg, 2008; Billott, 2010; see chapter 5). My initial "hunch" (Trafford and Leshem, 2008:41) was that having fibromyalgia impacts and threatens the construction of academic identity. I understood that the cognitive dysfunctions associated with fibromyalgia would have a bearing on academics' perception of self especially as and when memory and word retrieval or sequencing issues set in during public performances of conference presentations or lectures. I further felt that with no clear causes or triggers for either the particular symptoms or indeed the condition in its entirety, academics would find it difficult to rationalise their experiences and perceive fibromyalgia as a limitation to an otherwise productive "body-self" (Ellingson, 2017:13). In order to explore this hunch, I formulated the following two primary research questions:

> What is the relationship between fibromyalgia and academic identity?
> Can creative methods help explore changeable phenomena?

To explore the relationship between fibromyalgia and academic identity, I identified three subsidiary questions, which will form the basis for the analysis in this thesis:

> What is the role of academia for an academic?
> What does fibromyalgia mean for an academic?
> How is fibromyalgia experienced in academia?

The purpose of this research is to offer insights into academia as a workplace and to explore how this particular workplace may foster or potentially cause distress that becomes physically manifested in a disabling condition. Sociologists, medical anthropologists and social science researchers call for embodied and sensory approaches to generating, recording and disseminating data. I want to clarify that I do not wish or aim to attack existing disciplines, sociological or biomedical thought. Rather this thesis should be considered as an example for the cross-fertilisation and the generation of new knowledge that interdisciplinary approaches bring (see also Brown and Leigh, 2019). I see the purpose of my work and this thesis to consolidate and further advance this commitment to the embodied by drawing on sociological theorisation combined with elements from practice-based enquiries commonly applied in educational contexts (Clarke and Erickson, 2003; Lawrence and Murray, 2013). As with all research, there is no one unified or right way to conduct practice-based enquiry in educational contexts (Clarke and Erickson, 2003), which may include action research (Sumara and Carson, 1997), reflection in action and reflection on action (Schön, 1987) or case study explorations (Merriam, 1988). What binds all these forms together is that they focus on specificities of contexts. A major premise for practice-based enquiries in education is Bassey's concept of fuzzy generalisation (2000, 2001), according to which similar outcomes can be expected if a study is carried out in similar contexts under similar parameters. Taking this understanding as a foundation, teaching practitioners carry out research projects to explore best teaching practices and factors impacting teaching dynamics in a classroom in order to improve their pupils' learning. Assuming that similar parameters and similar contexts may lead to similar outcomes, the outcome or findings of such enquiries are only to a certain extent generalisable. This hedging may appear like a form of weak argumentation in other disciplines, but within education, it accounts for the unpredictable, changeable and unmeasurable elements of human emotions and behaviours amongst teachers and pupils as well as the huge numbers of variables at play in a classroom setting. The aim of practice-based enquiries is to gain in-depth understanding of very specific, contextualised, localised circumstances that then leads to more generally applicable conclusions. What this thesis does therefore is make abstract, theoretical and general the concrete, experiential and particular; and it does that from an educational starting point whilst applying sociological thought and drawing on sociological imagination (Mills, 2000) to formulate theories to explain what is happening.

The line of argument

In answering the above stated research questions, this thesis argues that academics in the neoliberal university feel trapped between their personal values and norms, their own character traits and the need to comply with external forces such as rules and regulations, practices and policies forever demanding higher levels of efficiency, excellence and productivity. The problem with contemporary academia in this context is that it appears to offer flexibility and autonomy, but in reality, works with and through pressurising individuals into compliance in return for the prospect of potential job security, for example. This setting then does not allow academics to appear weak or ill, so that individuals feel they cannot be open and honest about their personal health. On a personal level academics struggle with the fibromyalgia diagnosis and its meaning as a stigmatising condition and that therefore academics actively employ mechanisms and strategies in order to resist marginalisation processes and discourses. The management of fibromyalgia and its bodily symptoms is therefore a private and strongly controlled affair that invariably but involuntarily spills over into the academic's public life. In this sense, the doctoral thesis on hand demonstrates that the relationship between fibromyalgia and higher education plays out in three different interconnected and mutually dependent ways: (i) the working conditions of academia with extensive workloads, pressures to be productive under precarious contracts resulting in individuals pushing themselves to their physical breaking points (e.g.112ff.,156ff.,167), (ii) fibromyalgia as a physical manifestation of the tensions caused by the individuals' academic identity, which means individuals must reconcile internalised external values and pressures with personal values and expectations (e.g.117f.,124,134,142,147), and related to that (iii) the individuals' strong affiliation with the academy, which results in their active resistance against the sick role, which in turn results in fibromyalgia symptoms flaring up more strongly (e.g. p.122,128,166).

The argument of this thesis is organised around the following areas of interest: a) Aetiology and meaning of fibromyalgia; b) issues of methodology; c) significance of the higher education context; and d) experience of living with fibromyalgia.

a) Aetiology and meaning of fibromyalgia

I explore fibromyalgia research by focussing on milestones in the development of the label as well as very recent publications. My focus here is the discussion of how biomedical, social-constructionist and public discourses have shaped fibromyalgia as a condition and the issues around acceptance and lack thereof (see chapter 2). Through this discussion I demonstrate how the disciplinary focus leads to limited views and understandings of fibromyalgia, thus highlighting gaps, some of which this thesis bridges. At the same time, I show that non-academics and academics make sense of fibromyalgia in different ways. Where the non-academics adopt an attitude of combative acceptance in relation to their condition (see chapter 4), findings show that academics embody resistance against processes of marginalisation (Ware, 1999; see chapter 6). This difference in attitudes amongst academics and non-academics emerges because participants approach the aetiology of fibromyalgia differently. As the study shows for academics, the making sense of fibromyalgia happens at an experiential, emotional level but also as a quasi-scholarly activity at a scientific, cerebral level. Due to their ability to reflect and engage scholarly individuals understand the assigning of roles as patients (Parsons, 1991/1951) and discourses of resistance. As is shown in chapters 6 and 7 academics actively seek to avoid potential stigmatisation (Goffman, 1990/1963) related to being diagnosed with a somatic or psychosomatic condition and so actively manage their public persona by selecting support systems and adjustments they employ. Adjustments such as wrist or back supports, special, adaptable chairs or walking aids represent stigma symbols (Goffman, 1990/1963) and therefore are not always openly used in public, even if individuals rely on these in private realms. In sum, academics actively resist processes of marginalisation through carefully managing and controlling information (Goffman, 1990/1959) around their condition and its disclosure. Data shows that non-academics by contrast are less concerned about the contested nature and the cause of fibromyalgia. Non-academics still struggle with living with and making sense of fibromyalgia, but are more likely to take advantage of treatment options and adjustments to cope with the condition and less likely to worry about stigmatisation or marginalisation processes. Consequently, non-academics are more ready to withdraw from employment relationships, for example, whilst maintaining social relationships and connections. However, as the research shows, academics hold on to their academic roles, responsibilities and positions as these are irrevocably linked to academics' sense of identity.

b) Issues of methodology

As outlined above, existing fibromyalgia studies fail to capture the embodied experience and thus miss out on exploring the "emotionally expressive body" (Bendelow, 2009:25). Researchers are still impacted by the "dualistic legacies of the past" (Williams and Bendelow, 1998:3) to such an extent that dis-embodied research "functions as a set of naturalized norms" (Ellingson, 2017:6). Paying attention to embodiment in research dispels the myth of the "disembodied researcher" (Ellingson, 2017:6), puts "minds back into bodies, bodies back into society and society back into the body" (Williams and Bendelow, 1998:3,209) and therefore creates new opportunities for analysis and representation, which in turn results in exploring the "otherwise unknowable" (Ellingson, 2017:7). Recently, there have also been calls for more representative forms of research and dissemination (Denzin, 2016). There is a general consensus that this form of social science research aiming at improving society through better representation will require the social sciences to incorporate and embrace the arts, as this marriage provides "some fertile new terrain upon which evolving debates concerning dilemmas of human embodiment – including the relationship between "experience" and "representation", "reason" and "emotion", "aestheticism" and "eroticism", "reproduction" and "resistance" and so on – can take root and flourish" (Williams and Bendelow, 1998:205f). According to recent discourses within research theory and practice, the answer is to transcend disciplinary boundaries, to develop multimodal forms of enquiry (Dicks, 2014; Hurdley and Dicks, 2011; Jewitt et al., 2016), and to combine sensory and visual ethnography (Pink, 2013, 2015) with creative research methods (Kara, 2015). In focussing on the holistic fibromyalgia experience, I further existing debates around methods and methodology to account for the embodied and sensory within social science research. Drawing on the fact that human understanding is embodied and metaphorical and that language is often limited as a form of expression, I have developed the concept of identity boxes (see chapter 3) as a new field instrument for the generation of data. The value of the identity boxes as a method is outlined in chapter 4, which shows that fibromyalgia illness narratives of individuals from the general public differs to the conventional illness narratives. I further explore my methodological innovation in chapters 8 and 9, where I apply fictionalised narratives and where I evaluate the use of creative methods for analysis and dissemination.

c) Significance of the higher education context

Taking into account disciplinary conventions and exploring ways to transcend such boundaries, chapters 5 to 9 constitute the main body of the empirical research and specifically focus on the higher education context. I discuss the particular context of today's changing higher education context and its impact on individuals who have been diagnosed with fibromyalgia. I contend that the relationship between fibromyalgia symptoms, academics' personality and the working conditions in contemporary academia is complicated, as there is a continual interrelation, interconnection and interaction. Firstly, contemporary neoliberal academia is a competitive environment characterised by increasingly difficult working conditions with higher workloads, less job stability and more precarious contracts (Blix et al., 1994; Tytherleigh et al., 2005; Watts and Robertson, 2011). The findings in this research show that these external factors around working conditions heighten pressures, especially amongst those new to the profession. Secondly, academics' own personality traits and tendencies towards perfectionism, action-proneness and overexertion (Van Houdenhove et al., 2001) result in increased felt pressures to meet internalised societal expectations and norms. Thirdly, these internalised norms are at odds or in tension with personal values and expectations in relation to life as an academic in the context of the neoliberal university in contemporary academia. These felt external and internal pressures lead to emotional dissonance amongst individuals, which manifests itself in an aggravation of fibromyalgia symptoms.

Drawing on the context of higher education, I therefore argue that fibromyalgia in its psychosomatic and sociomatic qualities is a physical, embodied manifestation of tensions experienced in academia. However, as this study also shows, this is only part of the story. On an individual level academics grapple with the fibromyalgia diagnosis itself. In an environment where perfectionism, scholarly productivity and full cognitive functioning are highly valued, having fibromyalgia is equated with being weak and imperfect. Fibromyalgia symptoms such as issues with word retrieval, sequencing and logical reasoning that are commonly associated with brain fog, impact individuals' scholarly work and outputs. The data shows that academia is experienced and perceived as a particularly ableist environment where such weaknesses cannot be publicly disclosed and therefore require careful impression management and information control (Goffman, 1990/1959) to avoid stigmatisation (Goffman, 1990/1963). Chapters 5 to 7 in particular show that academics have internalised values, norms and expectations to such an extent that fibromyalgia symptoms are a bodily manifestation of internal struggles and tensions, but that academics do not see any alternative lifestyle for them. The originality in contribution here lies in the specificity of academia, which is best exemplified in the juxtaposition to the findings from chapter 4.

d) Experience of living with fibromyalgia

I further develop the analysis chapters 4 to 8 to evidence how new insights develop from the cross-fertilisation of disciplinary conventions. In their entirety, chapters 4 to 8 explore themes of negotiating and coping with fibromyalgia and related concerns, such as stigma.

Using the emerging deep understanding of the lived experience as a basis, I am able to draw on existing sociological theories to develop new conceptualisations around the experience of fibromyalgia. I newly implement an existing framework through applying the social course of chronic illness (Ware, 1999) to the specific context of fibromyalgia in higher education. The results presented in chapter 6 demonstrate that the academics' narrative of fibromyalgia is one of resistance against marginalisation (Ware, 1999). The four forms of resistance identified from the data amongst the academics with fibromyalgia are (1) the incorporation of cultural expectations and social conventions into personal life stories, (2) the re-making the lifeworld at a cerebral level through redefining reality and creating a new, socially acceptable reality, (3) active rejection of the fibromyalgia diagnosis and (4) active and pro-active countermeasures to assuming the sick role. The understanding of how academics manage their condition leads to my reconceptualization of bodywork (see chapter 7). The data in the form of academics' contributions and reflections in the research on hand show that bodywork is (a) the management of the fibromyalgia body, the deviant body, thus the management strategies employed in order to be able to fulfil the role as an academic and embody academic identity; (b) the management of the academic body as a public and private identity; and (c) the individual's work on and with the fibromyalgia body to make sense of one's self, whereby this final aspect incorporates physical, material bodily interventions as well as emotional labour involved in this process.

The value of this thesis

With this doctoral research I provide new insights into how academics make sense of being diagnosed with a condition that is not necessarily regarded as serious, but is problematic for its position on the cusp of the physical, the psychological and the somatic. My original contribution to knowledge is fourfold: (1) new field of investigation by focussing on the specificity of the higher education context in relation to the experience of fibromyalgia; (2) development of a new field instrument through the introduction of identity boxes; (3) new application of existing frameworks to new contexts, such as the exploration of the social course of chronic illness (Ware, 1999) within the context of fibromyalgia; and the (4) reconceptualization of existing frameworks on bodywork. The significance of the work relating to and coming out of this doctoral research and thesis are best evidenced in and with my publications in peer-reviewed journals and edited collections.[1]

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[1] Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology,* 1-15.

Brown, N. (2019). "Listen to your gut": a reflexive approach to data analysis. *The Qualitative Report*, 24(13), 31-43.

Brown, N. (2019). Emerging researcher perspectives: Finding your people: My challenge of developing a creative research methods network. *International Journal of Qualitative Methods, 18*, 1-3.

Brown, N. & Leigh, J.S. (2019). Creativity and playfulness in Higher Education research. In: Huisman, J. & Tight, M. (eds.) *Theory and Method in Higher Education Research Vol.4*. Emerald Publishing Limited, 49-66.

Brown, N. (2019). The embodied academic: body work in teacher education. In: Leigh, J.S. (ed.). *Conversations on Embodiment across Higher Education: Teaching, Practice and Research*. London: Routledge, 86-95.

Brown, N. & Leigh, J.S. (2018). Ableism in academia: Where are the disabled and ill academics? *Disability and Society*, 33(6), 985-989.

Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection. *Cogent Social Sciences.*

Brown, N. (2018). Video-conference interviews: Ethical and methodological concerns in the context of health research. *SAGE Research Methods Cases.*

Any research project needs to be contained and decisions are taken about such containment; and this thesis is no different. Having outlined the original contribution and significance of this thesis, I would now like to delineate what that thesis does not do.
With this thesis I do not intend to make claims around the cause or causality of fibromyalgia in general. Medical and sociological literature in relation to fibromyalgia is seeing a turn towards a more biopsychosocial understanding of the condition. We can therefore safely assume that there are social factors impacting and affecting individuals. Based on the findings presented in chapters 6 and 7, my argument is that the working environment of academia in the 21st century fosters external conditions that give rise to contested, medically unexplained conditions such as fibromyalgia.

As we have seen above, the fibromyalgia problem is one of genderisation within medical research. As someone who is interested in the particular experiences of individuals, I engage with gender roles and societal expectations of women academics, as this is a theme that participants found relevant and important. Yet, in this thesis I do not intend to apply a feminist lens for analysis. Although feminism does not follow one single, simple definition, it has long been argued that the relationship between feminism and disability studies is strained (Wendell, 1997; Tremain, 2017) despite the political activism linking both. Readings of fibromyalgia studies employing a feminist perspective confirm that gender hierarchies and power dynamics play an important role in the lives of those with fibromyalgia (White et al., 2001; McKiernan, 2018; Malterud, 1999), but that the concern with and around fibromyalgia is the lived experience of marginalisation and stigmatisation rather than fibromyalgia being a feminist issue (Yaghmaian and Miller Smedema, 2018).

As I stated earlier, disciplinary conventions often limit the generation of new knowledge. I am very conscious that in carrying out this research I myself have worked as someone who is heavily anchored in and tied to disciplinary conventions, but who has actively tried to break out of these. My approach to this research

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Brown, N. & Collins, J. (2018). Using LEGO® to understand emotion work in doctoral education. *International Journal of Management and Applied Research*, 5(4), 193-209.

Brown, N. (2017). The construction of academic identity under the influence of fibromyalgia. In: Henderson, H., Pennant, A. L., & Hand, M. (eds.). *Papers from the Education Doctoral Research Conference Saturday 26 November 2016. School of Education*. Birmingham: University of Birmingham. 18-25.

Collins, J. & Brown, N. (forthcoming) "Where's the validation?" – the role of emotion work and validation for doctoral students. *Higher Education Research and Development*.

therefore is an example for how educational and sociological may both benefit from a cross-fertilisation. What this thesis does not do, is take this interdisciplinary cross-fertilisation to the extreme. Naturally, accepting influences from other disciplines would further strengthen this thesis and would allow for yet different insights. For example, I could have drawn on psychology to develop a mixed-method research incorporating a quantitative testing of hypotheses and variables to gain understanding of individuals' character and personality traits. Realistically, I do not have the experience or knowledge required to do so successfully and coherently, and therefore I deliberately focused on this qualitative research presented here.

Throughout my study with academics as is reflected in this thesis I sought to explore the relationship between fibromyalgia symptoms and the context of higher education. As already stated, I consider myself firmly anchored within the interpretivist tradition of social science research. I therefore explore and study causal relationships according to Miles and Huberman's definition of "local causality" (1984:132), or what Shadish et al. (2002) refer to as "causal description" rather than "causal explanation" (9ff.). I appreciate that a "realist, process-oriented" (Maxwell, 2004a:8,b, 2012) model of causality that accounts for the "interpretive nature of our understanding" (8) as well as the "explanatory importance of the context" (9) studied would potentially have made the generalisations and causal relationships more explicit in many ways. However, the focus of my research had been the close study of a particular context, which did not necessarily lend itself to an experimental or quasi-experimental design for such generalized causal inferences.

The structure of the thesis

What follows in this thesis is an attempt to present in a linear fashion what is non-linear and messy. Naturally, any research process may be considered untidy and messy, where periods of chaos will alternate with order. In the context of this research, there are several levels of messiness and non-linearity to be considered. Firstly, the phenomena of academic identity and fibromyalgia are not easily contained or containable. As we have already seen, fibromyalgia is a rather contested condition with arbitrary diagnostic criteria, which is at one: a physical disease, a societal ill and/or a personal illness experience. Similarly, academic identity is a complex, fluid concept. Trying to grasp at these mouldable and moulding concepts is a difficult undertaking in itself. As humans, we tend to categorise and simplify through employing dualistic conceptualisations: body versus mind, healthy versus ill, academic staff versus professional services, and so exploring both concepts at the same time means that several boundaries and categories needed to be broken down or overcome. The second level of messiness therefore represented one of the biggest challenges within this process: to work with, along and through differences in disciplinary conventions. This research is a sociological exploration of an educational context. The two disciplines are quite closely aligned and are complementing each other in many ways. However, there are disciplinary conventions around what constitutes research and how research is disseminated that required navigation. Finally, the non-linearity of this thesis also relates to the data collected and generated, as the data sets are not linear and do not follow traditional, commonly applicable rules. My particular approach to analysis through artistic creations accounts for this non-linearity of experiences expressed by the participants. Appendices A and B showcase examples for my creative analysis processes. The remainder of the thesis connects these threads in the following structure:

Following the educational research tradition, chapter 2 provides an overview of our existing knowledge in relation to fibromyalgia. The bodies of literature presented in this chapter explore the historical development of the label and its significance. I demonstrate that there is a long historical tradition around fibromyalgia and fibromyalgia-like conditions, but that this does not mean that the condition is free from potential problems. Arbitrary diagnostic criteria, debates around prevalence and the symptoms associated with the condition make fibromyalgia contested. The public image of fibromyalgia reflects the ambivalence felt vis-à-vis the condition, which in turn influences how individuals with fibromyalgia live with and make sense of a fibromyalgia diagnosis. The conclusion in chapter 2 sets the stage for the more detailed analyses in the remainder of the thesis.

In chapter 3, I outline my interpretivist approach towards research that draws on principles of arts-based research. I discuss how ensuring good quality research within the interpretivist and arts-based framework requires transparency, criticality and reflexivity. I consider my own positionality, my research design and process. I offer insights into ethical considerations around the use of arts-based methods, but also the practicality of doing research with academics who are chronically ill. I present data analysis as an iterative sense-making process comprising of conventional coding and theme-generation alongside arts-based assemblage. I conclude this chapter with a reflection on the reality of using creative methods for enquiry.

Chapter 4 is an article I published in a peer-reviewed journal reporting on the pilot phase of this research. In this chapter, I use narratives of illness (Frank, 2013) and the concepts of biographical disruption (Bury, 1982), identity continuity (Wolfenden and Grace, 2012; Llewellyn et al., 2014), normalisation (Sanderson et al., 2011; Sanderson et al., 2015) and liminality (Turner, 1969) as a starting point for understanding the lived experience of fibromyalgia amongst members of the general public. The fibromyalgia narratives uncovered in this pilot phase are best described as a combative attitude, which is characterised by resistance to the illness narrative and a fighting spirit coupled with partial acceptance and levelled positivity.

Chapter 5 explores how academics make sense of their academic identity and I argue that the construction of academic identity is in two tiers: (1) at an external, public-facing level that is strongly influenced by and linked to society's stereotypical understandings of academia and (2) at a private, personal and internal level. I use the concepts of emotional labour, emotion work and emotional dissonance to explain that the bodily experience of fibromyalgia is the manifestation of tensions between internalised public and private values of being a good academic.

In chapter 6, I demonstrate that amongst academics the process of understanding and coming to terms with fibromyalgia is different to those of non-academics. I argue that academics make sense of fibromyalgia in two forms: as an academic, scientific, objective, cerebral activity and as an experiential, personal, emotional journey, although academics' scientific level of engagement with fibromyalgia is pseudo-objective or quasi-scholarly in nature. I show that the academics' narrative is one of resistance against processes of marginalisation (Ware, 1999).

In chapter 7, I present the research participants' lived experiences of working in academia and how academics view the interrelationship between working in academia and fibromyalgia. I argue that the current state of affairs in academia makes fibromyalgia symptoms worse and individuals more ill. I show that through using their scholarly mindset for critical reflections and analysis, academics are fully aware of the impact of working conditions and experiences of academia on the severity of fibromyalgia. I further contend that academics have subsumed the institutional values of the neoliberal university into their academic identity to such an extent that working in academia is ingrained in their beings as a lifestyle choice. Indeed, irrespective of the impact this work in academia may have on their illness experience academics see no alternative employment opportunities other than remaining in academia.

For chapter 8, I decided to draw on the arts-based research movement. Throughout the research participants shared narratives of difficult situations, discrimination, ableism and grievance procedures and tribunal panels. The academics were acutely aware of their vulnerability, should they be identifiable and worried about the reaction from colleagues, family members and friends, as in many of the narratives the social networks around the story-tellers were implicated as unsupportive, distrusting, lacking understanding and empathy. And yet, the participants wanted to share their experiences and regularly commented on the importance of not being silenced, but making their voices heard loud and clear. Through fictionalising data and converting these into short stories, I tell what would otherwise remain "untold" fibromyalgia stories. In the introduction to the chapter I provide an analytical foreword and annotation of how data are interwoven into the fictionalised accounts, and I highlight discussion points arising from the short stories.

In chapter 9, I offer an evaluative reflection regarding the research process and its particularities due to the use of creative methods. I argue that the use of creative methods requires considerations that are different to more commonly used interview approaches. I contend that the data generated through those processes are of a richer quality in terms of individuals' reflective work, but that the entire process is more demanding and complex due to the commitments required from individuals. I conclude that the most beneficial and advantageous aspect of this research was openness towards all forms of expression, so that participants could genuinely communicate how and how often they wanted to.

In the final chapter of my thesis, I bring together the key findings and core elements of this research. I do so by providing a brief summary of core debates and key ideas from the findings chapters, which I link back to the overarching research questions. In the subsequent section I reflect on the research with its current significance and provide a brief look ahead to other related work arising from this doctoral research.

2. The story of fibromyalgia

The purpose of this chapter is to present an overview of the scholarly engagement with and around fibromyalgia, to provide background to fibromyalgia as a condition and to offer a context for the issues within existing fibromyalgia research. Fibromyalgia has been described in literature for centuries (Wallace and Hallegua, 2001; White and Harth, 2001; FitzGibbons, 2007), but within the wider picture of medical and sociological research the condition is a relatively new field of study. A brief systematic literature review demonstrates that publications in recent decades have increased drastically. The following graph shows the numbers of publications in ten-year periods from the 1970s through to 2019. The numbers of publications have risen steadily until in the current decade 2010-2019 they have reached an unprecedented 11,108 publications by the end of June 2019.

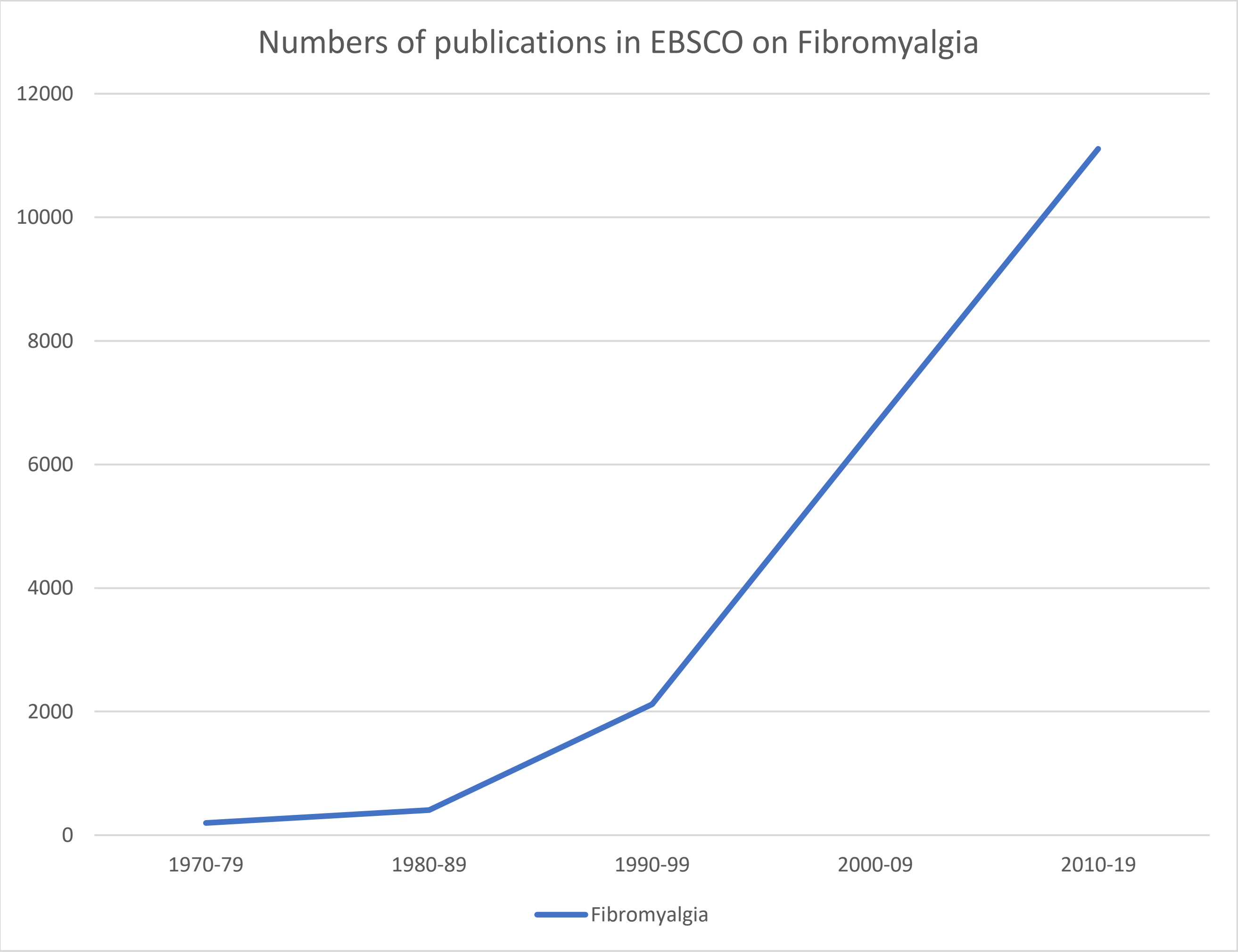

Figure 2.1: Numbers of publications in EBSCO on fibromyalgia

In order to contextualise the numbers of publications, I used the EBSCOhost reference system with all data bases activated and searched for fibromyalgia and the related conditions chronic fatigue syndrome and burnout. I entered the individual search terms in their most minimalistic forms, such as "fibromyalgia" rather than "fibromyalgia syndrome" for example and I narrowed the searches down to cover individual ten-year periods. The graphic illustration below shows the number of publications in each of the ten-year periods across three different categories "fibromyalgia", "chronic fatigue" and "burnout".

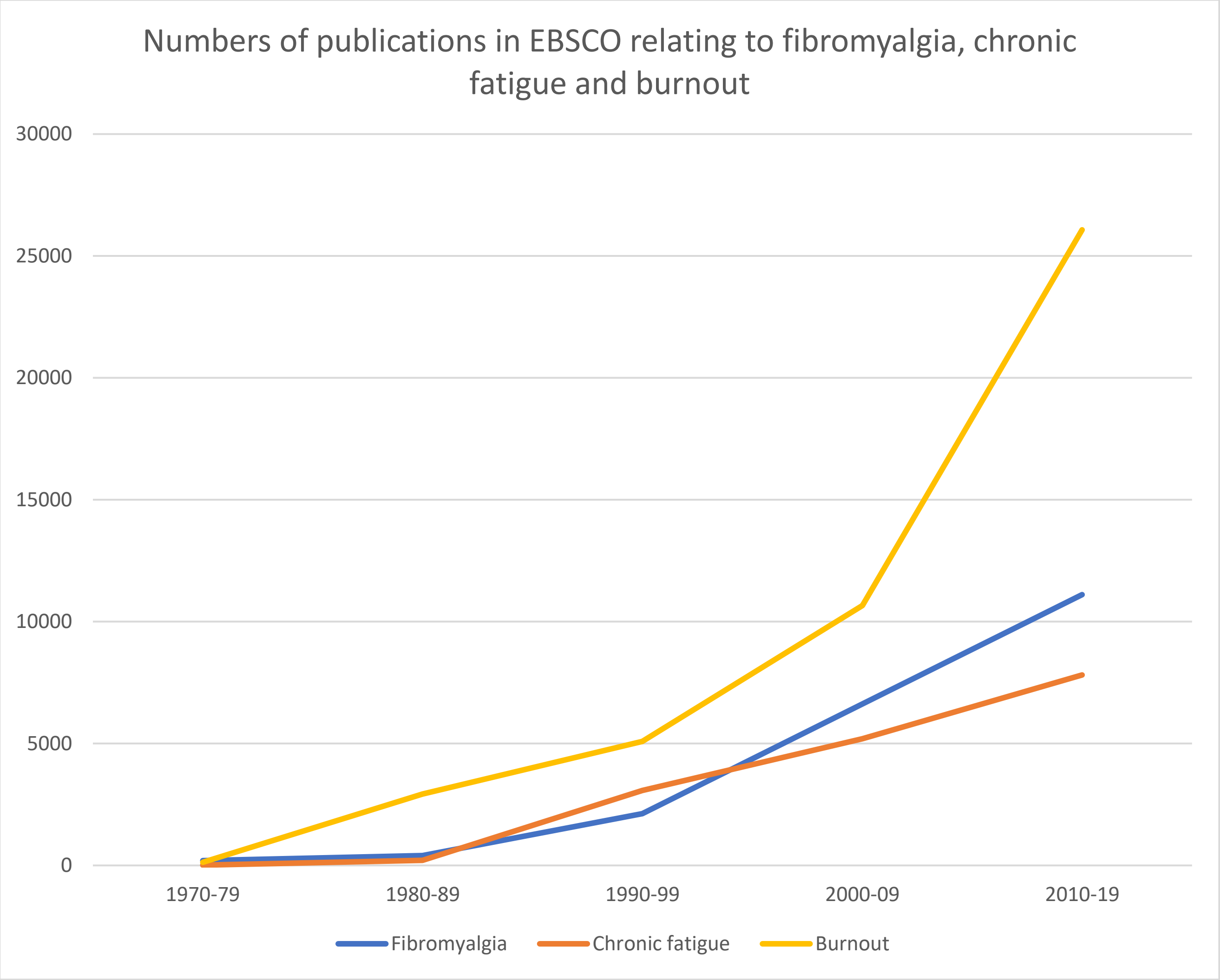

Figure 2.2: Numbers of publications in EBSCO relating to fibromyalgia, chronic fatigue and burnout

Although it is evident that burnout has been featured more prominently than for example fibromyalgia, it is equally noticeable how fibromyalgia has gained in relevance by comparison to chronic fatigue. It is interesting to note that the increase in numbers of publications in relation to chronic fatigue is less steep than fibromyalgia. This is, however, not the entire story, as chronic fatigue is nowadays often referred to as "myalgic encephalomyelitis". In order to show the relevance of a category or label, I also used "myalgic encephalomyelitis" as a search term in EBSCO, which has led to a quite different picture, as shown in Figure 2.3.

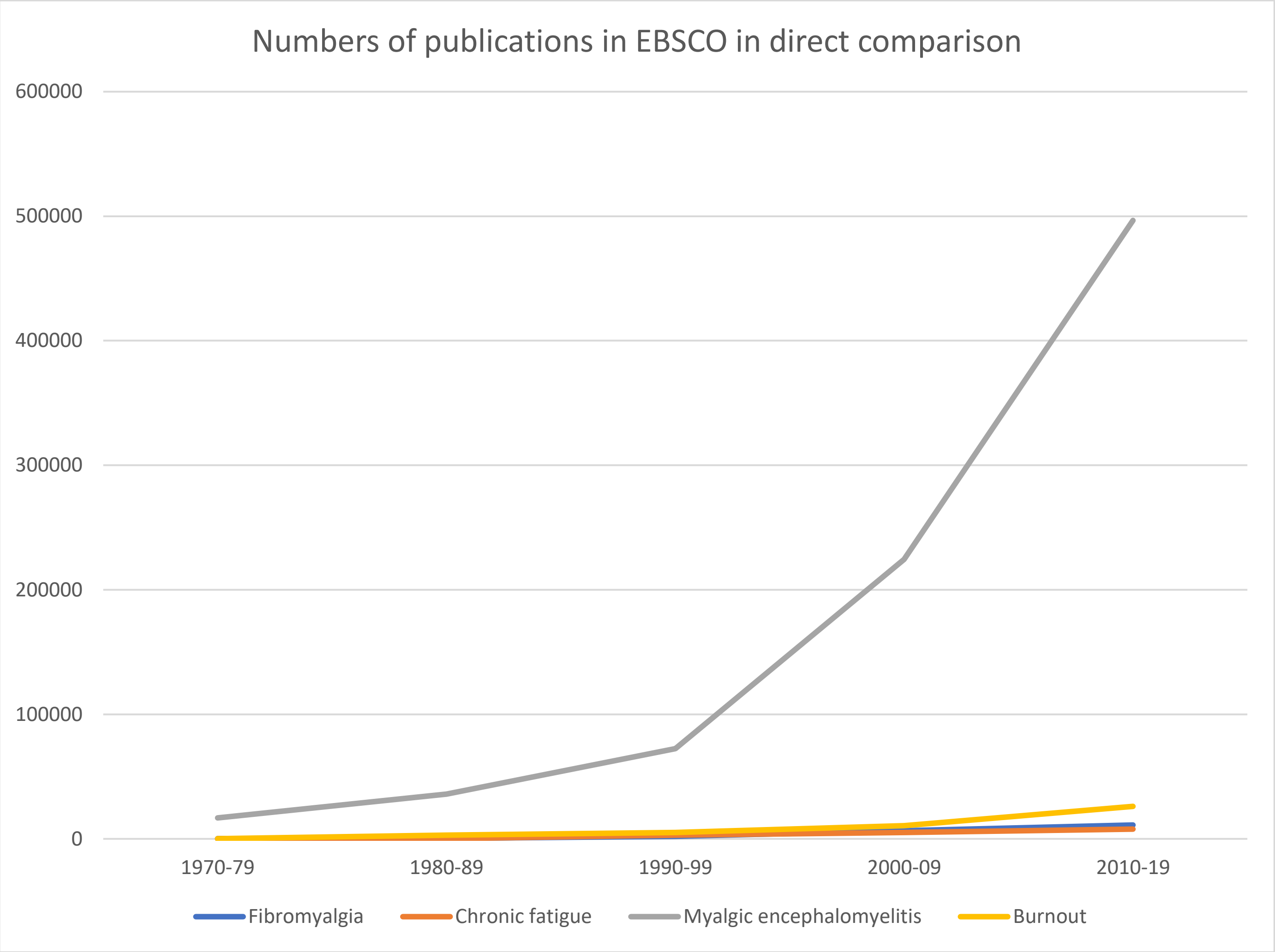

Figure 2.3: Numbers of publications in EBSCO in direct comparison

EBSCO is not the only available database, but the trends demonstrated here are replicated across other sources, such as Cochrane library, ProQuest and Google Scholar. Where the ProQuest search for "fibromyalgia" for the decade between 2000 and 2009 resulted in 11,543 publications, the number of publications from 2010 up to and including May 2019 had risen to 25,094. These figures may well be related to changes in publishing and the increased needs for publications for academics and institutions. However, these figures also only take into account the publications using the search term "fibromyalgia". The graphs show that publications from the 1970s on tended to use "myalgic encephalomyelitis" more consistently, whereas in the decades up to the 1970s "chronic fatigue" was the more prominently used term for what is effectively the same condition.

Despite the wealth of research publications available, the systematic literature review highlights the lack of qualitative research and lived experiences of fibromyalgia. Within EBSCO the combined Boolean search of "fibromyalgia and qualitative" led to 5018 results and "fibromyalgia and lived experience" led to 2775 results. In both cases, many of the results were theses, dissertations, wire feeds, duplicates and errata, and once these were excluded only 23 qualitative studies on fibromyalgia remained. The fibromyalgia story is therefore still heavily focussed on trying to understand cause, symptomology, prevalence and exploring treatment options.

However, the story of fibromyalgia is not linear and straightforward, but fraught with doubts, tensions and disputes amongst the general public as well as amongst the medical professionals. For the remainder of this chapter, I provide an overview of the problem of fibromyalgia. Naturally, there were many choices that needed to be made around which literature to include. I organised this literature review around five central, but interrelated areas of interest: (1) fibromyalgia in a historical context; (2) (bio)medical perspectives of fibromyalgia; (3) the contested nature of fibromyalgia; (4) the public image of fibromyalgia; and (5) the impact of the problem of fibromyalgia on individuals.

In the section "Fibromyalgia in a historical context" I demonstrate that fibromyalgia is not a new phenomenon or condition, but has been known for centuries, albeit under different names. Focussing on the construction and development of neurasthenia, I highlight how scientific developments and societal changes provided the context for the popularisation of what was initially a praise-worthy illness, but later seen as a neurosis or psychosis. The subsequent section "(Bio)medical perspectives of fibromyalgia" focusses more closely on the contemporary understanding of fibromyalgia and the rise of the "fibro wars" (Wolfe, 2009). After considering the major milestones in the emergence of the diagnostic criteria for fibromyalgia, I outline how the lack of a unique identifier and clear cause for or trigger of fibromyalgia has led to a multitude of explanatory models. In this discussion, I show that the (bio)medical perspectives are not able to provide definitive answers and that as a result, symptomology categories and diagnostic criteria remain vague, which in turn impacts treatment options. In the subsequent section "The contested nature of fibromyalgia" I demonstrate that as a consequence of the incomplete (bio)medical picture, fibromyalgia is contested and hardly understood. By focussing on the literature around prevalence, I hone in on the contrasting and sometimes conflicting reports of statistics, and in the course provide a commentary in relation to reading critically and engaging scholarly with research publications. Furthermore, I consider the diagnostic process and the relevance of categorisations for the medical professionals as well as individuals being treated for fibromyalgia. The two themes of prevalence and categorisations allow me to demonstrate the professional debates in and around fibromyalgia before I present the section "Fibromyalgia and its public image". In this section, I show that the attitude towards fibromyalgia amongst the general public reflects the medical professionals' confusion, which in turn is visible in how fibromyalgia is presented in the media and social media treatises. Drawing on examples from popular culture I outline the ambivalent reactions towards fibromyalgia. The final theme "The impact of the problem of fibromyalgia on individuals" weaves like a red thread through all the sections before it is discussed in detail in the conclusion of this chapter.

Fibromyalgia in a historical context

Fibromyalgia has been described in literature under many terms, such as fibrositis, fibromyalgia syndrome, rheumatoid illnesses, widespread pain or musculoskeletal pain (White and Harth, 2001; Hagen et al., 2005; Linares et al., 2008). The recognition of fibromyalgia as it is understood nowadays was gradual and dates back to the 18th and 19th centuries, when physicians described pain and exhaustion in connection with a far wider range of other symptoms (Wolfe and Walitt, 2013). In the middle of the 18th century Richard Manningham (n.d.) described an illness that he called "febricula or little fever"; fever with additional symptoms such as pain and cognitive processing difficulties which could not be explained. This fever was described as most prevalent amongst women and the wealthy leading sedentary and studious lives and was therefore most commonly connected with causes such as intense thoughts and grief (Manningham, n.d.). A first description and mention of trigger points and localised pain associated with today's concept of fibromyalgia dates back to William Balfour in 1815 when the specific pain described was considered to be linked to an inflammation within the body, a theory that found many proponents in the early 19th century (Inanici and Yunus, 2004). Around 1880 George Beard, an American neurologist, described and popularised neurasthenia, a fever condition that is accompanied by

> "tenderness of the scalp...tenderness of the spine...general or local itching...abnormalities of the secretions...tenderness of the teeth and gums...vague pains and flying neuralgias...flushing and fidgetiness...tremulous and variable pulse and occasional palpitations...sudden giving way of general or special

> functions...special idiosyncrasies in regard to food, medicine and external irritants...sensitiveness to changes in the weather...a feeling of profound exhaustion unaccompanied by positive pain...ticklishness...desire for stimulants and narcotics...insomnia...nervous dyspepsia (dyspepsie asthénique)...partial failure of memory...sexual exhaustion...deficient mental control...seminal emissions – partial or complete impotence...changes in the expression of the eyes and countenance" (Beard, 1878:2152-2153).

In Beard's terms neurasthenia was a form of nervous exhaustion, that could only be diagnosed on the basis of some symptoms and by exclusion of other diagnoses. The definition and classification of neurasthenia was heavily contextualised (Berger, 1973; Abbey and Garfinkel, 1991; Wessely, 1991; Luthra and Wessely, 2004), as Beard's underlying approach to neurasthenia was closely linked to the societal and technical developments of the time. In the late 19th century inventions and discoveries such as those related to electricity resulted in reinterpretations of functions and processes within the human body. In analogy to a battery that would require charge neurasthenia was therefore interpreted as too much energy having been spent, so that the body shuts down and needs time to recover. Additionally, electricity was thought to be working as a human function from within the body in the process of transmitting information between nerve endings. Neurasthenia was thus a "lack of nerve strength" (Beard, 1878:2152).

Another key influence was Charles Darwin's evolution theory, which resulted in the assumption that there would be a special genetic disposition for those suffering from neurasthenia. The typical neurasthenia sufferers at the time were high-achieving members of the public, whose nervous system would be more evolved than those of the less successful population. This more complex nervous system was thought to be the reason for high-achieving men and women to be more susceptible to overspending their bodies' energy, which would eventually lead to nervous exhaustion (Luthra and Wessely, 2004). Heredity was thought to be at play in that a person would have inherited specific traits to make them predisposed for developing neurasthenia at some stage in life. In line with the survival of the fittest it was thought more likely that high-achievers pass on their genes to subsequent generations (Berger, 1973; Abbey and Garfinkel, 1991).

The final pillar of Beard's neurasthenia concept was reflex action (Abbey and Garfinkel, 1991). Whilst one area of the body is under attack from external factors, a different area of the body reacts to this attack, so that for example extreme fatigue and overtiredness could cause pain. This principle of reflex action was particularly relevant where women were concerned. Child-bearing and child-birth were seen as difficult processes, which would naturally put the female body under extreme pressures and stresses, so that the body would react to child-bearing by developing issues such as fatigue, fevers and neurasthenia (Luthra and Wessely, 2004).

In addition to the scientific influences, societal changes also impacted the development and establishment of the neurasthenia concept. It was thought that women at the time were experiencing an inner conflict between their wants, dreams and societal rules. Women would now spend more of their bodies' energy in comparison to when they followed their traditional roles and dealt with their limited responsibilities. The fragile, female body would therefore be exhausted more quickly, particularly due to the additional demands of more advanced brain activities for more educated positions and tasks. Living within the constraints of a still largely Victorian society would also result in external pressures on the women to remain faithful to their assigned roles of home-makers and carers (Abbey and Garfinkel, 1991). Neurasthenia then was the physical manifestation of these tensions. The feeble female body, the weaker nervous system and the resultant lack of resilience by comparison to the male body were thought to be the reasons for the higher prevalence of neurasthenia amongst women. As far as men were concerned Beard's interpretation is one of what would nowadays be considered an identity crisis amongst those aged between 25 and 35 years of age. It is at that stage of their lives where men around the turn of the century would still enjoy their bachelor status but at the same needing to settle down, so similarly to the argument for women's neurasthenia diagnoses, men, too, were thought to be torn between different wants and needs. Beard acknowledged that in the late twenties and early thirties men were unsure of their ultimate life-time goals and therefore remained aimless, which in turn would drain the body of its energy. This theory seemed feasible as often at a later stage in men's lives the symptoms of neurasthenia subsided, which coincided with men becoming more settled and their Sturm-und-Drang period of their lives having been overcome (Sicherman, 1977). The men more likely to have neurasthenia would be those who were more successful. During the First World War, for example, neurasthenia was more commonly diagnosed amongst higher ranking soldiers than amongst those with lower ranks. This was consistent with the idea of the more evolved nervous system, as those amongst higher ranks would need to demonstrate responsibility, strategic thinking and zeal in their work, thus would generally be more educated and therefore have a more developed brain and body. Lower ranked soldiers by comparison only followed orders and were more likely to be diagnosed with hysteria rather than neurasthenia (Wessely, 1990).

For men, therefore, neurasthenia became the preferred diagnosis, as being physically ill due to hard work, responsibility and success better fitted the Victorian values at the time. Neurasthenia became established as its diagnosis fulfilled a specific purpose within society and the medical realm in that it was considered an illness with physical causes that happened to improve with some treatment that are usually associated with psychology. Physicians approved of the neurasthenia diagnosis as they could legitimately use psychological treatments, but patients, too, were content because they would not experience any of the stigmatisation that is associated with psychotic conditions. Also, the diagnosis of neurasthenia was more acceptable than other psychological disorders, which would result in patients being institutionalised. Although the symptoms of neurasthenia and hysteria for example were similar, wealthier people were treated at home as sufferers of neurasthenia rather than as in-patients on psychiatric wards where their obsessions, fears and depressions would have been treated more radically (Sicherman, 1977; Wessely, 1991; Ware and Kleinman, 1992; Wessely, 1994).

Like the steep rise of neurasthenia its rapid downfall and disappearance were also closely linked with societal and medical developments of the turn of the century. Whilst America seemed to be gripped by Beard's publications relating to what he considered a physical illness that responds to psychological treatment, in Europe work within psychiatry, especially publications connected with Sigmund Freud's psychoanalysis became more influential. The increased interest in how the mind works and how psychoses could develop meant that illnesses whose causes were perhaps not fully understood or medically explained would be considered as somatic or psychotic (Berger, 1973; Wessely, 1991). Neurasthenia or similar illnesses would therefore be treated within the psychiatric realm. In response to the new advances within medicine and psychiatry psychiatric treatment centres became more prominent and popular in Europe as well as in America. Consequently, neurasthenia was slowly but steadily considered a psychotic illness rather than a physical one (Sicherman, 1977). Research relating to the experiences of World War One soldiers demonstrated the psychoneurotic foundation of symptoms related to the neurasthenia concept (Straus, 1991). Additionally, neurasthenia had grown to include a far wider range of psychotic and non-psychotic conditions, and Freud's work on the mind led to some of them being removed from that wider definition of neurasthenia. Once anxiety disorders for example were removed, neurasthenia was left with symptoms that were limited to fatigue only (Berger, 1973). Finally and probably the most influential factor for the demise of neurasthenia was the change in societal responses to those diagnosed with neurasthenia. Initially, the illness was praise-worthy due to its association with positive values such as being successful, overworked and strained due to physical and mental demands. Now, thought processes were changing and neurasthenia became associated with laziness and workshyness. People with what we would nowadays consider as post-traumatic stress disorder, which would also have been part of the neurasthenia concept, were now treated as being weak of mind and having little willpower. After World War One doctors considered neurasthenia sufferers as neurotics, showed less sympathy towards the illness and even blamed the patients for their condition (Wessely, 1990; Wessely, 1991; Ware and Kleinman, 1992). This process was reinforced with further publications such as that of Weir Mitchell from 1877 onwards, which identifies neurasthenia symptoms amongst the less wealthy and less educated population, so that association of neurasthenia with being more evolved, more civilised, and more successful could no longer be upheld (Sicherman, 1977).

Although early on in the 20th century neurasthenia became lesser known and eventually forgotten, the symptoms re-emerged and the illness concept was revived in the latter half of the 20th century. In some publications neurasthenia itself is mentioned, but the condition is reborn in the guise of post-viral fatigue, chronic fatigue syndrome and myalgic encephalomyelitis (Berger, 1973; Wessely, 1990; Abbey and Garfinkel, 1991; Straus, 1991; Wessely, 1991; Ware and Kleinman, 1992; Ware and Weiss, 1994; Wessely, 1994; Luthra and Wessely, 2004; Harvey et al., 2009;). Again, the societal context and medical advances play important roles as far as the acceptance of neurasthenia symptoms is concerned. Research in the 20th century started to include relatively new areas such as virology and immunology, so that attempts were made to link the typical fatigue and pain symptoms to physiological causes. In America, the Eppstein-Barr virus was closely connected with the emergence of chronic fatigue syndrome, whilst in the United Kingdom the outbreak of myalgic encephalomyelitis was linked to mass hysteria about the viral infection. Subsequently, the patients' personalities were analysed to prove that sufferers were stable and successful and therefore myalgic encephalomyelitis could not constitute a neurosis, but must be of a different origin (Wessely, 1991). Advances in virology and immunology increasingly connected chronic fatigue syndrome with allergic reactions or overreactions of a weakened immune system to external, environmental factors, an idea that reverts back to Beard's neurasthenia concept (Wessely, 1990; Abbey and Garfinkel, 1991; Straus, 1991; Wessely, 1994). Fibromyalgia itself became established as a distinct diagnostic entity within the middle of the 20th century, as the next section will show.

(Bio)medical perspectives of fibromyalgia

In 1904, the British neurologist William Gowers introduced the term fibrositis highlighting the understanding that pain stems from inflamed muscle fibres (Gowers, 1904). Findings relating to thickening of fibrous tissues (Stockman, 1904) provided the substantiation for Gowers's fibrositis concept, and so this term entered the medical textbooks. Around the time of the Second World War rheumatic patients admitted to a British Army Hospital were diagnosed with fibrositis although no inflammation or degeneration was visible. The fibrositis diagnosis became linked with depression and stress under the terminology "psychogenic rheumatism" (Boland and Corr, 1943). A major milestone regarding the acceptance of fibromyalgia was the American College of Rheumatology set of criteria for the diagnosis of fibromyalgia in 1990 (Wolfe et al. 1990; Queiroz, 2013) and its revision in 2010 (Wolfe et al., 2010). In the same era, the World Health Organisation recognised fibromyalgia as a disease and in 1992 ascribed the International Classification of Diseases code M79.03, although the current 2015 version states fibromyalgia as M79.7 (WHO, 16 July 2015). In 1994 the International Association for the Study of Pain formally recognised the disease and categorised it as X33 and X8a (Linares et al., 2008). According to the American College of Rheumatology fibromyalgia is present if a person shows painful reactions to 11 out of 18 tender points or in the absence of reactions to tender points when specific scores relating to somatic symptoms and the widespread pain index are met (Wolfe et al., 2010). The original criteria for the diagnosis of fibromyalgia were revised on the basis of a number of criticisms: Not all patients responded to the relevant amount of tender points, but were clearly suffering from widespread and chronic pain and not all physicians knew how to ascertain the relevant tender points. Therefore, Wolfe et al. (2010) considered that many fibromyalgia sufferers would be left undiagnosed. Also, in the twenty years between the initial set of criteria and this revision it had been acknowledged that fibromyalgia could also produce another set of symptoms such as fatigue and cognitive dysfunctions, which had not been included in the original fibromyalgia diagnostic criteria. According to the revised version in the absence of reactions to 11 tender points fibromyalgia could still be diagnosed if the score relating to somatic symptoms is greater than five or nine, depending on the ultimate value of the widespread pain index. This revision of diagnostic criteria made fibromyalgia more prominent (Wolfe and Walitt, 2013), but also led to the understanding that it is a heterogeneous condition (Häuser et al., 2015) with a wide range of complex symptoms that include pain, fatigue, sleep dysfunctions, cognitive problems, increased sensitivity to temperature, light and sound, increased sensitivity to painful and non-noxious stimuli, central sensitisation and psychological disorders (White and Harth, 2001; FitzGibbons, 2007; Linares et al., 2008; Wolfe et al., 2013). In order to be able to explain this wide-ranging symptomology there is a clear aim at finding one unique identifier for fibromyalgia. Giacomelli et al. (2013) highlight the range of investigations into the causes of fibromyalgia with researchers considering physiological differences and undertaking genome sequencing, but also testing conduction velocity and comparing fibromyalgia more closely with Sjögren's syndrome or lupus. For example, Menzies et al. (2013) report differences in the methylation patterns, Feng et al. (2013) describe the connection between C11orf40 mutation and plasma levels of cytokines, MCP-1 and IP-40, and Yigit et al. (2013) find significant changes in the genome of IL4. However, to date none of these studies is completely conclusive and results have not been replicated. Nowadays, the generally accepted consensus is that fibromyalgia is related to central sensitisation. Central sensitisation is a measurable process relating to C fibre activation in the body (Yunus, 2008; Yunus, 2009). When there is an external stimulus, C fibres are responsible for transmitting this information to the spine, where neurons are activated, which leads to experience of pain. Certain chemicals such as substance P and serotonin regulate the flow of information transmitted from the C fibres and therefore moderate the pain experience. With central sensitisation substance P and serotonin are no longer mediating the C fibres. Instead hyperexcitability and overreaction occur as post-synaptic receptors are stimulated, which in turn leads to hyperexcitability of central neurons, thus central sensitisation. In lay literature (Pain management talk, 2016) the simplistic explanation is that nerve endings are overfiring, which results in experience of pain in response to even non-painful stimuli. In Bennett's (2004) view the C fibre activation and resulting overreaction is only one of three factors leading to sensitisation. Bennett (2004) names "peripheral pain generators, inflammatory conditions, and psychological stressors" (381) as causes to the development of fibromyalgia.

Although central sensitisation is a key component in the fibromyalgia story, it is not sufficient as a sole explanation for fibromyalgia (Wolfe et al., 2012). In their study relating to hearing loss amongst fibromyalgia and rheumatic disorder patients, the authors conclude that fibromyalgia patients over-report symptoms and experiences relating to hearing loss, which is consistent with psychological issues (Wolfe et al., 2012). Another key approach to today's understanding of fibromyalgia relates to the differences in range and severity of the symptoms amongst all fibromyalgia patients, which results in it being interpreted as a spectrum disorder (Bennett, 2004; Inanici and Yunus, 2004). One argument in favour of the spectrum theory is that many patients develop fibromyalgia gradually over time and are usually not younger than 30 or 40 years of age (compare participant statistics presented in chapter 3). Going beyond this immediate interpretation of the spectrum, some experts include chronic fatigue syndrome or myalgic encephalomyelitis (Jenner, 2011) stating the experienced levels of pain or fatigue as primary symptoms to be the main difference. Chronic fatigue syndrome is defined as abnormal fatigue (Wessely, 1994), but the definition of abnormal fatigue is arbitrary, in that we cannot know what is normal and how a person therefore experiences abnormal levels of fatigue. Similarly, the line between normal and abnormal fatigue is not clear-cut, but relative to other levels of fatigue. In analogy, this argument is used for fibromyalgia and the patients' experiences of their pains and cognitive abilities. In order to explain the multitude of symptoms, fibromyalgia could also be understood as a dimensional and continuum disorder (Wolfe et al., 2013).

Overlaps of and comorbidity between fibromyalgia and chronic fatigue syndrome are commonly considered (Queiroz, 2013; Van Houdenhove et al., 2001) whereby chronic fatigue syndrome is associated with low levels of inflammation and fever, whilst the elevated levels of substance P, a peptide of eleven amino acid residues, only occur amongst fibromyalgia patients (Martínez-Lavín, 2001). Ultimately, "few patients with FM will undergo expensive spinal taps or sleep EEGs or studies that are not generally available (or necessary)" (Wallace and Hallegua, 2001:317), which results in fibromyalgia and comorbid illnesses not being scientifically proven, despite the fact that many individuals diagnosed with fibromyalgia report similar or related conditions and symptoms (see chapters 3 and 6).

As a result of the diagnostic insecurity and unestablished causes for fibromyalgia medical professionals become frustrated and overwhelmed with the condition. Traditionally, medical professions are organised in disciplinary contexts. However, fibromyalgia does not neatly fit within the realm of either rheumatology, virology or immunology, for example. Consequently, no specific discipline takes responsibility for and charge of the diagnosis and treatment of fibromyalgia, which, in turn, leads to a wide range of treatment options being offered.

Treatment of fibromyalgia

As has been shown the cause or causes of fibromyalgia are not fully established within pertinent literature. Consequently, the approach to treating fibromyalgia is equally diverse. Where medical professionals may feel overwhelmed or frustrated because of the vast range of treatment options available, the impact on individuals is even more profound (see chapters 4 and 6). At a personal level, being diagnosed with fibromyalgia requires individuals to accept the responsibility associated with the sick role and therefore to take the right decisions in order to be healed (Parsons, 1951). At a more public level, fibromyalgia treatments are perceived as stigmatising (Goffman, 1991/1963), as they often include prescriptions or regimens that are commonly associated with purely psychological disorders.

Within the German speaking world, the association for pain therapy (Deutsche Interdisziplinäre Vereinigung für Schmerztherapie) publishes regular updates relating to treatment options and their effectiveness. The current guidelines from December 2012 demonstrate the wide range of therapies and treatments that are available within conventional medicine as well as the complementary and alternative sector. As the cause or causes of fibromyalgia are not clear fibromyalgia treatment only seeks to improve and manage symptoms. Typically, fibromyalgia is treated in a multidimensional way with pharmacologic approaches and lifestyle changes, exercise sessions and pain education classes (Barkhuizen, 2001; Hammond and Freeman, 2006; FitzGibbons, 2007; Jones et al., 2012; Lami et al., 2013; Cording et al., 2015).

The guidelines published by the Deutsche Interdisziplinäre Vereinigung für Schmerztherapie are particularly interesting in this respect, as the 2012 publication includes a comprehensive review of the levels of the 2008 recommendations. The changes made from 2008 to 2012 are largely due to newer research findings and wider verifications amongst test and control groups. However, it has to be asked why certain recommendations were made in the first place, when perhaps not enough reliable information and data had been available. For example, many of the pharmacological options such as the prescription of amitriptyline, duloxetine, muscle relaxants or serotonin receptor agonists were reviewed from 2008 to 2012 and the level of recommendation for all of these medical interventions was reduced. For amitriptyline the level went from "strongly recommended" to "recommended", for duloxetine the recommendation was reduced from "recommended" to "recommended subject to comorbid depressive or general anxiety", as for the serotonin receptor agonists the recommendation was changed from "open recommendation", which refers to there no being a value judgement possibly due to lack of data, to the use of these medications to be "strongly discouraged" (Deutsche Interdisziplinäre Vereinigung für Schmerztherapie, 2012:7-8).

Similarly, the range of alternative and complementary treatments is vast (see chapters 6 and 7), which may partly be due to the range of symptoms and the differences in the severity of each of those symptoms. Typically, a fibromyalgia patient is offered pain medication as well as pain education classes and subsequent programmes including cognitive behavioural therapies, exercise and relaxation programmes and advice regarding "pacing" (see chapters 4, 6 and 7). In reality, the typical fibromyalgia patient will find this aspect of treatment particularly difficult, as patients' self-esteem is directly connected with high achievement and any changes would therefore work against the personality traits of an "action-prone" person, who will demonstrate an outburst of activity on good days irrespective of potential consequences (Van Houdenhove et al., 2001; see chapters 6 and 7).

Research and anecdotal evidence point towards effective treatment of fibromyalgia with specific diets and the use of nutritional supplements. Currently, research findings claim that the introduction of a magnesium-based, monosodium-glutamate-free and vegan diet is most effective in reducing pain levels for fibromyalgia patients (Rossi et al., 2015; Giacomelli et al., 2013). Tovoli et al. (2012) conducted a specific study into the correlation of fibromyalgia and celiac disease by building on a previous research that had identified that 7% of celiac disease patients also suffered from fibromyalgia, thereby verifying the anecdotal evidence that a gluten-free diet would ameliorate fibromyalgia symptoms. The findings clearly show a higher prevalence of fibromyalgia amongst those with celiac disease, but where the prevalence of celiac disease was concerned within the fibromyalgia patients the correlation was the same as within the general population and non-fibromyalgia sufferers. The development of a gluten-free diet is thus another unproven and unsubstantiated treatment for fibromyalgia. Tovoli et al. (2012) see these findings as proof for yet another myth that is perpetuated within the fibromyalgia community and beyond, wherein lies the basis for the contested nature of fibromyalgia.

The contested nature of fibromyalgia

The difficulties around diagnosis and diagnostic criteria result in an incoherent or incomplete picture of fibromyalgia. As a consequence, the condition is often seen as imaginary and unreal (see chapters 4 and 6). For individuals with fibromyalgia the lack of an unambiguous diagnosis means that the condition itself is stigmatising and they are "discreditable" (Goffman, 1991/1963, 14; see chapter 6). The more openly fibromyalgia is discussed as a contested condition, the less likely individuals will accept a diagnosis thereby perpetuating the vicious circle of stigmatisation of fibromyalgia. For medical professionals the issues surrounding aetiology and diagnostic criteria results in reluctance to diagnose or intentional and unintentional misdiagnoses, as alternative diagnoses provide a better fit for either the doctor or the patient (see the statements of Hanna, Amy and Kate in chapter 6).

Nonetheless, studies in various countries provide some insight into the prevalence of fibromyalgia, although there is little consensus in the results. Critiques of the results also relate to the current lack of long-term studies. According to Assumpção et al. (2009) the prevalence of fibromyalgia ranges between 0.66% and 10.5% of the general population with the percentages being higher amongst women and in middle age. Bellato et al. (2012) estimate that 3.4% of the female population and 0.5% of the male population suffer from fibromyalgia, whilst Grodman et al. (2011) provide a 9:1 ratio between female and male patients. Jenner (2011) relates this gender-specific difference to the relationship of fibromyalgia and genes as well as hormone levels. A different study (Wolfe et al., 2013), by contrast, shows very limited differences between the numbers of male and female sufferers and the authors argue that many of the cited figures probably stem from the fact that 90% of the patients amongst the clinical population are women. Not many men are seen in clinics and women are more likely to demonstrate health and help-seeking behaviours, so that therefore more studies work with biased figures (Wolfe et al., 2013). Pamuk et al. (2009), Martínez-Lavín (2001), Lami et al. (2013), Hammond and Freeman (2006) partially relying on wider research and further studies state that around 2% of the population suffers from fibromyalgia.

The gradual widening of the diagnostic criteria that led to the 2010 revisions meant that "FM has reached epidemic proportions" (White and Harth, 2001:322) and resulted in a higher percentage of diagnoses by as much as 25% (Salaffi and Sarzi-Puttini, 2012). The global mean prevalence of fibromyalgia is recognised as 2.7% with a prevalence range from 0.4% in Greece to 9.3% in Tunisia (Queiroz, 2013, 356) and higher prevalence amongst lower educated people and those from lower household incomes (Queiroz, 2013). In contradiction, there is a high representation of students, teachers, medical staff and doctors amongst sufferers of chronic fatigue syndrome, myalgic encephalomyelitis and neurasthenia (Wessely, 1990, 1994). The reason for the overrepresentation of these groups may be that the selection of research participants was biased in that higher educated patients are considered to have easier access to specialists, which would also explain the higher levels of diagnoses amongst medical staff, nurses and those sufferers that are also authors of work related to their respective illnesses (Wessely, 1990, 1994).

The results amongst research are often conflicting, and should therefore not be considered uncritically, as there are many stakeholders in the fibromyalgia story. For the sake of my argument here I do not focus on the patients and lobbyists, but on academics, medical professionals and pharmaceutical companies. There are academics and medical professionals who have built their entire careers on the pursuit of understanding fibromyalgia. Naturally, it is in their best interests to ensure that fibromyalgia as a problem is explored but only to such an extent that it does not interfere with or intrude on their own scholarly work. Additionally, pharmaceutical companies fund medical research with specific aims and targets, as they are interested in developing and marketing medication aiming at managing or treating fibromyalgia. The genderisation of fibromyalgia as discussed in chapter 1 (see also Barker, 2005) is one conspicuous example for how stakeholder interests shape medical research.

In an article about the relationship between chronic musculoskeletal pain and low socioeconomic status the reasons given for some discrepancies are in the variability of definitions (Hagen et al., 2005). For example, the socioeconomic status may be measured according to patients' wealth, their education levels or their living areas. Also, there are differences based on the location and duration of pain, whether pain is widespread or regional and how many months are considered to signify chronic pain, in some cases this may be three months, in others six months or more. The study by Hagen et al. (2005) highlights that there is higher prevalence of chronic musculoskeletal pain amongst those with higher levels of education but also that these specific patients develop better coping strategies than those with lower levels of education. The reason for this could lie in the fact that those with higher levels of education may have more resources available, but also that those with lower levels of education live with lower expectations and their socio-economic status becomes a self-fulfilling prophecy (see in contrast to this chapters 5 and 6). In their study of the Dutch context Picavet and Schouten (2003) also demonstrate that the generalisations of previous pain studies in correlation with the education levels of patients are too simplified and therefore not accurate enough, as the location of pain differed depending on the patients' level of education. For example, patients with secondary or vocational education suffered more from low back pain but less from pain in hips or knees (Picavet and Schouten, 2003). Whilst this is an interesting observation this study also highlights potential issues with such claims made in studies, as the levels of education or socio-economic status are not clearly identified as high or low within their own interpretations of the data. Ultimately, prevalence statistics depend on the identification and use of clear, neat categories. However, despite the diagnostic criteria for fibromyalgia, the condition, its diagnosis and therefore any classifications are ambiguous.

Relevance of categorisations

Despite the existing diagnostic criteria, the classification of fibromyalgia is so unclear that there is still no real consensus over whether fibromyalgia should be seen as a disease, an illness or a syndrome. In medical research and socio-medical fields each of these terms is associated with clear connotations (regarding correct terminologies see also chapter 9). Whilst disease refers to the experience of faults within the structural function of the body, thus the physiological and biological errors, illness is described as the perceived experience of being unwell or suffering from symptoms. Whilst the physician therefore treats the disease, it is predominantly the psychiatrist's task to deal with illnesses (Turner and Samson, 1995). A syndrome is merely a set of symptoms, which is often interpreted as being medically unexplained and therefore situated between disease and illness. For some the decision of whether fibromyalgia is a disease, an illness or a syndrome may be irrelevant, as the treatment and management of the symptoms should take priority (Bennett, 2004; Ehrlich, 2003). However, categorisations, classifications and labels become important to identify whether physicians and psychiatrists are responsible for treating and diagnosing fibromyalgia.

The diagnostic process for any condition is a mutual understanding and relationship between a diagnostician and a patient. The role distribution requires the diagnostician to provide clear medical categories, a definitive label and a distinct action plan regarding treatment. The patient, in return, is obliged to comply and accept the assigned label and treatment in order to be healed (Parsons, 1951; see also chapter 6). To this end, a clear label and unambiguous diagnostic criteria are required. Despite intensive research, so far, no uniform explanation for fibromyalgia has been found. As a consequence, two opposing (bio)medical camps developed: those who believe in an organic or physical component to the condition and those for whom fibromyalgia is a behavioural or psychogenic condition. For some anxiety and depression are the causes for the pain experience, whereas for others the experience of pain leads to anxiety and depression (Goldenberg, 1999; Yunus, 1994; Hudson and Pope; 1996). And therein lies the crux of the issue around fibromyalgia. For medical professionals, the condition is problematic, as it highlights professional instability and insecurity. Diagnostically, fibromyalgia lies within the range of a rheumatologist whose professional task is to identify and treat causes of pain. The wide range of symptoms and illness experiences associated with fibromyalgia and the lack defining biomarkers mean that rheumatology as a field is overwhelmed and out of its depth (Barker, 2005) with fields such as psychology and psychiatry being equally under strain. At the same time, medical professionals are faced with patients, who require clear diagnoses and rely on the professional's knowledge to provide those. For some, the fibromyalgia label may be a welcome relief from anxiety around more severe and life-threatening diseases. For the individual, an accurate and unambiguous categorisation also means gaining access to treatments, healthcare and insurance entitlements. For others, the relatively vague status of fibromyalgia between somatisation, psychological disorders and physiological causes may be reason enough to reject the diagnosis and refuse treatment (see chapters 4 to 8). In this sense, the medical professional must negotiate a balance between the individual's condition and societal norms and expectations.

The difficulties relating to classifications and labelling become apparent when considering Yunus's (1994, 2008, 2009) terminologies of "dysregulation or dysfunctional spectrum syndrome", which he changed to "central sensitisation syndrome". Whilst Yunus (1994, 2008, 2009) always stresses that fibromyalgia is neither a purely psychosomatic nor a purely physical illness, and therefore difficult to categorise, he also argues in favour of a label that indicates the causes of an illness and provides a clearer picture for potential treatments. In Yunus's (2008) view the label is crucial because the consideration of comorbid conditions as a family of illnesses would provide medical staff with a clearer picture relating to the complexity of the syndromes and offer ways into treatment options that may otherwise remain unconsidered. Even in the 21st century patient care is still very much subject to the classic dualism of body and mind and Yunus's (2008) attempt to create a new category for illnesses such as fibromyalgia could mean that the biocentric and psychocentric fields would be brought together more closely. Similarly, Wessely (1994) highlights the relevance of a multi-disciplinary and cross-disciplinary approach to treatments for neurasthenia and chronic fatigue. In this case the debate relates heavily to whether or not depression or illness comes first within the chronic fatigue. Whilst doctors tend to focus on the depression as a cause, sufferers say that the physical fatigue, thus the illness is the root of chronic fatigue. Although one may think that this discussion is irrelevant as long as treatment is provided and the patient gets better, Wessely (1990, 1994) develops this idea in greater detail. If chronic fatigue syndrome is associated with depression as a primary cause then that would equate a psychiatric illness that is "all in sufferers' minds" and not a legitimate illness. Patients would therefore be subject to the stigma associated with mental health issues, but would also be considered as lazy and work-shy or hysterical, which in itself could have severe financial consequences where insurance pay-outs are concerned, for example.

On the other hand, however, the classification of fibromyalgia and related illnesses may result in underlying medical issues and problems potentially not being detected. This is due to the fact that the range of symptoms of fibromyalgia is so vast that many symptoms would be attributed to fibromyalgia or one of the related illnesses without another series of medical investigations. Amongst fibromyalgia patients pain experiences for example are so common that even the patients themselves would possibly not consider wider issues or different causes for pain (Wolfe et al., 2010) and would therefore not receive relevant treatment.

Fibromyalgia and its public image

As this chapter has shown so far, scientific research and medical professions are overwhelmed with the problem of fibromyalgia. As a result, diagnostic criteria and treatment options are at best vague and at worst contested. Over the past decade or so, popular culture has attempted to lead discourses in relation to lesser known, potentially more contested conditions, to the circumstances in which they occur and to the reality of the lived experiences. In some instances, these attempts have been welcomed by charities and lobbyists seeking to raise awareness. Individuals like Kirsty Young, Lady Gaga, Morgan Freeman, Sinead O'Connor and Florence Nightingale became public examples as famous people diagnosed with fibromyalgia.

Similarly, television programmes and movies have also addressed more "dubious" conditions. For example, in 1990 season 5 episode 2 of the series "The Golden Girls" focussed on the storyline of Dorothy Zbornak fighting for her chronic fatigue to be recognised as a serious, debilitating condition rather than a mere figment of her imagination. In 2014 the film "Cake" depicted the life of Claire Bennett, whose car accident leaves her with chronic pain and partial disability. This film explored the relationship between the physical and mental, emotional pain.

Some depictions are less helpful for the general cause, such as the pilot episode of the medical series "House" broadcast in 2004, during which one minor character seeks treatment for either chronic fatigue syndrome or fibromyalgia. Dr House sees the patient as a hypochondriac and treats him through the prescription of mints – with success. In the 2009 pilot episode of the medical comedy drama "Royal Pains" the endearing teenager Libby suggests she may have fibromyalgia as she experiences widespread pain and tactile allodynia (a pain response from stimuli that should not provoke pain), fatigue, sleep disturbances, cognitive dysfunctions, anxiety and depression. Dr Hank Lawson diagnoses Libby with cyberchondriasis, a form of hypochondriasis related to and exacerbated by searching for health information online (Muse et al., 2012). As these examples show, despite the increase of plotlines around contested or complex conditions, fibromyalgia continues to be associated with hypochondriac behaviours and health anxieties. Although in both TV shows the characters are not actually diagnosed with fibromyalgia, the programmes do not attempt to redress the public image of fibromyalgia being a condition "often found in individuals who will not or cannot cope with everyday stresses of life" (Capen, 1995:207).

How the general public is split into two camps around fibromyalgia is best exemplified through singer-songwriter Lady Gaga. In September 2017, Lady Gaga officially confirmed that she had been diagnosed with fibromyalgia. Her followers and fans had long known about mental health issues related to post-traumatic stress disorder and the trauma of having been raped aged 19. It was also public knowledge that the popstar suffered from chronic pain. After all, she often posted pictures on social media of treatment regimens such as massages, acupuncture and cryotherapy. However, her diagnosis of fibromyalgia was not public until September 2017, when her documentary "Five Foot Two" was first broadcast (The Mighty, September 2017). Suddenly, fibromyalgia entered the public discourse of social media and news broadcasters. And with the footage of Gaga suffering pain and receiving treatment from her personal physiotherapist and doctor, came critical comments about the singer engaging in attention-seeking behaviour, not really being ill, and her diagnosis not being valid. Social media became divided over what is a divisive illness. The public discourse around Gaga was similarly divided. On the one hand, critics referred to Gaga's weakness, selfishness and her wallowing in self-pity. On the other hand, those with fibromyalgia felt that her financial stability and fame would allow her to access specialist treatments and so help her manage the condition in ways they themselves would not be able to. The criticism here was that her ability to remain relatively active and continue the physical intensity of a world tour would not accurately depict how debilitating the condition can be (The Mighty, November 2017). It is the lack of tangible test results that leads to the fibromyalgia experience often being negated or trivialised (The Mighty, August 2017), an experience that Lady Gaga also had to contend with (Twitter, September 2017). After having cancelled individual appearances in September 2017 and having recovered from the fibromyalgia flare-up, Lady Gaga continued her tour until in February 2018 the symptoms she experienced were so debilitating that the popstar eventually decided to halt her "Joanne" world tour. Within the fibromyalgia community, it was almost welcome news that the severe pain caused by and connected with fibromyalgia represented the premature end of the tour, as it showed how "serious" the condition could be. Where academia is concerned, fibromyalgia came into the focus of news reports in connection with non-disclosure agreements in the spring of 2019 (Croxford, 2019). Anahid Kassabian, a music professor, had signed a non-disclosure agreement in relation to a settlement over unfair dismissal and health concerns, one of which was fibromyalgia (BBC, April 2019a,b).

These examples from popular culture highlight what was first touched upon in the systematic literature review at the beginning of this chapter: the ever-increasing presence of fibromyalgia. In the case of fibromyalgia, however, this rising interest is not comparable to the meteoritic rise and indeed popularity of neurasthenia. Where neurasthenia was originally linked to positive values and attitudes, fibromyalgia has always had to contend with the image of the malingerers.

Concluding thoughts

The bodies of literature presented in this chapter explore the historical development of the label and its significance. I demonstrate that there is a long historical tradition around fibromyalgia and fibromyalgia-like conditions, but that this does not mean that the condition is free from potential problems. I used this literature chapter to outline fibromyalgia as a contested condition with an unknown aetiology, arbitrary diagnostic criteria, and critical debates around prevalence and a wide range of symptoms. Drawing on the long-standing history of conditions similar to and linked with fibromyalgia I have shown that the construction, acknowledgement and acceptance of illnesses is strongly related to what is fashionable within society at the given time. For example, having a highly developed nervous system and being successful alongside the concepts of spent energies and the body requiring recovery has enabled the popularisation of neurasthenia. In the case of fibromyalgia, the story is somewhat different, as it is not associated with the positivity of the original neurasthenia image. And yet, (bio)medical perspectives have not been able to provide clear answers to the root of the condition. As a result, symptomology categories and diagnostic criteria are vague, which in turn impacts treatment options. For individuals this means entering the moral career of a discreditable person (Goffman, 1991/1963), whereas for medical professionals and academics this is a professional dilemma and frustration.

The insecurity and vagueness around aetiology and the resulting arbitrariness of diagnostic criteria emphasise the limits and limitations of the (bio)medical perspectives of fibromyalgia. What is missing is a socio-cultural, constructionist perspective. As human beings we do not live in a vacuum but shape and are shaped by the societal and cultural contexts that surround us. These contexts also affect our experiences and understanding of health and illness. Medical anthropologists and sociologists are particularly interested in how the individual experience shapes and is shaped by the wider influences (see Williams and Bendelow, 1998; Kleinman, 1988; Morris, 1991). These are best exemplified and illustrated with experiences of pain. In today's western society pain is considered a medical concern that needs to be treated and resolved, often through pharmaceutical solutions. In some societies, however, pain is a fact of life, a sign of becoming older or of having undertaken strenuous work, and is therefore not treated, and indeed not even reported (Helman, 2007). The response to pain is regulated not only on an individual level, but also on the societal understanding of what pain represents as pain occurs at the intersection of bodies, minds and cultures (Morris, 1991). Pain is seen as subjective and personal whilst at the same time being experienced within a particular social and cultural context, particularly as one person's pain will affect that person's family, friends and colleagues, who in turn impact the individual's experiences and lifeworld (see Kleinman, 1988; Frank, 2002; Frank, 2013; Good et al., 1992). In these discourses, pain and other bodily functions and experiences, need to be considered as a form of language, as the body communicates and expresses. Pain is understood as mimetic, "a form of hysteria whereby people mimic socially acceptable ways of exhibiting distress" (Bendelow, 2009:41). The human body in its "performative" (Good et al., 1992:17) function takes on a particular role in expressing health and illness (see Leder, 1990; Frank, 2013; Corbin, 2003).

It is in this connection that the higher education context becomes particularly relevant. Within research as well as within academia mental health and well-being amongst staff and students have become more focal concerns in recent years, as education is the sector with the highest rates of stress, depression or anxiety (HSE, 2018). Globally, 21.2% of years lived with disability are due to mental health problems (Vos et al., 2015). In the UK, 51.2% of women and 35.2% of men believe that they suffer from mental health problems (Mental Health Foundation, 2016). One third of the women believing to suffer from mental health disorders have received a formal, professional diagnosis with a steady increase being particularly noticeable since 2000 (Mental Health Foundation, 2016). Interest in chronic pain and its impact has also increased with studies estimating that 43% of the UK population experience chronic pain (Fayaz et al., 2016). Within the context of UK higher education, the Association of University Teachers found that 93% of its nearly 160,000 academic staff members experienced work-related stress and 62% "excessive" strain (Tytherleigh et al., 2005). Diagnoses of mental health issues, psychological disorders, medically unexplained syndromes and stress-related illnesses are more openly discussed than ever (Deaville, 10 December 2012; Kelsky, 19 April 2013; Wood, 15 December 2013; Lock, 20 December 2013; Davis, 11 January 2014; Dunstan, 9 March 2014; Muller, 18 April 2014; Taylor-Jones, 5 June 2014; Pryal, 13 June 2014). However, the fact that these narratives do not appear in scholarly articles but as part of the public profiles of academics hints at further complexities within academia: the issue of disclosure (see chapter 7). The proportion of staff in universities declaring health conditions or impairments were 3.9% in 2012-13 (HESA, 2017), although 16% of working age adults (GOV, 2014) and nearly 13% of undergraduates have a known disability (HESA, 2017).

As we have seen, the vagueness of the condition and issues around the psychological role in the illness make fibromyalgia a contested condition. These factors coupled with the one-sided representations and mis-representations in the media result in fibromyalgia being viewed and experienced as stigmatizing (Sabik, 2010). Therein lies the challenge of fibromyalgia in higher education. Being ill is considered a weakness and a fault, and as personal satisfaction and self-fulfilment stem from academic work, it is in the interest of academics to maintain a public face (Goffman, 1990/1959) of perfection to avoid stigmatisation (Goffman, 1990/1963) and discrimination.

3. Research approach

Basic foundational principles, assumptions and philosophical outlooks on what constitutes knowledge or truth underly all research as the theoretical framework is the blueprint to what is the house of the research (Grant and Osanloo, 2014). In this chapter I provide an outline of my interpretivist approach towards research (Willis et al., 2007) that draws on principles of arts-based research. I then discuss how ensuring good quality research within the interpretivist and arts-based framework requires transparency, criticality and reflexivity. With these three pillars in mind, I continue with a section on my own positionality within the research on hand. Next, I outline the recruitment process as well as details on participant sample and size. I discuss my research design by presenting the data collection methods and how I came to develop the approach using identity boxes and also representations. I offer insights into ethical considerations around the use of arts-based methods, but also the practicality of doing research with academics who are chronically ill. In the data analysis section, I explain theoretical foundations and principles as well as the steps involved in the iterative sense-making process. The analytical processes described comprise of conventional coding and theme-generation alongside arts-based assemblage and the creation of an illustrated poem and a 3-D installation. I offer details on these artistic ways of making sense in connection with and in the context of considerations regarding the research in practice and the reality of using creative methods for enquiry.

In this chapter I combine contents from five peer-reviewed publications with additional, unpublished contents. The publications are three articles in *International Journal of Social Research Methodology*, *Sage Research Methods Cases*, *Cogent Social Sciences* and two book chapters in Huisman and Tight's *Theory and Method in Higher Education Research Vol. 4* and in Leigh's *Conversations on Embodiment across Higher Education: Teaching, Practice and Research*.

Creativity and playfulness in qualitative research[2]

The foundation of interpretivist research is to seek deep understanding of situated knowledge and contextualised particulars (Willis et al., 2007). The researcher's task is to connect the individual experiences, with the social and historical contexts, the

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[2] This section draws on my published chapter: Brown, N. & Leigh, J.S. (2019). Creativity and playfulness in Higher Education research. In: Huisman, J. & Tight, M. (eds.) *Theory and Method in Higher Education Research Vol.4*. Emerald Publishing Limited, 49-66.

practical application of "sociological imagination" (Mills, 2000). In the spirit of interpretivist enquiries, there cannot be a singularly applicable and right framework in order to achieve this task. For some commentators, the answer is to refer to symbolic interactionism to explore the intersection of the biographical, historical and social, as it examines the influence of the social context on people's feelings, thoughts and actions and provides tools to explore the relationship between real, living people who think, feel, and act and the social forces that shape their thoughts, emotions, and behaviours (Charmaz et al., 2019:6). Other scholars emphasise the element of social justice within the research endeavour of sociological imagination and so call for researchers to focus on the communality of social justice and to engage in research processes that will allow "to make life better for a person, or a group of persons" (Denzin, 2016:42). To this end, interpretivist research should and indeed needs to draw on a range of methods for data generation, analysis and dissemination.

Research is often seen as too distanced and remote from the physical bodily experience instead of seeking to insert the body into the theoretical understanding (Ellingson, 2017). Ultimately, an embodied approach (Ellingson, 2017) is needed that transcends "dualistic legacies of the past" (Williams and Bendelow, 1998:3) and that puts "minds back into bodies, bodies back into society and society back into the body" (Williams and Bendelow, 1998:3,209). According to recent discourses within research theory and practice, the answer is to transcend disciplinary boundaries, to develop multimodal forms of enquiry (Dicks, 2014; Hurdley and Dicks, 2011; Jewitt et al., 2016), and to combine sensory and visual ethnography (Pink, 2013, 2015) with creative research methods (Kara, 2015). Despite their very individual and individualised designs and philosophies, all of these approaches are founded on three basic principles. The first premise is that human language is limited and limiting, especially when individuals try to explain and describe sensations, such as pain, or other embodied and bodily experiences (Scarry, 1985; Sontag, 2003; Eccleston, 2016; McKiernan, 2018). Secondly and related to the limitation of language, human understanding and experiences are fundamentally embodied (Finlay, 2015). And thirdly, because of the embodiedness of human understanding and the arbitrariness of language, humans turn to metaphorical expressions and forms of communication in order to compensate (Lakoff and Johnson, 2003). The aim of the creative, sensory and multimodal methods is to overcome these challenges to research; and they do that by drawing on creativity and playfulness. Although creativity and playfulness are not commonly used in higher education research, they have already entered the field within social sciences research. Being creative means to engage with the research tools that are available from a range of disciplines and to playfully connect what may otherwise not be linked. Existing research into lived experiences include the process of creating representations through the use of Lego (Gauntlett, 2007) or the use of metaphors in sandboxes (Mannay and Edwards, 2013). In both cases, the activities remind us of attitudes children would bring to their play. In addition, social sciences draw on art workshops (Tarr et al., 2018) or collaborations between artists and research participants (Bartlett, 2015) to explore personal experiences and social interactions amongst humans. However, an open and playful attitude can also be a much subtler thing, that results in an openness towards different and varied approaches towards research rather than fixed theoretical or disciplinary ideas that bound and constrain the acquisition of new knowledge; hence my turn towards arts-based research.

Arts-based research

Like many frameworks and paradigms arts-based research has also evolved over the course of time and so cannot be neatly packaged into one category. Depending on the focus of the enquiry, the aim of the research and the positionality of the artist-practitioner-researcher there is "arts-inquiring pedagogy, arts-based inquiry, arts-informed inquiry, arts-informing inquiry, arts-engaging inquiry, and arts-related evaluation" (Savin-Baden and Wimpenny, 2014:5). In all of these forms of arts-based enquiries, the arts are used to "raise significant questions and engender conversations; to capture meanings; to diversify the pantry of methods that researchers can use to address the problems they care about; and to contribute to human understanding" (Barone and Eisner, 2012:164-172). Within the context of seeking understanding of pain experiences, but also to represent those experiences and thereby to create outputs that would challenge existing social structures "turning to the arts and literature is often recommended as a strategy" (Williams and Bendelow, 1998; Bendelow, 2000:64). More specifically, according to Leavy (2015) employing arts-based research helps

> to provide new insights and learning; to describe, explore, discover, problem-solve; to forge micro-macro connections; to engage holistically; to be evocative and provocative; to raise awareness and empathy; to unsettle stereotypes, challenge dominant ideologies, and include marginalized voices and perspectives; and to open up avenues for public scholarship, usefulness and social justice (Leavy, 2015:21-27).

Mills (2000), Bochner and Ellis (2016) and Denzin (2016) all talk about sociological research needing to connect the personal with the historical and the social. In the case of autoethnographies, the personal relates to the personal of the researcher, thus the researcher's own experiences. Arts-based researchers suggest that such connections are possible and more easily achievable through the use of arts, as the arts express and foster emotions and emotional responses. Through personally touching audiences it is possible to draw in individuals, thus to raise awareness of wider social and societal issues, and to cause action.

Ensuring good quality in research[3]

The role the arts can play as a form of expression is largely undisputed, but criticism around the use of the arts in research is rife. From a research point of view, the arts are not seen as "scientific" enough to provide relevant data and analyses for generalised and generalisable understandings. From an arts and aesthetics point of view, the research outputs are not artistic or beautiful enough to genuinely count as pieces of art. With this in mind, we do need to consider what constitutes as good quality within arts-based research. Qualitative research per se often has to contend with the criticism of not being generalisable in the same way as positivist, quantitative frameworks are. As a consequence, qualitative researchers tend to focus on concepts such as transferability (Lincoln and Guba, 1985), applicability (Lincoln and Guba, 1990), credibility (Creswell and Miller, 2000) or fuzzy generalisation (Bassey, 2000, 2001) to ensure robustness and high quality of data, which in turn ensures comparability. As there is an abundance of frameworks for qualitative research, there is equally a multitude of evaluative frameworks providing specific criteria for judging, ensuring and assuring the quality in qualitative research. Tracy (2010) for example suggests eight criteria: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence. Barone and Eisner (2012) focus on incisiveness, concision, coherence, generativity, social significance and evocation and illumination. Leavy (2015) highlights methodology, usefulness, significance, or substantive contribution, public scholarship, audience response, aesthetics or artfulness, personal fingerprint or creativity, and ethical practice. Lafrenière and Cox (2013) provide a framework to assess arts-based works based on normative, substantive and performative criteria; the substantive and performative criteria refer to the technical and artistic skills and

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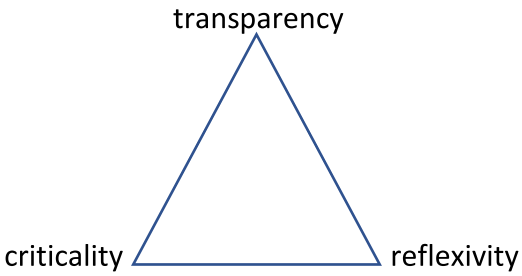
[3] This section has been published in the article: Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology,* 1-15.

the effects on an audience, whereas normative criteria refer to methodological and ethical considerations of the research process.

These existing frameworks provide criteria or notions we as researchers may want to pursue to evaluate the final research outcome, but not enough attention is paid to the process of creating, making, assembling that installation, poem, fiction, or painting. How can we as researchers be sure that we have undertaken all the necessary steps to ensure and assure quality during that creative process? And which steps are necessary at all? By their very nature, creative processes happen organically and dynamically, and as soon as there are specific steps, guidelines or rules to follow, the process is no longer as open, creative and playful as it could be.

I argue that there can only be basic principles underpinning the creative analysis based on three interconnected strands for ensuring and assuring good quality research – transparency, criticality and reflexivity:



These three cornerstones of good qualitative research cannot be seen in isolation from one another, but as interconnected facets of the same issue. One major criticism of qualitative and arts-based research relates to the "anything-goes, navel-gazing" attitude that will allow individuals to engage in forms of expression that is to their liking and not necessarily scientific. In order to counteract this criticism, it is necessary to critically engage with the study and its methods, the data and their interpretation, and the choices that researchers and participants make throughout the process. Researchers need to critically view and re-view the entire research process in its individual stages in a reflective and reflexive cycle. During analysis, for example, tending to merely one level of interpretation of data does not demonstrate critical engagement with the analytical process. Instead, it is necessary to look for different, potentially opposing interpretations. The critical engagement on its own, however, is not sufficient.

Researchers need to be transparent, open and honest about the choices and selections they make, the limitations and challenges they experienced, about what they do in analysis, how they do it and which thought processes go into that analytical shaping of themes and ideas. Researchers can only engage critically in and be transparent about the choices make, when they firstly consider their personal views and the lenses through which they carry out their research. As such transparency for the benefit of readers of research, requires firstly critical transparency towards and of one's self: reflexivity.

Thinking reflexively about biases, prejudices and worldviews allows to recognise where and how researchers shape data collection and analysis. Research reports and publications relating to qualitative research in the social sciences often explore elements of positionality in relation to personal biases, experiences and pre-existing knowledge brought to the research. Through detailing and exemplifying such factors researchers seek to validate and objectivise their analyses and any potential influences on findings and outcomes, thus to make their research "at least quasi-objective" (Foley, 2002:473). This is, however, problematic. The stages or phases of reflections and individual learning or recognition are usually not made transparent or indeed critically engaged with. It is merely the researcher's final conclusion that is shared. Yet, if a researcher is truly committed to reflexivity and its "process of self-scrutiny" (Chiseri-Strater, 1996:130), then reflections about reflections or justifications must be superimposed openly and explicitly.

Positionality[4]

Having considered basic assumptions, frameworks and criteria for good quality research I will at this point outline my personal position and my own understanding of my positionality within the research on hand, as only through engaging with our own selves, we can gain deep understanding of the matters under study (Ellingson, 2006). Despite increased calls for a more reflexive and embodied research approach, there are stark warnings regarding risking too much, exposing oneself too openly and thus making the researcher-self vulnerable (Delamont, 2018). And yet, as we have

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[4] This section is an amalgamation of extracts from two of my published articles:
Brown, N. (2019). The embodied academic: body work in teacher education. In: Leigh, J.S. (ed.). *Conversations on Embodiment across Higher Education: Teaching, Practice and Research*. London: Routledge, 86-95.
Brown, N. (2018). Video-conference interviews: Ethical and methodological concerns in the context of health research. *SAGE Research Methods Cases.*

seen above, transparency, criticality and reflexivity are required in order to ensure good quality research.

It is at this point that I ought to reveal my true self. I am hearing-impaired with a by now severe to profound hearing loss in both ears, so I wear hearing aids. I have also been diagnosed with fibromyalgia. It would be a blatant lie if I was to say that these bodily experiences did not influence me as an academic. If I am honest with myself, my interest in embodiment and the use of the body stems from my personal experiences of and with a body that betrays me, often unannounced. The fact that I have been diagnosed with fibromyalgia supposedly makes me an insider researcher. However, due to the variability and uniqueness of the fibromyalgia illness experience I still remain very much an outsider to my research participants' stories. I am acutely aware of the tensions around disclosing to the research participants and declaring myself an insider, whilst maintaining an academic, research persona instead of becoming "the fibromyalgia patient". At the same time, the physical experience of fibromyalgia cannot be excluded from the research process. I often experience fibromyalgia symptoms in response to environmental and contextual influences. This has led me to consider my positionality in relation to a wider range of bodily responses, such as "hearing voices" when reading interview transcripts, or experiencing bodily fatigue and brain fog after an interview. Upon reflection, I realised how difficult it was for me to extract my researcher self from my fibromyalgia self.

Not only was my researcher self tied to and bound up with my fibromyalgia self, I also noted my professional and disciplinary backgrounds influencing my thought processes and ways of working. Professionally, I started out as a secondary school teacher. After a career break, I volunteered to help teach research methods at university level, which turned into an academic contract to work as a teacher educator at postgraduate level and lecturer in education at undergraduate level. Throughout this time, I saw research as a process of exploring personal teaching practices in order to improve teaching quality and learning experiences within the secondary, undergraduate and postgraduate classroom. Research took on the form of a practice-based enquiry following an action research approach that would allow for a multitude of data collection methods within that contextualised framework of a specific classroom, but that would not necessarily consider social or historical factors outside that classroom (Hammersley, 2007). I made sense of experiences and learning within my classroom, and referred all findings back to my own practices –

good or bad. I did not seek to understand how factors external to the classroom would impact the dynamics within or, vice versa, how the events within a classroom would seep into the outside world. It was this realisation that led me to develop a research approach, which would allow for participatory meaning-making processes between me as researcher and my participants, and which would also allow me to draw on the arts to understand and disseminate data. The thesis on hand is my attempt to reconcile the many different strands of research – aims, purpose, philosophical underpinnings – and the conventions from various disciplinary backgrounds – education, health, sociology.

Recruitment of participants, sample and size

Having gained full ethical approval from the University of Kent to undertake this research, I sought to recruit participants from academic and non-academic backgrounds. I had planned for several stages to the data collection. Phase 1 would be with non-academics with fibromyalgia who would undertake the identity box project, phase 2 was going to ask academics to supply their CVs as well as their fibromyalgia and academic timelines, phase 3 was going to be the identity box project with academics with fibromyalgia, and phase 4 was going to be academics jointly creating a representation of life in academia under the influence of fibromyalgia. All participants were fully informed about the different stages and were given opportunities to opt in to any phases, as they would see fit, and they were told that they could withdraw at any point without giving reasons. I summarise the different data collection phases in the following table:

	Research participants	**Data collection method**
Phase 1	non-academics	identity boxes with interview
Phase 2	academics	CVs and timelines
Phase 3	academics	identity boxes with interview
Phase 4	academics	co-creation of representations

Figure 3.1: Summary of data collection phases

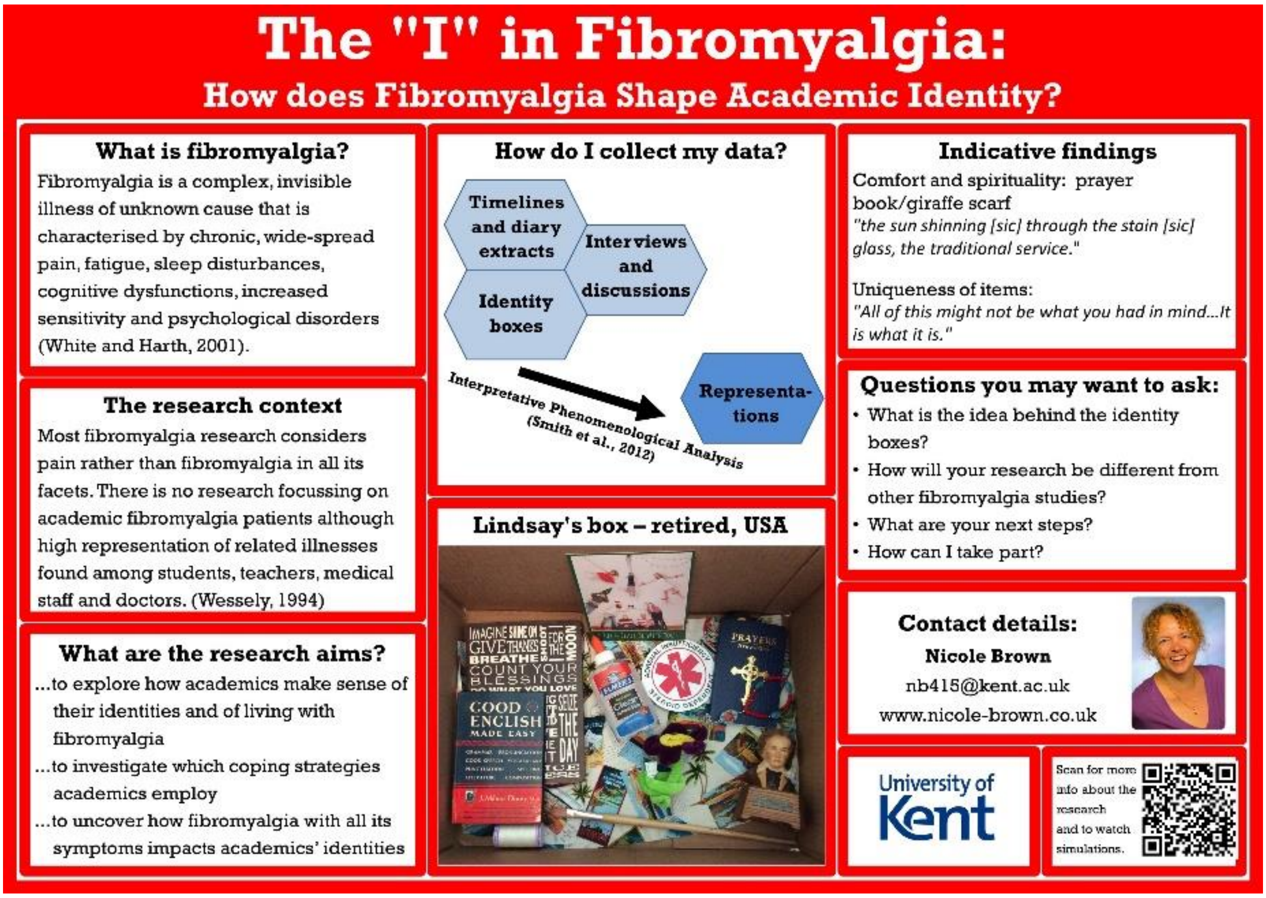
My reasoning to use non-academics for phase one was two-fold. On the one hand, I wanted to ensure that I would have an opportunity to test my approach with identity boxes to iron out any difficulties before commencing the main study with academic participants. On the other hand, I wanted to ensure that I would have some data that I could compare to. I felt that talking about the specificity of academia required a better understanding of the experiences of non-academic participants as a baseline. In order to allow for comparisons between academic and non-academic participants, I ensured to have two entirely separate studies. I specifically recruited participants for phase 1 and using the three principles, hermeneutics, idiography and phenomenology from Interpretative Phenomenological Analysis (Smith et al., 2012) I focussed on the specific experiences of participants with fibromyalgia who did not identify as academics, but who were nonetheless educated to at least undergraduate level. As per the principles of Interpretative Phenomenological Analysis, the findings from that study are made relevant due to the heavy focus on the homogeneity of the participants under study. The participants recruited for the main study, phases 2 to 4, were also homogenous in the sense that all participants identified as academics.

As fibromyalgia is not particularly well understood, and often seen as a contentious diagnosis with somewhat arbitrary diagnostic criteria, the journey from experiencing symptoms to diagnosis is long, and diagnosticians are reluctant to firmly diagnose fibromyalgia. This complex status of the illness also results in those diagnosed with fibromyalgia to not necessarily disclose the diagnosis for fear of stigmatisation or because they themselves have not quite come to terms with the diagnosis. Finding potential participants with fibromyalgia therefore required a strategy that would combine several techniques to one coherent approach. The recruitment techniques I used were: direct recruitment via advertising in support groups; direct mailings; advertising through flyers and posters at conferences; and subsequent referrals.

As someone who is diagnosed with fibromyalgia, I had been a member of several support groups within the UK and online. My first approach to recruiting participants therefore was to work with the relevant support group administrators to advertise within the particular fibromyalgia networks according to the groups' rules and guidelines. In some rare cases, I was asked not to recruit, but largely the support groups welcomed the potential of raising awareness regarding the lived experience with fibromyalgia, and group administrators actively supported calls for participation. I provided details via the information sheets, research summary files and consent forms, and occasionally, I was asked to present my proposal and research context as for example to the Fibromyalgia support group for Faversham, Sittingbourne and Sheppey in Kent, UK. This method was very successful regarding the recruitment of non-academic participants for phase 1. I recruited 16 non-academic participants, of whom 1 was male and 15 were female. The inclusion criteria for phase 1 were a formal diagnosis of fibromyalgia. At the time of signing up for the research, all participants had received a formal diagnosis of fibromyalgia and had been living with fibromyalgia for a minimum of 3 years.

Reaching academics with fibromyalgia required a different approach. Academics with fibromyalgia tended not to be part of general support groups, but more specific social networks, and they tended not to disclose their fibromyalgia diagnosis, but focus on their academic life, experience, reputation and network. Consequently, I decided to advertise directly during conferences and through direct mailing. I approached equality, disability, inclusion and wellbeing teams at universities across the UK asking to have my call for participation forwarded to staff and members of the relevant staff networks. I attended several national conferences where I distributed leaflets to attendees of keynote speeches. The emails and leaflets contained the research summary, information about participation and links to my email address. Through this approach academics with and without fibromyalgia were able to get in touch with me to enquire about my research and/or pass on my details to relevant colleagues and friends.

I had also applied to present a research poster at national conferences. The poster presented information on the purpose of the research, the research methods as well as some indicative findings from the non-academic sample. A QR code on the poster led viewers directly to a specific area on my personal web site, which would provide more information. I also included my contact details and next to the poster I displayed a pocket with flyers and business cards for those interested in the research to take away.



The "I" in Fibromyalgia:

How does Fibromyalgia Shape Academic Identity?

What is fibromyalgia?

Fibromyalgia is a complex, invisible illness of unknown cause that is characterised by chronic, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, increased sensitivity and psychological disorders (White and Harth, 2001).

The research context

Most fibromyalgia research considers pain rather than fibromyalgia in all its facets. There is no research focussing on academic fibromyalgia patients although high representation of related illnesses found among students, teachers, medical staff and doctors. (Wessely, 1994)

What are the research aims?

...to explore how academics make sense of their identities and of living with fibromyalgia

...to investigate which coping strategies academics employ

...to uncover how fibromyalgia with all its symptoms impacts academics' identities

How do I collect my data?

Timelines and diary extracts

Interviews and discussions

Identity boxes

Representa-tions

Interpretative Phenomenological Analysis (Smith et al., 2012)

Lindsay's box – retired, USA

Indicative findings

Comfort and spirituality: prayer book/giraffe scarf

"the sun shinning [sic] through the stain [sic] glass, the traditional service."

Uniqueness of items:

"All of this might not be what you had in mind...It is what it is."

Questions you may want to ask:

- What is the idea behind the identity boxes?
- How will your research be different from other fibromyalgia studies?
- What are your next steps?
- How can I take part?

Contact details:

Nicole Brown

nb415@kent.ac.uk

www.nicole-brown.co.uk

University of Kent

Scan for more info about the research and to watch simulations.

Figure 3.2: Research poster used for recruitment

The exposure at conferences through the poster and leaflets combined with the connected social media exposure through tweets and likes led to academics with fibromyalgia getting in touch asking for the full information and consent forms in order to sign up as research participants. Most academic research participants either contacted me directly or were referred to me via the conference leafleting or my social media presence.

In order to be included in phases 2 to 4 the research participants needed to have been diagnosed with fibromyalgia and they needed to self-identify as academics. This led to the sample size being varied in terms of the academic positions, roles and workplaces represented. I recruited 28 academic participants, of whom 2 were male and 26 were female. Academic roles ranged from early careers researchers currently undertaking their PhD studies, to mid-career academic practitioners and lecturers to professors in later career stages. Participants' working conditions ranged from independent research positions and self-employment, to hourly paid lecturers, part- and full-time employments in Further Education and Higher Education contexts. The fibromyalgia diagnosis as inclusion criterion was more clearly defined and led to fewer variabilities. All participants had received a formal diagnosis at some point in their lives, with the time lived with a formal fibromyalgia diagnosis between 3 and 10 years. During the course of my research and work with participants, two participants' fibromyalgia diagnoses were re-evaluated and refined. The fibromyalgia diagnosis was not entirely revoked but reframed within the context of Ehlers-Danlos Syndrome and Central Sensitisation Disorder, respectively. As the fibromyalgia diagnosis continued to be relevant and both participants' treatments for fibromyalgia were also continued, the participants' contributions to the research were not excluded. Participation varied amongst and across participants with some starting the research and dropping out and others temporarily withdrawing from the research tasks but then returning to them in order to complete them. Overall, 18 participants provided their CVs, 17 participants submitted their academic and fibromyalgia timelines, 10 participants completed the identity boxes, and 10 academics participated in the co-creation of a representation of life with fibromyalgia. 22 participants were involved in one-to-one conversations and 4 participants supplied extra materials and resources to complement the conversations. Of the 28 academics signed up, 8 participants can be considered as having dropped out entirely. In the list overview below, the eight participants who dropped out are indicated by an asterisk. Their stories and input up to the point of dropping out were still very relevant for this study and were used in the analysis. The following table shows a list of the academic participants and the data collection methods they engaged with. All names are pseudonyms, which I assigned from popular names.

Pseudonyms	**CV**	**Timelines**	**Identity box**	**Interviews**	**Facebook group**	**Additional and alternative media**
Alison	x	x	x	x	x	
Amy	x	x	x	x		
Angela	x	x		x		
April*				x		x
Bernie	x	x	x	x	x	
Beth				x	x	
Calli	x	x			x	
Carmen	x	x		x		
Dana	x	x	x	x		x
Elena	x	x		x		x
Erica	x				x	
Eryn*				x		
Faith*				x		

Hanna		x	x	x		
Jackie	x	x		x		
Jill	x	x		x		
John	x	x			x	
Joyce*	x				x	
Kate	x	x	x	x	x	x
Lana*				x		
Patricia*				x		
Peg	x	x	x			
Rebecca*				x		
Scott	x				x	
Sherry	x	x	x	x		
Sian	x	x	x	x		
Tami*				x		
Yasmin		x	x	x	x	

Figure 3.3: Data collection by participant

Where variables are concerned, classification categories are often arbitrary. For example, it is difficult to draw an exact line between an early career academic and a mid-career academic. Equally, contractual details may be such that an academic is considered as established in their career and yet may not necessarily count as a mid-career academic. This phenomenon of an academic belonging to several categories is particularly prominent in disciplines relating to professional practices, such as teaching/teacher education and medicine/medical education. Similarly, there is a marked difference between the educational contexts of higher and further education institutes. This arbitrariness of academic identity and roles will be explored in chapter 5. For the purpose of providing an overview of the participants' roles and occupations, I defined early career academics as those academics who either were in their first postdoctoral position after completion of their doctorate or their first academic position without doctorate. Participants whose work had led to them being established in an academic position and having undergone promotions were considered as mid-career academics. I defined professors as late career academics. The following table outlines the classification of the participants according to their career stages, their employment statuses and their institutional contexts.

Pseudonyms	**Career stage**	**Employment**	**Institution**
Alison	early career	temporary/hourly paid	HE
Amy	mid career	open-ended	HE
Angela	early career	open-ended	HE
April*	mid career	unemployed	not applicable
Bernie	mid career	open-ended	FE

Beth	mid career	temporary/hourly paid	FE
Calli	mid career	open-ended	HE
Carmen	early career	PhD GTA	HE
Dana	late career	open-ended	HE
Elena	early career	PhD GTA	HE
Erica	early career	PhD GTA	HE
Eryn*	early career	temporary/hourly paid	HE
Faith*	mid career	open-ended	HE
Hanna	early career	temporary/hourly paid	HE
Jackie	mid career	open-ended	HE
Jill	early career	temporary/hourly paid	HE
John	mid career	open-ended	HE
Joyce*	early career	unemployed	not applicable
Kate	mid career	open-ended	FE
Lana*	early career	unemployed	not applicable
Patricia*	late career	unemployed/retired	not applicable
Peg	mid career	open-ended	HE
Rebecca*	early career	temporary/hourly paid	HE
Scott	early career	freelance	not applicable
Sherry	late career	temporary/hourly paid	FE
Sian	early career	open-ended	HE
Tami*	early career	temporary/hourly paid	HE
Yasmin	mid career	open-ended	FE

Figure 3.4: Summary of participants' career status

Commonly, sociological research reports on projects where participant numbers are between 30 and 40 to ensure a representative sample size and data saturation. However, there is hardly any consideration of or justification for particular sample sizes and their relationship to data saturation (Vasileiou et al., 2018). Where saturation is discussed, the comments are arbitrary and problematic, as they confound and oversimplify methodological considerations (Low, 2019). In general, considerations around sample size and data saturation are largely driven by expectations and conventions (Vasileiou et al., 2018). As such, authors tend to refer to sample size and data saturation only within the context of limitations of a qualitative research, by highlighting how the small sample size of their research may limit validity and generalisability. Considering the randomness of sample sizes, as highlighted by Vasileiou et al. (2018), coupled with the interpretivist aim to provide understanding and not necessarily generalisability, we have to ask ourselves: what constitutes sufficient data? The commonly accepted definition of data saturation is when the study can be reproduced (O'Reilly and Parker, 2012), when no new information can be added to the existing analytical units (Guest et al., 2006) and when coding becomes unfeasible (Guest et al., 2006). Ultimately, the decision of when enough is enough, rests with the researcher and will depend upon the richness, thickness and depth of the data collected (Fusch and Ness, 2015). The richness of data generated in this research stems from the different tasks set throughout. In the end, I had data from conversations by email, supporting materials, photographs, diary excerpts or poems and 22 interviews. All interviews and supplementary materials were transcribed, coded and analysed as data until I reached "pragmatic saturation" (Low, 2019:137).

Research design

In view of the complexity of fibromyalgia, the fact that many of the related illness experiences are difficult to express and in view of my aim to explore the holistic experiences rather than honing in on specific aspects, I needed to develop a research approach that would account for embodied perspectives. I therefore drew on arts-based (Barone and Eisner, 2012), creative (Kara, 2015) and sensory methods (Pink, 2013, 2015). Naturally, the verbalisation of experiences and explanations of created data still played an important role, but expression through metaphors representations provided a first stage for data generation. As I wanted to ensure that all participants would find the data generation process accessible, I offered a wide range of creative approaches and formats for the tasks I set. The data collection methods were guided by the three sub-questions to my research question "What is the relationship between fibromyalgia and academic identity?". I approached each of the sub-questions with a particular method in mind, although in practice, there were many overlaps. The data collection methods I used were timelines, Curricula Vitae, identity boxes combined with email statements and interviews, as well as representations.

Timelines

Participants were asked to create two timelines, one for their academic career and a second one for their illness trajectory towards diagnosis. I was interested to find out whether the illness trajectory had impacted academics' career choices, or if the career would possibly have had an effect on the development of fibromyalgia. As we have seen in chapters 1 and 2 the journey to a fibromyalgia diagnosis is often long and typically diagnoses do not occur until the mid- to late 30s. Through the timelines, I was hoping to identify at which points in their lives participants had first experienced symptoms and were finally diagnosed with fibromyalgia. The timelines then provided the opportunity to relate critical incidents throughout a participant's life with fibromyalgia. This was in response to calls for researchers allowing individuals to tell their life stories (McMahon et al., 2012a), which in reality represented a snapshot of critical incidents throughout life. By asking for two separate timelines I hoped to overlay them and cross-reference cornerstones in participants' lives. In line with my openness to the phenomenon and to forms of expression, the format of the timelines was not prescribed. Participants were able to use sketches, photographs, essays, notes, diary extracts, references to popular culture and personal writings in order to best express their academic and fibromyalgia trajectories.

Curricula Vitae (CVs)

During the course of the study and as my relationship with participants developed, I noticed tensions between participants' public academic identity and their more informal, private academic identity. I felt that the data generated through the timelines, identity boxes and interviews did not provide a detailed enough picture of the complexity of academic identity, and that I needed means to explore the public enactment of academic identity. Academics' presenter biographies, blog posts and professional social media profiles provide a detailed insight into the construction of academic identity (King, 2013). Given the variability of participants' professional contexts and career stages, not all participants entertain web spaces and academic profiles, whereas all academics keep their CVs updated and adhere to commonly emerged conventions. This meant that gathering CVs would allow for relatively consistent data across all participants, which, in turn, would enable data triangulation. Thus, the analysis of the CVs was used to further explore, validate and triangulate data regarding the three sub-questions.

Identity boxes[5]

For the question "How is fibromyalgia experienced in academia?" I developed an approach that accounts for the vagueness and incorrectness of language, the embodied human understanding in relation to fibromyalgia, as well as the role of reflective practice in identity formation together with the fluidity of identity and the changeability of fibromyalgia. My research approach needed to allow for flexibility, variability and expressiveness, whilst maintaining the options for research

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[5] This section has been published in the article: Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection. *Cogent Social Sciences.*

participants to expand and elaborate. Generally, academics are used to reflective practice within research work and teaching; however, within their personal lives and illness experiences they would not necessarily have the practical experience of reflections. Often, reflections remain superficial and descriptive (Körkkö et al., 2016) or refer to particular incidents, which are used as a basis for professional development as teacher or researcher (Cochran-Smith and Zeichner 2005; Loughran 2002). In order to be able to study the lived experience of fibromyalgia in academia in detail, I wanted participants to practise phenomenology: to "go to the thing itself" (Husserl, 1970/1900, 2001/1901). This led to the development of identity boxes (Brown, 2017; Brown, 2018a, 2018b, 2018c, 2019a) as a method in order to achieve relevant representations of the holistic, embodied, lived experiences of identity and fibromyalgia.

I developed my identity boxes project from three existing strands of work: memory boxes for dementia patients, memory boxes for cancer patients and Joseph Cornell's shadowboxes. Cornell's shadowboxes are artistic installations and sculptures that align everyday objects in order to represent deeper meanings (Waldman, 2002; Sommers and Drake, 2006). In the context of health care, memory boxes are used to support memory retrieval amongst dementia patients (Nolan et al., 2001; Hagens et al., 2003). Dementia patients and their families are encouraged to create a box of objects and items that can be kept in patients' rooms to help trigger memories. The idea is that through the engagement with the meaningful objects relating to past experiences and hobbies dementia patients' memories of those times are triggered. For dementia patients, whose capacity for short-time memory tends to fail first, the present is experienced as confusing and distressing. Through engaging with relevant objects, patients' long-term memories are triggered to such an extent that patients become centred and grounded in known experiences and memories, which they find more comforting so that they are therefore less likely to be agitated and confused. Memory boxes are also used with cancer patients in their terminal stages (Macmillan, 2014). Patients are asked to create boxes of objects and photographs for their family members. On the one hand, this is a process of preparing the patients and their families for the impending reality of death. But on the other hand, this is also about helping families to deal with grief and sense of loss. The families can use the objects and photographs to remember the patient that has passed away. For the patients, the creation of the memory box is a way of deciding how they want to be remembered and what they want to be remembered by; the memory box is therefore providing a sense of control in a phase of life that is otherwise most uncontrollable. In all these cases, the objects and boxes really are specifically created, meaningful assemblages that are used as forms of communications to represent experiences and emotions, or to stand for some specific qualities and characteristics. The identity box project is similar, in that it also uses objects, but instead of seeking to trigger memories, objects are used to represent answers to questions. Research participants were provided with a question, and in response to that question they were asked to find an object to represent their answer. In total, there were five questions: "Who are you?", "What affects you?", "How do others see you?", "What role does fibromyalgia play?" and "What is life with fibromyalgia like?". Once the participants had chosen their object or objects to put into their box, they took a photo of the box at that stage, which they emailed to me together with a brief explanation of which objects were in the photo and what these objects represented. The photograph and the explanatory email were necessary to ensure that potentially weak photographs would not hamper the success of the project. The email with the photograph was also required to make sense of the participants' views, as items used in the boxes were very personal and individual. The aim of the identity box project was to provide participants with means to focus their thoughts, deepen their reflections and express their experiences more easily. As a consequence, participants reflected holistically on their personal experiences, reduced those to an essence, which they then represented in objects, and finally elaborated on them in the subsequent meaning-making process (Finlay, 2008).

Interviews

In order to clarify how participants make sense of their experiences with fibromyalgia and so, to answer the question "What is the role of academia for an academic?" I included an interview element within the research design. Once the participants had completed the timelines and/or identity boxes, participants were asked to attend an interview. This interview followed Brinkmann and Kvale's (2015) concept of interview as an interaction between two people in order to ensure that as researcher I was able to make sense of the participants' experiences but without superimposing my views, thoughts and analyses. During the course of these conversations, participants elaborated on their initial thought processes and provided a deeper, less tentative interpretation and analysis of their own data, the objects and photos. The objects in the boxes combined with the interviews are "resources, mediators that […] give shape to ideas" (Radley, 2010:268). 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 taking on the role of a traveller through the research journey (Brinkmann and Kvale, 2015) and 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. I as a researcher and my participants became partners in exploring a phenomenon. Research here was therefore the researcher making sense of the participant making sense of a phenomenon (Smith et al., 2012). The power differential between researcher and participant could not be entirely obliterated, as I was still the partner with a specific agenda in answering particular research questions, but participants were actively involved and engaged in the data generation and meaning-making process.

Representations

As the research process developed and evolved, it became apparent that a second layer of analysis and interpretation would be useful to deepen my and my participants' understanding of the lived experience of fibromyalgia. To this end, I introduced representations, which are artistic forms of analysis. Following my interpretations and analysis of the objects, the timelines, CVs, and the interview transcripts, I sought to develop artistic expressions to combine and represent participants' experiences. Once I had achieved what I had deemed an incisive, coherent, socially significant, evocative, illuminating, ethical and artful representation (see Barone and Eisner, 2012; Leavy, 2015), I shared that with participants asking for further clarification, additions and potential changes. Through this process participants were able to further develop their own thought processes around personal experiences and the meanings they had attributed and shared. At the same time, this conscious manipulation and handling of data on my part allowed me to more reflexively and critically engage with my own role as a fibromyalgia patient researching other fibromyalgia patients' experiences. The resulting representations, poems and installations, are "accounting(s) of what has occurred […] that succeed in luring audience members into having an important conversation about socially significant themes and issues" (Barone and Eisner, 2012:59). Thus, the representations are no longer merely data, but also outcomes of the research that support the social justice element and angle of research, as they can be shared in public to raise awareness and further the understanding of what it feels like to be an academic who has fibromyalgia. The process of creating representations required intense and intensive communication on the part of those involved. This was achieved through emails and instant messaging services via a specifically created Facebook group. The Facebook group was closed and hidden, and was only accessible via me as the gatekeeper.

Ethical considerations[6]

Whilst for the majority of the research my contact was with academics who are generally used to the processes of data collection and interpretation, I was very aware that my research participants needed to be considered as vulnerable. What constitutes vulnerability and what makes individuals vulnerable is socially constructed and generally accepted as the ability to give informed consent, or rather the lack thereof as a consequence of physical, mental or emotional responses (Nordentoft and Kappel, 2011). Vulnerable participants are therefore commonly participants who have

> diminished autonomy due to physiological/psychological factors or status inequalities. Examples of such persons are pregnant women; children; persons with mental retardation [sic]; mental disabilities or physical handicaps [sic]; persons in prisons; elderly persons; students and employees. (Silva, 1995:5)

In wider society, academics are often seen as elite and privileged. However, many of my research participants worked in precarious circumstances, had not necessarily disclosed their illness and disabilities at their work places, and were diagnosed with fibromyalgia – they needed to be seen as vulnerable. One of the major ethical considerations therefore was to develop a relationship to the participants that would enable them to feel comfortable sharing their experiences, and yet, satisfying their individual needs with regards to interview schedules and timings or forms of communication. For many, the fibromyalgia diagnosis meant the fluctuation of their symptoms, which would in turn impact their ability to take part in the research. Therefore, although ethical clearance was provided formally, I was very aware of the additional strain the tasks would represent for individuals. In order to ensure that the participation in the research would not unnecessarily burden my research participants, I remained in regular contact with them all (Eide and Kahn, 2008). The variability of the symptoms and the different waves of responsibilities at work and in private lives resulted in participants dropping out of my research, but then eventually returning to it again. The high number of returning participants is evidence for the

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[6] This section has been published in the article: Brown, N. (2018). Video-conference interviews: Ethical and methodological concerns in the context of health research. *SAGE Research Methods Cases.*

relevance and importance of my research for the participants. On the one hand, participants may have felt vulnerable exposing their personal health issues or may have found it difficult emotionally and physically to remain fully engaged with the research process. But on the other hand, they wanted their stories to be told and shared.

In addition to the vulnerability of the research participants, another ethical issue that emerged relates to the forms of communication, in particular to the use of skype video-calls (see Brown, 2018a). The very nature of fibromyalgia, its unpredictability and variability, leads to those diagnosed with fibromyalgia having to pace themselves by responding to their daily state of health and wellbeing. In reality, for many fibromyalgia patients pacing means cancelling pre-arranged appointments and dates. This obviously also applies to potential interview arrangements. For me, it would have been morally and ethically unacceptable to put additional pressure on my research participants by expecting them to travel. Equally, as someone with fibromyalgia myself making complicated interview arrangements and prolonged travels would have put undue pressure on my own health. Given the fluctuating symptoms of fibromyalgia and the wide distances between participants and myself, it seemed natural to use video-call facilities to allow for flexible scheduling. By arranging interviews online, scheduling and rescheduling became a real option for participants, as they would not have made any travel arrangements, but also as they knew that I, too, would not have made any arrangements, and therefore would not incur any unnecessary costs. In fact, many conference calls had to be rescheduled at the last moment due to the participants having experienced aggravated symptoms or having required emergency medical appointments. Obviously, the cancellation of a Skype interview could potentially be inconvenient for me, too. But participants felt that they were more able to admit difficulties and reschedule than had I been on a journey to an interview location already. On the other hand, as the interviews were arranged to be via Skype, participants did not need to go through particular efforts, as they would be able to remain in their own homes. This meant that for some participants, the interview location was their living room, for others it was their bedroom, where they would be able to lie down and stretch out. Having the interviews in this home context meant that it was more likely the interviews were taking place, even when a participant was having a difficult time. This is because for many participants suffering a flare-up is usually a solitary experience, as not many members of their families or friends would understand their experience.

The social contact with me as an interviewer was therefore potentially the only social encounter they experienced within a matter of several days. It was during such sessions in particular, but also in general that the benefit of Skype interviews became apparent: participants were happy to arrange for several meetings over a longer period of time. In practice, even on the participants' good days interviews would not be much longer than one hour, as fatigue and cognitive dysfunctions would set in. However, these short bouts of several interviews made data richer and more interesting. This is because participants remained refreshed and did not experience the fatigue that tends to set in when a research situation takes longer. With participants being more alert, they were also more in tune with their visceral experiences and were able to engage more naturally in a conversation. Also, this led to a shift in the power differential between me as the interviewer and them as participants, and I was able to build a meaningful relationship with my participants, which in turn allowed for a more conversational tone in subsequent interviews. Using Skype led to further unintended and unforeseen outcomes. Skype allowed me to meet my research participants within the comfort of their homes without fully invading their private space, whilst at the same time enabling them to show me around and provide a tour of their home in order to emphasise specific thoughts. My "being in the house" and entering their private environment via Skype allowed the participants to show as much or as little of themselves as they felt comfortable with. If an interview was carried out in the participants' home, the participant would be forced to lay open his or her personal space. So, carrying out the interviews via Skype allowed for a certain level of closeness, which would not have been achieved in other set-ups.

For many participants video-call facilities and other social media platforms were the commonly used forms of communication within their own circle of friends and family, as fibromyalgia symptoms and the illness experience for them meant that they were unable to enact traditional forms of socialising. By using Skype, participants used a medium that they knew. In a more formal setting with a video camera it may well be that participants become more self-conscious about being recorded. At the beginning of each conversation I always ask participants if they agree to being recorded, but actually they do not see, feel, or experience the difference between being recorded and the conversation not being recorded. Also, as most of the participants would have used Skype or some other form of video calling for private conversations with friends and family members, they felt less self-conscious about the video. This, in turn, meant that academics would potentially divulge more openly their intimate thoughts and feelings. This certainly strengthened the relationship between my research participants and myself but made me more consciously aware of my role as an outsider-researcher and insider-friend, and to act upon the stories I had been entrusted with.

Data analysis through iterative sense-making[7]

Qualitative data analysis is more than merely following specific steps to achieve meaning. Indeed, analysis is a craft that requires "reading beyond data" (James, 2013:574) and falling back upon "the repertoire of implicit knowledge that researchers themselves possess" (James, 2013:574). Therefore, data analysis can never be an objective process of having themes "emerge". It is a very subjective, personal and active process of the researcher making sense of data and pulling out specific themes and meanings (Morgan, 2018). The researcher is "a trickster, a person who is a jack-of-all-trades, a person who can fix things with the materials that are at hand" (Denzin, 2016:36), and thus consciously manipulates, assembles and reassembles data (Deleuze and Guattari, 2016). As researchers we let data speak and grab our attention, and then follow our "gut feelings" in tending to those "hot spots" (MacLure, 2011). Bearing in mind the key elements of good research – transparency, criticality and reflexivity – I employed an analytical process that accounted for the interpretivist aims of achieving understanding, as well as calling to action.

Although attuned to and aware of the methodological and ideological principles associated with grounded theory (Glaser and Strauss, 2017; Charmaz, 2002, 2006) and double hermeneutics (Smith et al., 2012), I used thematic analysis (Braun and Clarke, 2006) in its intended reflexive form of research practice (Braun and Clarke, 2019). In order to account for the wealth of supplementary materials appropriately, I combined the iterative, inductive, semantic thematic analysis with analytical approaches commonly used within and borrowed from visual methodologies (Prosser, 1998; Rose, 2016). Initially, photographs and emails were reviewed in isolation of one another. As a first step, the visual materials were coded with descriptive, organisational and conceptual observations. Subsequently, the textual data from emails were also subjected to this first coding before I combined the data to provide a third level of analysis, one where the textual and visual data were considered in conjunction with one another. As such, the process was an iterative spiral process (Brown, 2018b) that allowed me to deepen my understanding of data

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[7] The iterative sense-making was first described in Brown, N. (2018b). Exploring the lived experience of fibromyalgia using creative data collection. *Cogent Social Sciences.*

task by task, on a single and multi-layered level. Based on my observations from the objects in the box and the connected emails I had been sent, I developed a personalised interview schedule for the video-conference conversation. The basic framework for questions related around the organisation of the objects within box from one task to the next, and around probing more deeply for meanings hidden in and behind the objects and their physicality. These conversations were recorded and transcribed and then subjected to a further analysis. In reality, my analysis of the data stemming from the identity box project is that double hermeneutic meta-analysis of the researcher making sense of the participant making sense of an experience (Smith et al., 2012).

Once an interview was transcribed, I began the coding bearing in mind the questions I wanted to answer. To this end, I entered all textual and non-textual data into the computer software NVivo. I created case files for each participant and different folders for each data type. I then commenced the coding process. At first, I coded for bigger themes around academic identity, academic work, diagnostic process for fibromyalgia and the impact of fibromyalgia on academic work. After I had considered all data in connection to these bigger themes, I sought to break down these broader themes into more detailed categories. I specifically looked for participants' descriptions of body work and management of symptoms in relation to fibromyalgia, expressions of making sense of illness and academic identity, participants' explorations of their character traits, social positions or personal circumstances. This led to my formulation of categories such as "perfectionism", "disclosure" and "privilege".

I also drew on coding practices and the identification of themes in connection with computer assisted analysis and relevant software (eg. Saldaña, 2009; Bazeley, 2013; Bazeley and Jackson, 2014). Engaging with these textbooks allowed me to take advantage of the software, so that some themes from the coding processes were brought about with the help of the computer assisted qualitative data analysis. For example, as one of the functionalities NVivo can sort all categories and codes by levels of popularity, the amount of references that have been assigned to specific categories. When I looked at the categories in that way, I discovered concerns and insights that I may not have been able to identify without the software. Some categories or themes were by far more prominently discussed and mentioned than others. The category that became the least populated was "being well", which, given that this study was about the lived experience of a fibromyalgia, may not be surprising. After all I was quite specifically asking about their experiences under the influence of an illness, thus their being unwell. Indeed, within the category of "being unwell or sick" participants did make references to being well in relational terms as a comparison or binary to being unwell or sick. On the other end of the scale, however, the most populated categories were "academic work" and "fibromyalgia impacting on work". Although the focus of the study was very much on identity and the illness experience, participants emphasised academic "work" and not "identity". This discovery influenced and shaped the discussion around the question "What is the role of academia for an academic with fibromyalgia?".

As stated in the introduction to my thesis, I intended to draw on my extensive experience with practice-based enquiries to inform this sociological research. Qualitative research per se often has to contend with the criticism of not being generalisable in the same way as positivist, quantitative frameworks are. As a consequence, qualitative researchers tend to focus on concepts such as transferability (Lincoln and Guba, 1985), applicability (Lincoln and Guba, 1990), credibility (Creswell and Miller, 2000) or fuzzy generalisation (Bassey, 2000, 2001) to ensure robustness and high quality of data, which in turn ensures comparability. Once I had established findings from the initial study with non-academic participants and the results from the findings with academic participants, I realised that despite similar parameters and similar variables, the outcomes were not similar, as would be expected according to fuzzy generalisation (Bassey, 2000, 2001), but differed. Non-academic participants experienced fibromyalgia in terms of losses and gains, whereas academic participants did not experience gains and could not find a silver lining in having fibromyalgia. The conclusion to be drawn from this difference was that the parameters – the identification as academic or non-academic – were not similar enough. Previous fibromyalgia research had considered the socio-economic backgrounds (Picavet and Schouten, 2003; Assumpção et al., 2009; Queiroz, 2013; Fitzcharles et al., 2014) of participants but had not specifically focussed on the higher education context, where work is such a strong part of identity that they can rarely be separated. What my study showed here is that in cases, such as within higher education, where identity and work are inextricably linked, participants reacted differently to the meaning-making process of the condition, which resulted in individuals attempting to hold on to their primary identifier, the academic identity, rather than social networks, for example. This same phenomenon may well be observable in other contexts where personal and work identity converge to a similar extent, such as for example among artists or medical professionals, but this is clearly outside the scope of this thesis.

Research in practice

Bearing in mind the participants' vulnerability, personal needs, fluctuating symptoms, illness trajectory, work pressures and career development, the research process needed to be particularly flexible and open to ensure the success of the data generation. Initially, there had been plans that the data collection phases would be tightly organised, so that clear delineation of phases and data would be possible. I had envisaged one phase following another between January 2017 and July 2018. In reality, all collection phases overlapped with some participants providing timelines whilst others had finished supplying all their contributions to the research. Also, I wanted participants to feel they are given opportunities and means to express what is often difficult to voice. So, instead of following a rigid schedule, my data collection process became more fluid, organic and flexible than I had anticipated. As a result of this open and flexible approach, the raw data in this research came in many forms, media, sizes and quantities. The benefit of the great variety of forms and media is the richness of the data represented in addition to the interview transcriptions. The fact that data is represented in so many different forms may be considered inconsistent or messy. In practice, however, it is this variety that provides the basis of the mosaic approach (Clark and Moss, 2011) and enables triangulation through combining data triangulation with methodological triangulation (Denzin, 2017).

Analysing data generated through creative data collection methods[8]

One of the key elements guiding this research project was around the development of methods and methodologies that would account for challenges around human understanding. As such, with this research, I aimed to explore innovations in and to the disciplinary conventions of sociological and higher education research by specifically tending to embodiment in qualitative research (Ellingson, 2017). This would not be a sufficiently reflexive, critical and transparent thesis, if I did not consider the impact and outcomes of the choices I made and decisions I took throughout the research process.

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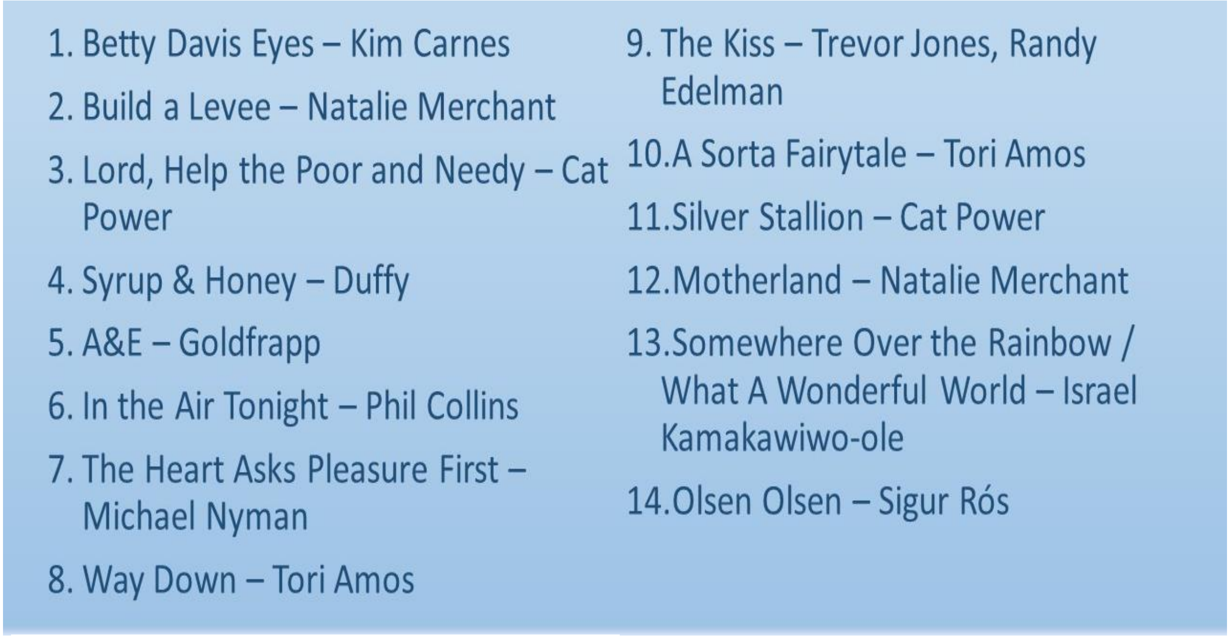
[8] This section is an amalgamation of two published articles:
Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology,* 1-15.
Brown, N. (2019). "Listen to your gut" – A reflexive approach to data analysis. *The Qualitative Report, 24(13),* 31-43.

What was probably the most daunting but at the same time most exhilarating outcome of the research approach with the variety of forms of communication was the wealth, breadth and depth of data that I had by the end of it. By allowing the forms of communication that were most comfortable, participants were able to express their innermost feelings and thoughts freely. As a result, I now have photographs, identity boxes, poems, song lists, sketches and mind maps, and so on in my data set. In the following, I provide some examples for the variety and kinds of data submitted to me (see also Appendix C):



1. Betty Davis Eyes – Kim Carnes
2. Build a Levee – Natalie Merchant
3. Lord, Help the Poor and Needy – Cat Power
4. Syrup & Honey – Duffy
5. A&E – Goldfrapp
6. In the Air Tonight – Phil Collins
7. The Heart Asks Pleasure First – Michael Nyman
8. Way Down – Tori Amos
9. The Kiss – Trevor Jones, Randy Edelman
10. A Sorta Fairytale – Tori Amos
11. Silver Stallion – Cat Power
12. Motherland – Natalie Merchant
13. Somewhere Over the Rainbow / What A Wonderful World – Israel Kamakawiwo-ole
14. Olsen Olsen – Sigur Rós

Figure 3.5: Alison's song list

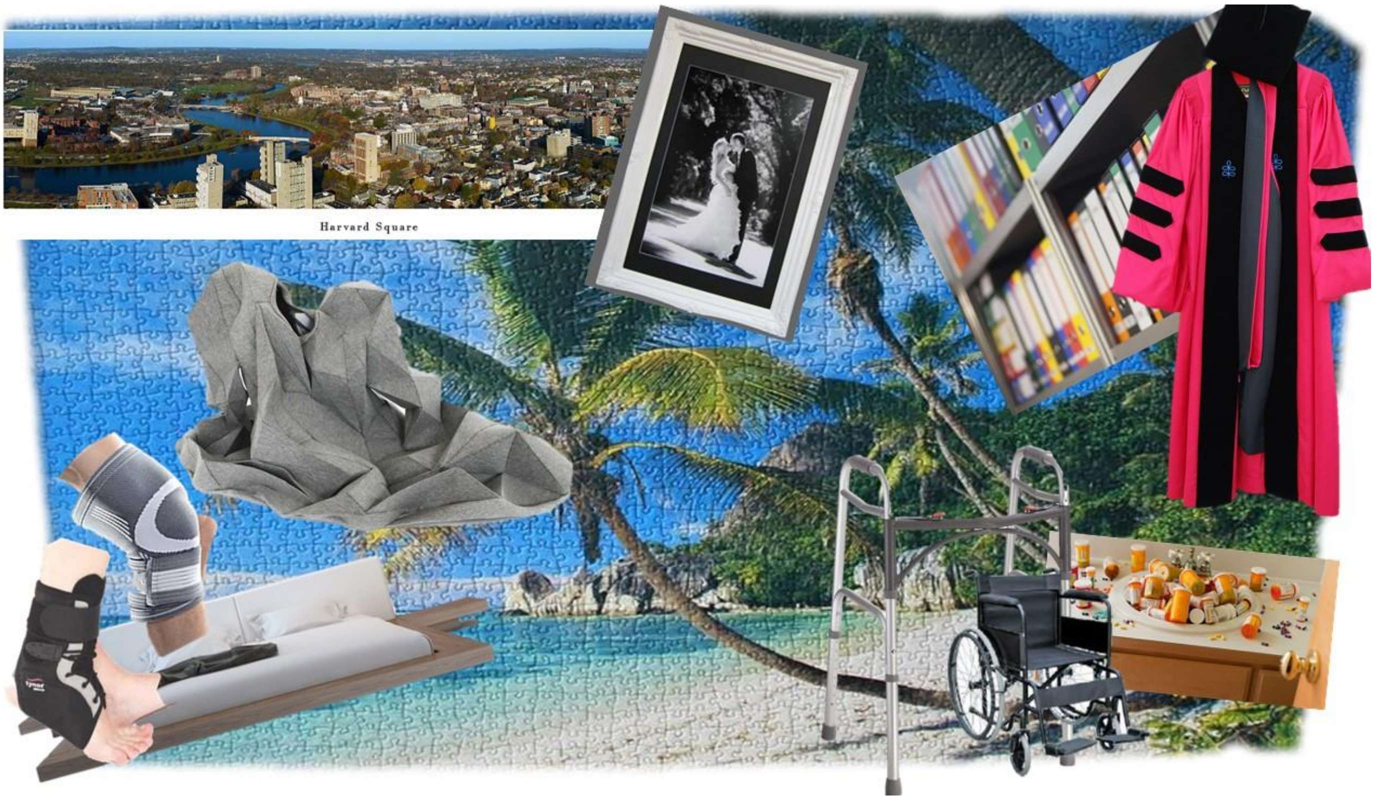
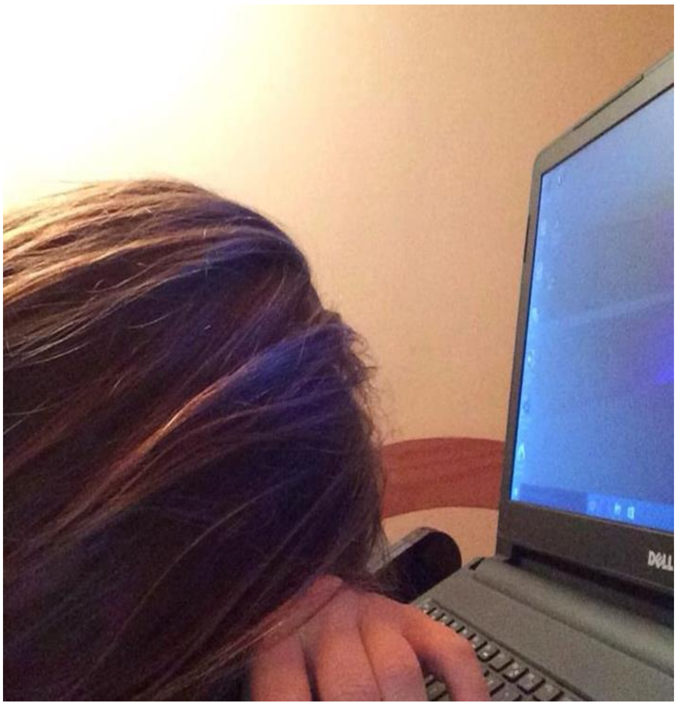


Figure 3.6: Sian's collage



Figures 3.7 and 3.8: Two photos from Kate's photograph series

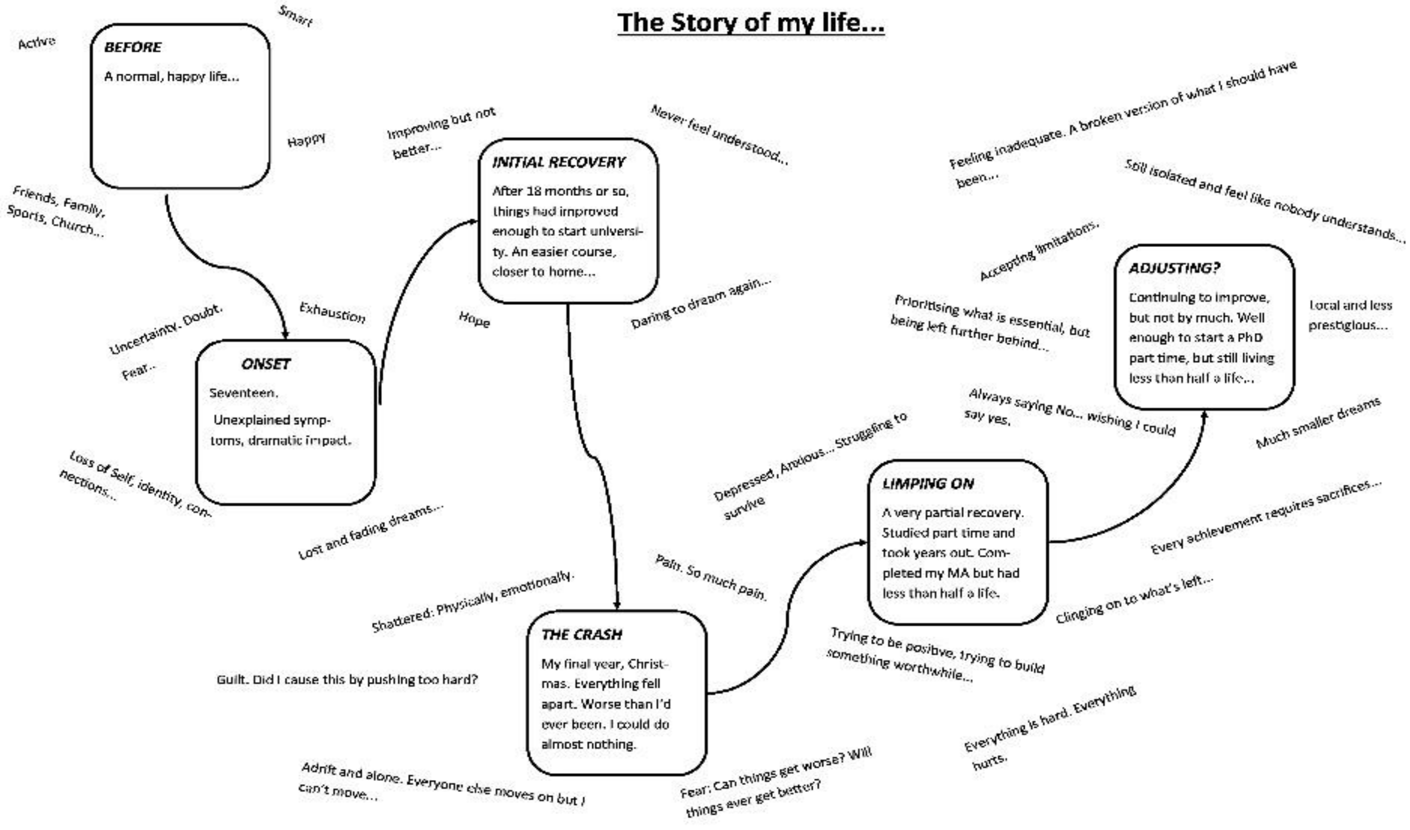
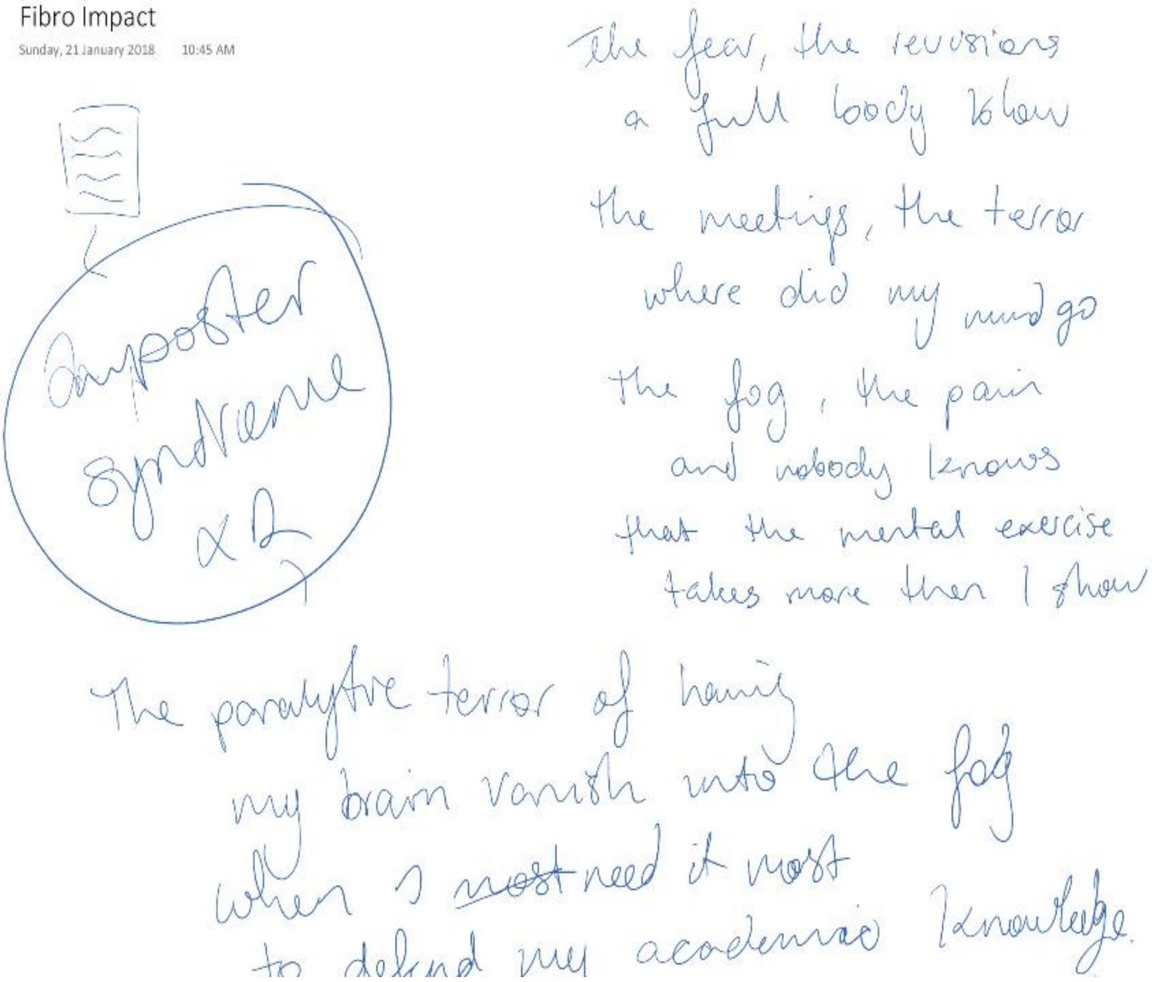


Figure 3.9: John's timeline


Fibro Impact
Sunday, 21 January 2018 10:45 AM

Imposter
syndrome
x2

The fear, the revisions
a full body blow
the meetings, the terror
where did my mind go
the fog, the pain
and nobody knows
that the mental exercise
takes more then I show

The paralytic terror of having
my brain vanish into the fog
when I ~~most~~ need it most
to defend my academic knowledge.

Figure 3.10: Excerpt of Yasmin's mind map/timeline

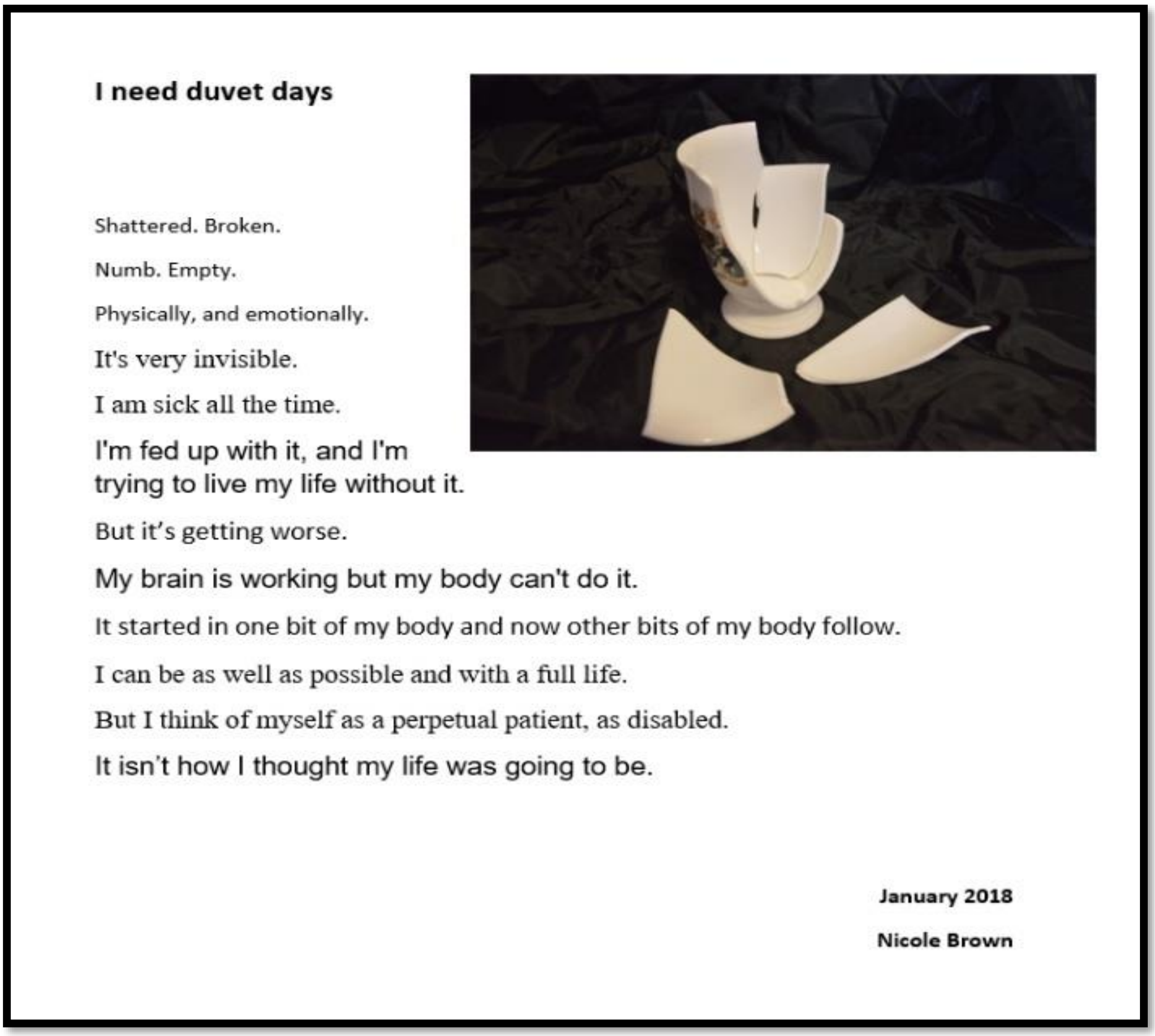
This variety and range brought a major concern: how do we deal with data that is so non-linear and non-uniform at the level of interpretation and analysis. There are no specific analytical frameworks that can be applied on a step-by-step basis for where non-conventional data is concerned. I realised that the analysis of the raw data would require a more nuanced approach. I felt that the conventional analysis process through coding and identifying themes was somehow limiting and limited, as it did not necessarily allow for a good representation of experiences. I attempted to put into words what participants had expressed metaphorically through objects. With this in mind, I applied a second layer of analysis. Whilst the individual photographs and objects were very specific to individuals, there were many commonalities expressed around the participants' experiences of life with fibromyalgia. What the identity box project therefore lent itself to, was a more creative approach towards analysis in addition to the traditional textual analysis. This was very much in line with the idea of the researcher as assembler and bricoleur (Denzin, 2016). In the following, I outline two examples for how I approached this process by creating an illustrated poem and an installation.

The creation of the illustrated poem: I need duvet days

As a first stage, I watched back the video-recordings of conversations about the experience of fibromyalgia, while reading along the transcripts of those conversations. Rather than actively seeking out emerging themes or attempting to code in a traditional sense, I focussed on the nature and tonality of speech. I let words, phrases and sentences speak to me trying to hone in on the "I" voices (Chadwick, 2017). In the course of this process, particular sections, phrases or words became "hot spots" (MacLure, 2011:1003) to be followed up. They were sections that differed from the individuals' remaining speech patterns, either through increased emphases using changed tonal ranges or through voice patterns indicating heightened levels of emotions. Emotions conveyed were sadness, melancholy, but also upset and anger.

Reflecting back on the hot spots I realised that I needed to find a way of expressing these particular emotions through the original wordings and phases used by the research participants. I re-read the transcripts again, trying to identify sections where emotions became particularly foregrounded. From these sections, I extracted individual phrases and words, which I then copied into a new document. Developing this form of an I-poem (Edwards and Weller, 2012; Kucan, 2007; Koelsch, 2015) meant that I actively decided on rules around what would be included or excluded, which parts of the transcripts would be used and how. My two ground rules were to include phrases from conversations where re-reading the transcripts affected me in an embodied way and to not change or edit any of the original wordings. This new document contained extracts from conversations with five different participants, and yet, there were recurring themes of the broken body, the continuous experience of illness and the experience of progressive development of fibromyalgia. I subsequently rearranged the phrases to better connect and reinforce the themes. Through applying a range of fonts and font sizes I attempted to indicate tonality, but also the individuals whose speeches the sections were drawn from.

The objects used or described by the participants are in themselves powerful tools of expression. I therefore decided to draw on these metaphorical representations, which form part of my data collection, to add a second layer of creative analysis to the description of experiences with fibromyalgia. Through their particular objects, participants described fibromyalgia: as long-known, comfortable but unwanted and annoying, as a burden and hindrance, but as impossible to get rid of. In order to capture this multitude of descriptions, I chose to use a shattered mug. The brokenness represents the broken body, but at the same time the mug also stands for the attachment we have to special objects that we feel we cannot throw away, although they no longer fulfil their original purpose. By the end of the process, this illustrated poem had become a helpful tool for me to make sense of participants' experiences, whilst at the same time participants felt that they were able to demonstrate and show their feelings. However, they felt that the illustrated poem required a certain pre-understanding in order to be able to fully comprehend its meaning.



I need duvet days

Shattered. Broken.
Numb. Empty.
Physically, and emotionally.
It's very invisible.
I am sick all the time.
I'm fed up with it, and I'm
trying to live my life without it.
But it's getting worse.
My brain is working but my body can't do it.
It started in one bit of my body and now other bits of my body follow.
I can be as well as possible and with a full life.
But I think of myself as a perpetual patient, as disabled.
It isn't how I thought my life was going to be.

January 2018
Nicole Brown

Figure 3.11: Illustrated Poem

In the following, I describe the art installation Peace Treaty, which participants felt allowed for better engagement with life with fibromyalgia for those who do not have any prior knowledge.

The creation of the living room installation: Peace Treaty

The approach to the creation of the installation was slightly different to the approach to the illustrated poem. Whilst both aimed for a representation of experiences, the art installation also aimed at providing information about the lived experiences of fibromyalgia.

As a first step, I read the transcripts of conversations and email correspondences in relation to the experience of fibromyalgia symptoms. I combined this reading with the consideration of the photographs sent to me in response to the identity box project (Brown, 2017, 2018a, 2018b, 2019). Based on the participants' responses I created an artistic representation through assemblage. In artistic terms assemblages are collections of items that are specifically arranged to convey the artist's message. However, assemblages are also found as a research strategy if understood as constellations in Deleuzoguattarian terms. In this context, the constellation or assemblage is the arrangement, integration or combination of a variety of concepts, theories and component parts. As a research framework, the assemblage allows for an interpretation of the basic components, which eventually lead into the consideration of relationships and connections. These, in turn, are not stable and fixed, but are fluid, variable and moveable (Deleuze and Guattari, 2016).

The approach to assemblage worked on two levels: artistically and philosophically, whereby I do not see these as mutually exclusive. The materiality of the installation and the representation of lived experience and feelings helped me identify a new form of domesticity in the context of a chronically ill and disabled person; a person, whose physical condition confines him/her to the living room instead of a workplace. In this sense, through the means of arts, the installation sought to inform, teach, raise awareness, develop empathy and understanding and thus to have a long-lasting effect on viewers. Assembling the particular objects with an explanation for their relevance helped me to distance myself from my personal experiences.

Figures 3.12 to 3.14 are some examples from all the identity box projects to demonstrate one key element for the installation "Peace Treaty" (Figure 3.15). In answer to the questions "What role does fibromyalgia play?" and "What does life with fibromyalgia feel like?", participants tended to focus on strategies and mechanisms they use to deal and cope with the symptoms on a daily basis. Whilst the findings and interpretation of the data are in chapters 4 to 9, I want to show here how the objects informed this layer of analysis. The back rest in Figure 3.14 is one such example for how Kate is making sure she can be as comfortable as possible at work, despite the persistent pain she experiences in her back. Other examples for practical mechanisms included the use of ice packs or heating pads, blankets and socks. However, the experience of life with fibromyalgia was also evident in and seeped through the participants' responses to other questions. For example, in response to "Who are you?", Cathy added the gardening glove to her box (Figure 3.13); tellingly, there is only one glove, and that was Cathy's deliberate choice to demonstrate the limitations she experiences. She would like to be able to be a better gardener, especially because the gardening distracts her from pain and psychological disorder, which she experiences as distressing symptoms of fibromyalgia. Lisa used her paint brush in a similar vein (Figure 3.12). Lisa sees herself as an artistic and creative person, but feels that her creativity is hampered in the everyday experience and routine of living with fibromyalgia.

Figure 3.12: Lisa's identity box

Figure 3.13: Cathy's identity box

Figure 3.14: Kate's identity box

What is interesting to note though, is that I combined the objects and representations provided by the research participants with a poem that I myself had written some time ago. As such, the creation of the installation echoed Chadwick's (2017) philosophy of ethnopoetic transcriptions in that they both highlight discrepancies, in this case discrepancies between individuals' experiences. In terms of the installation, the discordances are particularly manifest in the use of the ice pack alongside the hot water bottle. I personally would never use ice packs to help alleviate symptoms. And yet, the synthesis of experiences of the researched and the researcher required the inclusion of the contradictory pain management aids. Once the installation was completed, I realised that the boundaries between my own experiences and those of the participants had become blurred in the Deleuzoguattarian interpretation of fluidity and movement. And yet, this process still allowed me to consider all elements as "quasi-objective" (Foley, 2002:473). The outcome of the installation is newly created knowledge that seeks to foster empathy and to deepen the understanding of lived experiences with fibromyalgia on the part of the audience, which would not have been possible without the reflective and reflexive activities.

Figure 3.15: Installation – Peace Treaty

"Peace Treaty" (Figure 3.15) was shown in an art gallery in the Southeast of England as part of a three-week exhibition "Art is something much more dangerous" (O'Sullivan, 2001:128) on themes around domesticity, relationships and belonging. Through artistic means, the installation sought to inform, teach, raise awareness, and to develop empathy and understanding. "Peace Treaty" represented the lived experience and feelings of a chronically ill and disabled person; a person, whose physical condition confines him/her to the living room (Figure 3.15).

The relationship between the identity boxes and the final installation becomes evident, when we consider, for example, one of the objects in "Peace Treaty": a ball of wool with knitting needles. The wool and needles represent the participants' strategies used to distract from persistent pain. However, there is no finished knitting, which stands for the limitations of the repetitive movement of knitting, that would cause additional pain. Of course, in reality, those diagnosed with fibromyalgia are producing knitwear, but through intentionally highlighting failure and limitation, I aimed to communicate my participants' difficulties. The wool with knitting needles in Figure 3.15 is an active and assembled representation of the paint brush in Figure 3.12 and the gardening glove in Figure 3.13. In its final design, the installation used a wide range of objects, which were all described and explained on a hand-out available to gallery visitors (Figure 3.16).

Nicole Brown

Peace treaty

Imagine you have the flu, but on top of that, you get sunburnt, and you fall down a flight of stairs. Now imagine you haven't slept for 36 hours. And then imagine that nobody sees any of that.

This is what fibromyalgia feels like.

Fibromyalgia is characterised by widespread chronic pain, psychological disorders, sleep disturbances and cognitive dysfunctions, which people describe as brain fog. As there is no definitive medical test for fibromyalgia, diagnosis is purely based on the exclusion of other conditions. Therefore, the condition is contested and considered invisible. My installation "Peace treaty" is the artistic outcome and representation of a research project into the experience of those diagnosed with fibromyalgia. With this installation I aim to provide an insight into life with fibromyalgia. The objects on display all relate to how those diagnosed with fibromyalgia manage their condition.

Armchair, TV and telephone:

Many of those with fibromyalgia experience flare-ups of their symptoms, which mean they become house- or even bed-bound. In those times their lives revolve around the TV set, and the telephone to remain linked to their social network and the outside world.

Blanket, hot water bottle, ice pack:

Depending on the kind of pain, sufferers will use warmth and cold to try and manage their pain levels, in addition to the medication they are prescribed.

Medication:

Tablets prescribed for fibromyalgia include pain killers, anti-depressants, anti-convulsants, anti-inflammatories. In addition, it is highly recommended to take vitamins, especially vitamin B complex tablets to support the body's self-healing properties and promote general wellbeing.

Tea and tea lights:

Many fibromyalgia patients talk about trying to relax their bodies and minds, which they do by drinking teas, lighting candles and using aromatherapy scents. It appears that those with fibromyalgia respond particularly well to fruity, lemony and flowery scents.

Book, wool and knitting needles:

Fibromyalgia can be very disabling and patients often give up their jobs. In order to keep active and maintain a purpose in their lives, they try to engage in creative activities, like knitting and reading. However, pain levels often mean that they cannot actually do the activities, and the brain fog results in processing issues so that reading is a difficult, impossible task.

For more information, please, see www.nicole-brown.co.uk or contact me on nicole.brown@ucl.ac.uk

Figure 3.16: Description of objects in Peace Treaty

Concluding thoughts

In this chapter, I outlined my research approach and process, but also some key considerations in relation to creativity, playfulness and arts-based research in social sciences. In doing that, I have touched upon key concerns around knowledge generation and representation, and the important role the researcher plays throughout the research process. In the following chapters I continue in the same vein I outlined here, in that I present data in two ways. Chapters 5 to 7 follow the more traditional conventions and linear presentation of findings and theorisation. These chapters are based on the data sets from the timelines, CVs, identity boxes and interviews. However, the photographs, objects, timelines and CVs participants shared with me were of such a personal nature that reprinting those would potentially allow the identification of individual participants. The raw data I therefore present in the following chapters have been chosen carefully to illustrate key themes, but at the same time to protect individuals' identities. In chapter 8, I present fictionalised narratives as outcomes of the analytic process demonstrated with the illustrated poem and installation to revisit key themes. This approach allows me to tell what would otherwise remain untold. Throughout the research participants shared unique stories and critical incidents involving sensitive information, which needed to be treated highly confidentially.

4. Exploring the lived experience of fibromyalgia [9]

As I outlined in the literature review in chapters 1 and 2, fibromyalgia research in relation to the lived experience is sparse. Therefore, in order to identify a baseline for the analysis of academics' experience of living with fibromyalgia, I carried out a pilot study with non-academic participants to allow for subsequent comparisons between academics and non-academics with fibromyalgia. In this chapter, I show that through the application of identity boxes the non-academic participants' fibromyalgia narratives focussing on losses and gains lie in-between the spaces of the narratives of restitution, chaos and quest (Frank, 2013).

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 et al., 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 et al., 2013). These and other narrative explorations (Ezzy, 2000; Garrett, 2001; Smith and Sparkes, 2005, 2008; Prussing et al., 2005; Bally et al., 2014; Carless and Douglas, 2008, 2013) 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

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[9] This chapter has been published: Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection. *Cogent Social Sciences.*

disruption on the experience of rheumatoid arthritis patients[10], the concept of disruption has since been explored in the context of cancer (Navon and Morag, 2004; Trusson et al., 2016), chronic pain (Richardson et al, 2006), multiple sclerosis (Green et al., 2007), spinal cord injuries (Dickson et al., 2008), Parkinson's disease (Gisquet, 2008) and stroke (Wolfenden and 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 (Wolfenden and Grace, 2012; Llewellyn et al., 2014) and normalisation (Sanderson et al., 2011; Sanderson et al., 2015) both refer to a chronically ill individual's attempt to incorporate the illness experience within an adapted lifestory. 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 lifestory 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

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[10] 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.

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" (9). I conclude that in the narratives' fluctuating discourses between acceptance and resistance the fibromyalgia plot is best described as combative acceptance. As I directly responded to calls for narrative approaches to exploring the lived experience of fibromyalgia (McMahon et al., 2012a; Sallinen et al., 2011), the focus for analysis in this chapter is on the holistic experience of fibromyalgia in relation to illness narrative concepts. The detailed exploration of the illness experience amongst non-academics is required in order to outline the specificities of the higher education context in chapters 5 to 8 in this thesis.

Method and methodology

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 (Scarry, 1985; Sontag, 2003; Eccleston, 2016). 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 and 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 (Smith et al., 2012). The overall theoretical framework for the research is phenomenological and hermeneutic in tradition. At the core of interpretative phenomenological analysis (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., 2012:35). 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.

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 44 participants were recruited. The study works with 40 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 interpretative phenomenological analysis 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.

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.

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 (Nolan et al., 2001; Hagens et al., 2003) 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.

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 interpretative phenomenological analysis (Smith et al., 2012), 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.

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?**
Dorothy	pony tail, Hessian libra wall hanging, needle and thread in red	photo of twin sister and brother, two letters, carboard 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"

Lisa	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
Sally	a plain box, a candle, a glittery heel, passport	sunglasses, makeup, condom, staff badge	pen, pawn, safety pins, box of hay fever medication	a mind map explaining thoughts	a pillow on top of the box

Figure 4.1: Summary of participant responses to identity box questions

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.

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?" Lisa 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. (Lisa, email)

In a similar vein Dorothy 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 (Dorothy, email).

While Dorothy appears to demonstrate hints of sarcastic humour in her communication, Lisa is very factual, curt and abrupt in her email. The conversation with her demonstrated that Lisa 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 [sic] 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. (Lisa, 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).

Sally, 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 (Sally, 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.

Gains

Three women highlighted their attempt to focus on a silver lining of the fibromyalgia cloud. Sally's description of fibromyalgia being both "gift and curse" (Sally, mind map) was most poignant and encapsulated her largely, ambivalent feelings towards the illness. Dorothy, Sally and Lisa 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 (Dorothy, email).

or:

> Sometimes life throw[s] you a curve ball, turn it into an opportunity (Lisa, 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 greatful [sic] for what I have; puts life in perspective (Sally, mind map).

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" (Sally, 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 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 (Sally, 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 the next section.

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, Lisa and Dorothy, 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 (Lisa, 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 (Dorothy, email).

Dorothy's, Lisa'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 Sally 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 Sally, 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 (Sally, mind map).

Lisa's reflections about the support system appears particularly relevant in that Charlotte, Sally 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 multi-layered and therefore very complex. The following section provides a more holistic discussion regarding the experiences described.

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.

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 Sally's own words "to me fibro robbed me of my dreams" (Sally, 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. (Lisa, 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 and 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. Lisa's description of "[n]ot knowing if it will be a good day or not" (Lisa, email) encapsulates this variability. In a way she demonstrates that fibromyalgia must be equated with liminality, living between good days and bad. Sally also expresses liminality, when she explains that it is important to stay in control and then life with fibromyalgia is "not that bad" (Sally, 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.

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 et al., 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, Sally and Dorothy sit alongside hope, levelled optimism and pragmatism regarding dealing with fibromyalgia. Charlotte, Sally 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 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, Lisa'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 et al.'s (2012b) data. In their analysis, McMahon et al. (2012b) 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 et al. (2012b) 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. Sally 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.

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. 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 (for more on this process of reduction, representation and subsequent elaboration, refer to Brown, 2017, 2018a, 2018b; Brown and Collins, 2018; Brown and Leigh, 2019; Panjwani and Brown, 2019). 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 (Frank, 2013). 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 must be seen as fluid, in flux and not as stable units (Frank, 2013). The 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. For the non-academic participants in this pilot study, fibromyalgia represents the loss of a previous self, of employment and in some instances of relationships. However, the condition also represents gains in that the women found themselves to have become more tolerant, empathetic, patient and compassionate because of their own illness experience. Fibromyalgia in this sense is equated with personal growth. This does not at all mean that the non-academic participants have succumbed to the condition or the diagnosis. This merely means that they have learnt to identify their personal priorities and accept certain changes in their lifestyles in order to better deal with the fibromyalgia symptoms. As a result, non-employment is not perceived as an intrusion on the self, but a coping strategy.

In order to allow for a comparison between academic and non-academic participants, I ensured to have two entirely separate studies using homogeneity from interpretative phenomenological analysis as a basis. Naturally, it could be argued that the different professions and occupations represented in phase 1 and the career stages and ages represented in phases 2 to 4 make both samples inhomogeneous and comparisons impossible. Indeed, this is the main criticism that interpretative phenomenological analysis faces within the field of psychology itself.

In the chapters 5 to 8, which are based on the data from the main PhD study with academics as participants, I detail how different academics' illness experience of fibromyalgia is. Suffice it to say at this point that personal growth for academics comes through and is linked to scholarly work and productivity and as such there is no gain to be had from fibromyalgia. Instead, academics with fibromyalgia are preoccupied with being a "discreditable" person (Goffman, 1990/1963:14) and therefore carefully manage their identities as well as the information about them (Goffman, 1990/1963).

5. Making sense of academic identity

Having reported on the pilot phase in chapter 4, from now I turn to the main phases of the research. I commence in this chapter by exploring the question of academic identity and how identity is constructed within the context of neoliberal higher education of the 21st century. Over the last three decades the UK higher education sector has seen drastic changes: it has become marketized and bureaucratised (Hussey and Smith, 2002; Tilak, 2008; Gewirtz and Cribb, 2013). Government cuts to direct funding and the introduction of new funding systems have devolved financial responsibility to higher education institutions (Thompson and Bekhradnia, 2010; Department of Business Innovation and Skills, 2011). This means that institutions are under increasing pressure to attract students who are effectively the financers of their own studies and higher education institutions compete directly for students. The process of universities turning into corporate businesses is stimulated further by globalisation and internationalisation (Law and Hoey, 2018). As emerging Asian and South American economies look towards English speaking countries to provide education for their students, competition within the UK higher education sector becomes fiercer, particularly so as international students bring in more money than home students. The result of such cost-benefit approaches is consumerist behaviour on the part of students and their parents and a tertiary sector that is about meeting students' expectations, bettering value for money, improving employment opportunities, employability skills and achieving specific outcomes, degrees (Hussey and Smith, 2002; Department of Business Innovation and Skills, 2016; Robinson and Hilli, 2016). These external factors related to neoliberalism within higher education (Hussey and Smith, 2002; Tilak, 2008; Gewirtz and Cribb, 2013) and the resultant changes to the career paths amongst academics, budgetary developments and different student intakes impact academics' roles and identity (Marr and Forsyth, 2011; Henkel, 2000).

Identity refers to an individual person's concept of self (Stryker and Burke, 2000), to the collective understanding and sense of belonging to a group (Tajfel, 2010) or to humans' culture (Calhoun, 1994). A human's core identity is therefore made up by different aspects of interrelated sub-identities, which are consistently negotiated (Gee, 2000; Watson, 2008). Traditionally, academic identity has been premised on being embedded "with strong normative power" in a larger "community" or a "discipline" (Henkel, 2001:8). Over the last decade, academic "identities have become both more provisional and more multidimensional" (Henkel, 2001:9).

Academic identity is multi-layered, evolving in nature, involves emotions and values, and is related to a sense of belonging or not-belonging to a group (Davey, 2013). Overall, academic identity formation is now seen as more discontinuous. Due to the complexity of the construction of identity, most literature uses roles, responsibilities and work tasks in order to define what makes an academic. The role of work in relation to identity is well-documented (Wrzesniewski and Dutton, 2001; Witt et al., 2002; Kirpal, 2004a, 2004b; Walsh and Gordon, 2007; Haslam et al., 2000). Work is not merely a means to be productive, it influences and moulds us, so that we find our selves in and through work (Gini, 1998). Within the context of higher education, work identity and the interrelationship between work and identity are commonly explored in the context of professional identity (Trede et al., 2012) or in terms of belonging to a community (Smith et al., 2010; Billett and Somerville, 2004). Academia as a community is worth striving for (Bauman, 2008) as it evokes the image of like-minded individuals sharing knowledge and expertise in collegial collaboration for the betterment of society and the common good (Lewis, 2008; Tilak, 2008).

What is often disregarded in these discourses is that higher education institutions embody hierarchical power-relations that determine individuals' agency. Higher education institutions, like organisations more generally, are not neutral or apolitical, but incorporate a structure of dominancy and hierarchy (Clegg et al., 2006). In the higher education sector, dominancy and hierarchy are founded on systems of structures and rules as well as on discourses of expertise coupled with norms and values, which result in authority and power. Power is accepted as a given in organisations (Clegg et al., 2006). Domination, thus the exertion of power, occurs where dominated and oppressed individuals reinforce the discourse of domination (Luthar and Šadl, 2008:250). In Simmel's terms (1950) two forms of subordination are at play in work relationships. Based on contractual conditions individuals subordinate themselves to the power of the employer, whilst at the same time subordinating themselves to the power of the "cooperative process" (Simmel, 1950:263). The individual experiences freedom and autonomy from direct power-relations, whilst continuing to be positioned within the larger structure of institutional values and norms. This framework explains that structures of domination establish "naturally" and "rationally" in organisations and how individuals experience agency within a system of structural constraints (Mumby, 1987:115). The binary of structure and agency as a dichotomous debate between determination through society versus free will is therefore unsatisfying as it leaves unconnected the relationship between the structural conditions of higher education and academics' agentive behaviours

(Collins, 2008). In the academy, structural constraints are described as a combination of (a) an environment of dependency and reciprocity, particularly, in small institutions or tight academics networks, (b) an authoritarian, patriarchal structure that seeks to maintain particular interests rather than opening up for debates, and (c) the processes of internationalisation, marketization and neoliberalisation that lead to increasing surveillance, workplace restructuring, the introduction of fixed-term contracts (Luthar and Šadl, 2008).

These economic and socio-political processes result in institutes becoming business enterprises, and consequently academic identity is aligned with the corporate identity of a specific institution (Clegg, 2008; Churchman and King, 2009; Billot, 2010; Waitere et al., 2011). Whilst institutes favour a uniform, coherent, brand-like identity, academics' unauthorised, personal identities are generally characterised by plurality (Churchman and King, 2009). Consequently, identity formation within academia is a balancing act between the official, corporate, strategic image and the individual, personal story (MacDonald, 2013) requiring the negotiation of a fine line between public, institutional identity and the personal, academic identity (Billot, 2010).

In this chapter, I argue that the construction of academic identity happens on two levels. Firstly, academics explore and experience academic identity at an external, public-facing, institution-related level that is strongly influenced by and linked to society's stereotypical understandings of academia. The public academic identity in this sense is a chosen and openly constructed identity with individuals deciding to openly declare and disclose their academic status through clear, transparent identifiers. Weblogs, profile pages, acknowledgements and book biographies all add to paint a picture of who an individual academic is (Hyland, 2012; Ewins, 2005). Whilst this is a formal process relating to the construction of a public persona and an academic identity, this identity is intertwined with other aspects such as the disciplines and institution the scholars are part of (Henkel, 2000) and the roles academics play in their professional environment. This represents the second level of the sense-making process in relation to academic identity where academics develop their understanding at a private, personal, internal and internalised level. In relation to the overall thesis argument, I focus on the significance of the higher education context; a context that is linked to privileges and flexibilities but which is fraught with pressures of precarious working conditions.

In the section "The public level of academic identity" I show that at a first, superficial level academics understand academic identity in relation to the public and stereotypical image of a male, white professor and that academics also equate academic identity with contractual details of working in higher education. I further outline how socialisation and self-categorisation are key in making sense of that public level of academic identity. I then demonstrate how this virtual social identity is at odds with the participants' actual social identity (Goffman, 1990/1963) in the section "The personal interpretation of academic identity". I show that what is considered to be a typical and stereotypical description of academic identity is not what individuals aim and strive for, and that academic identity at this personal level is equated with traits of giftedness and curiosity and experienced as being different and othered. I outline that for academics their real sense of and for academic identity lies somewhere between the public and personal values. In the subsequent section "Academic identity in the neoliberal academy" I focus specifically on the contemporary higher education sector and the impact the processes of internationalisation, bureaucratisation and marketisation have on individuals making sense of their academic identities. I show how the width and breadth of contracts lead to precarious employment conditions and job insecurity but also to lack of recognition for academic work, especially for academics on a "business support contract". I further highlight how these external factors result in ambivalence regarding their academic identities and in a disrupted sense of belonging. In the section "Privilege, autonomy and flexibility – the false friends in academia" I show that irrespective of the negative experiences, workload pressures and contractual instabilities academia remains a community to strive for and that for the participants academia is equated with flexibility, autonomy and privileges. However, I also demonstrate that the positives of flexible working hours and working locations, freedom and autonomy come at a price, which for individuals is that there are no boundaries between work and life. I further highlight that academics often could not achieve what they do without the financial and moral support from family, in particular, and that therefore they feel they owe themselves and others that they succeed in academia. My consideration of this sense of responsibility and self-imposed pressure leads naturally into the final section of this chapter "Character traits of academics" in which I show that academics not only are high-achieving and have high expectations of themselves, but that they also pride themselves in their high-achieving nature. I then outline that despite the pride in success and striving for more academics do not necessarily realise or acknowledge their perfectionist tendencies. I conclude this section with an outline of how the perfectionist tendencies and working environment of neoliberal academy are linked to participants' state of wellbeing and health.

The public level of academic identity

When asked to describe academic identity and what an academic is or looks like, research participants refer to stereotypical, traditional images. An academic then is someone who engages in research, produces regular outputs and holds a substantial list of publications, whilst teaching subject contents that are related to this research:

> My image I guess is a male professor. that says a lot doesn't it, a male professor stood at a microphone holding their 98th publication.
>
> Amy

> A big book, open on a lectern in front of a screen at the bottom of a big wooden lecture hall. So, the book on the lectern is the main part, but the farther out you pull back the more you can see.
>
> Sian

> To me an academic, these days will usually be white; if you're like in senior levels you will be a man, with something slightly edgy but not actually new […]; you'll probably come from some kind of privilege, if that's not at least a middle class background originally, there'll be some kind of external income at some point that has tidied you over […]; and you will either have made certain sacrifices that to this day feel somewhat dramatic or you will feel that that sacrifice is an inherent part of being in the academy.
>
> Alison

Alison's comment shows that for her academic identity is related to experiencing a sense of belonging, to that knowledge-producing community. At this initial, public level, participants focus on the "male, white lecturer" as the stereotypical academic. This virtual social identity (Goffman, 1990/1963) of a stereotypical academic is at odds with participants' actual social identity (Goffman, 1990/1963) and personal experience of being a woman trying to make and break it in academia. Despite the general opening up of academia and allowing for gender equality (Davies and Petersen, 2005a), academia is still experienced as a male-centred and male-centric environment (Monroe et al., 2008; Valian, 2005). As women, the participants believe that their community does not accept them as people belonging to that very community. At the same time, they feel that they legitimately belong because of their academic successes such as research, articles, monographs and grants and awards won. Participants have also expressed the relevance of knowledge-production and research in relation to their sense of belonging to the academic world:

> So at that stage I thought maybe, you know, when I start to explore a figure that I am interested in and I do more research and contribute to research, contribute to knowledge.
>
> Kate

> It was well paid, it was a nice working environment, umm, so I spent the summer basically working as a as a kind of like a research secretary stroke lowest, lowest level of research assistance, and that I guess gave me a taste for what it was the academics did when they weren't teaching.
>
> Hanna

Academic identity cannot be described clearly and pin-pointed to specific criteria, but it is strongly linked with the gaining of a PhD. The qualification may be obtained differently depending on the individual disciplines of scholarship, and yet, signifies academic belonging across all disciplines (Henkel, 2000). Participants see academia as a traditional environment where qualifying with a PhD provides access. They acknowledge the process and learning as a relevant journey towards becoming an academic on a public level. As such, the doctoral qualification is thought of as a gatekeeping tool to ensure not everyone can enter the sphere of academia:

> I kind of realized that if I wanted to stay in academia I thought "Oh, I better get a PhD" because it does feel like the currency, but equally to me it has been a bit of a box ticking exercise. I've met some brilliant researchers who don't have a PhD but I would say they have brilliant research skills, so for me, actually that's interesting because therefore having an academic identity I don't, personally, I don't think a PhD is necessary. However, the more years that we go on the more people have a PhD and it has now become sort of main stream that you are expected to have a PhD, and I think it's gonna get harder and harder to progress without one, yeah, which I think is a shame.
>
> Amy

At the same time, however, having or not having this qualification does not necessarily determine whether or not someone feels that sense of belonging to academia:

> Maybe, if I continue, maybe if I did something, you know, in research and if I looked into, you know, collaborating with somebody or publishing maybe that that will kind of keep me in that area of being an academic.
>
> Kate

These statements demonstrate the tension between what is an academic and how participants feel on a personal level. Although doctoral qualification plays an important in relation to building a sense of belonging to academia as a community, belonging and identity within academia are also linked to specific criteria like disciplines, roles and positions. What follows then is that the fragmentation of higher education (Barnett, 2003, 2005; Holden and Hamblett, 2007) aggravates the problem of individuals struggling to gain some sense of belonging. This missing sense of community particularly affects those academics who work in interdisciplinary fields or in service roles, such as in student support services, or in business and enterprise positions. The relationship between professional and academic careers leads to a new, different understanding of what academic identity means. For many, especially those from medical, nursing and educational professions or professional services, the professional career and experience provide the necessary grounding for an academic career. Nurse practitioners (Findlow, 2012) and teacher educators (White et al., 2014) commonly experience their selves as semi-academic or second-order. Following a historical trend, teacher educators are "an ill-defined occupational group of low academic status, consigned in most Western countries to the 'backwater' of educational priority" (Davey, 2013:175). Due to this negative self-view academic identity is not truly developed amongst teacher educators, who struggle with "stress and doubts about their abilities to perform their roles [and] feel lonely and marginalised" (Izadinia, 2014:436). In this context working at a university and holding an academic contract does not reflect the contemporary academic or what academic identity can also mean:

> People usually associate being an academic with higher education. But then a few people in FE [Further Education] were interested in doing some research or maybe enrolling on Master programmes.
>
> Kate

In this sense, academic identity is largely equated with the traditional identity of researchers and lecturers rather than the professional-academic identity of those entering academia from practice (Findlow, 2012). However, there are regular shifts between what is considered traditional, contemporary or a personal interpretation of academic identity. Self-categorisation plays a key role in the development and assumption of identity. A person chooses and therefore knows to belong to a social category or group (Hogg and Abrams, 1988). There is a clear focus on collectivism and sense of belonging to a group and how as humans we define ourselves as similar to and different from other groups. Identity in this context is strongly related to and influenced by the communal perceptions amongst those belonging to the same in-group (Stets and Burke, 2000). In simple terms, we choose the group that we identify with easiest and best, and then reinforce our identity by adjusting our behaviours and appropriating the communalities of that group. The public level of academic identity is then the institution-identity of someone working within a higher education institute. This definition echoes the participants' views and highlights the plight of PhD students who would not necessarily be included within that category of academic identity because doctoral researchers are students rather than staff members. The discrepancy between wanting to belong, developing a particular understanding of academic identity and yet, not fitting the general expectations associated with a traditional academic is a source of emotional pain (Frost, 2003). This negotiation of the space between being a student and a researcher is at the core of the "cognitive and emotive process" (Fitzmaurice, 2013:622) of identity formation amongst doctoral researchers. Emotional dissonance is a prevalent feature of the PhD experience, particularly around the recognition of the need for work life balance, set against the guilt incurred for not prioritising the PhD research at the expense of other areas of life (Brown and Collins, 2018). While early-career academics actively choose to adopt a certain identity through self-categorisation and find meaning within the wider picture of university life (Schulze, 2014), the socialisation process heavily depends on the individuals' connections with colleagues and institutes (Fitzmaurice, 2013) and the community of practice within (Schulze, 2014):

> I'm not sure whether I see a clear dividing line between when I was an academic and when I was not. I'd certainly consider myself an academic now, as all of my 'work' (and to be honest, most of my life) is focused on research, dissemination and teaching. […] Even back during my 'Initial Recover' phase, as an undergraduate, I knew I was training to be and becoming an academic – it was always what I'd wanted to do. I don't think the label of 'an academic' is something that can be applied to undergraduates though. […] I think what makes me an academic is expertise in my field (which I undoubtedly have) and the fact that I'm involved in both research that is on the cutting edge of my (admittedly quite specialised and small) sub-discipline as well as doing some teaching. I think it's probably the research, more than the teaching, which makes me consider myself an academic.
>
> John

The participants' understanding of academic identity is very much in line with literature that also focuses on the roles individuals perform in academia, namely teaching, conducting research and disseminating knowledge in publications (Feather, 2010). Early careers academics struggle with the development of a strong academic self that is negotiated between past and present experiences of academia (McAlpine et al., 2014). As such the socialisation process into academia is considered as most crucial for the development of an academic identity (Delamont et al., 1997). Within the hard sciences, for example, laboratory work and collaborative research projects are ingrained in the training programme for academics. The image of an academic within the hard sciences is therefore quite different from that of a social scientist, who is largely seen to be researching alone. Socialisation processes often do not include activities such as networking or conference attendances, grant writing processes and reviewing, which are all completed behind the closed doors of established academics (Gale, 2011). Due to the lack of support or time for such activities early careers academics tend to reconsider their roles and identities in view of their own experiences from student days, that an academic is a good teacher, and so early careers academics, especially within the soft sciences, focus heavily on their teaching and lecturing roles.

The personal interpretation of academic identity

On a personal and individual level academic identity is experienced as and associated with isolation rather than a sense of belonging. This is due to increased workloads, the debates and tensions between research and teaching and less cooperation with peers due to performance related assessments (Billot, 2010). What needs to be considered, therefore, is not so much the navigation of academic identity in relation to the public discourses, but the construction of academic identity on a personal level (Barcan, 2013).

> I went on to complete my PhD but had been thinking of myself as "an academic" for years before I actually completed. I'm still struggling to form an academic identity.
>
> Beth

Beth's apparently contradictory statement in particular highlights how having a qualification, being an academic and having an academic identity are three different but interrelated processes. On the one hand, the doctoral qualification is seen as an entry to the academic environment, but on the other it does not necessarily lead to or help the construction of an academic identity. The understanding of what constitutes academic identity does not develop in a vacuum but is shaped by the stereotypical and public image of academics. In the case of Amy who draws on the image of the "male professor stood at a microphone", this is not the full truth. In subsequent sections of the conversation she clarified how virtual social identity and actual social identity (Goffman, 1990/1963) differed from one another:

> That's not the kind of academic that I aspire to. That's just the image that came to my head.
>
> Amy

In fact, during the course of the conversations, most participants tended to rephrase their interpretations of academic identity in relation to their personal experiences. In their personal views and in relation to their personal experiences, participants returned to their childhood and forming years of primary and secondary education. Academic identity in that sense is strongly linked to and even equated with being a gifted learner:

> I've always been the "academic one" in my family. For as long as I can remember, that's been the role I've been assigned. Even though my mother and my two sisters are all incredibly capable, smart, strong women, I've been the one deemed "intelligent".
>
> Alison

> I started schooling at the age of 3 years. In hindsight I would see myself as being an academic at that age. […] Also, when I was born according to my horoscope (an Indian or possibly Hindu thing), I was meant to be immersed in education all my life. My view of an academic might have been influenced by this.
>
> Dana

> I suppose my first "academic" memory starts just before I moved schools, aged 7. […] I hadn't realised that I was so far ahead of other children, I just read. I spent the remained [sic] of my time in that school (8mths) sitting in the corridor, making clay models while literacy lessons were going on.
>
> Bernie

Academic identity and giftedness are not necessarily thought of as positive experiences. Indeed, Alison talks about being "othered" and Bernie goes on to describe how she was "a fish out of water" (Bernie). At its most extreme, the lack of belonging to peers and feelings of disconnect are described as forms of bullying:

> I moved to a different school for sixth form because I was badly bullied in high school and didn't think I had anything to lose by going somewhere else.
>
> Jill

On this very personal level, therefore, academic identity does not meet the criteria of academic qualifications and research or publication work. At this level, academic identity is associated with emotions in relation to learning, knowledge acquisition and simultaneously with feelings of disconnect to peers. When this definition from the childhood is transferred back into the sphere of adulthood, academic identity is related to research activities:

> Having a thirst for knowledge which never quite gets quenched, no matter how long you're been drinking?
>
> Bernie

> Constantly asking why and what, never being satisfied, and systematically seeking answers - then communicating what you've learned to the next generation so they can continue the quest.
>
> Beth

> I consider an academic to be someone who pursues the truth through study and research. An academic should be willing to question everything. To always ask "what if all I know and believe is not true?"
>
> Sherry

> I did my MA over three years and in the last two of those I was heavily focused on my own research and definitely identified myself as "a Psychologist of Religion". Prior to that, I certainly considered myself academic but probably not "an academic".
>
> John

The fluidity and flexibility of academic identity on this personal level is best described in the words of Angela, whose distinction between being an academic and a scholar highlights the different nuances related to academic identity.

> I think one thing, that we, that I've noticed as, as an academic, is, that the term scholar and the term academic are not necessarily the same thing, right? That people use them interchangeably but actually there's, there's a different, almost like a different vibe when you, when you say "academic writings", there's something kind of accessible about that, but when we say things like "scholarly pursuits" that implies also like *leisure time*? Something more cerebral, more cognitive and something that's almost unapproachable, so, in a weird way I do consider myself a scholar, but it's hard to.
>
> Angela

Angela demonstrates here that identity work in academia equates to emotional work seeking to bridge the gap between public, traditional values and an individual's own understanding of academia and academic work (Arvaja, 2018). Implied in Angela's statement is that the academic identity as explained from childhood experiences relates to being an academic, whereas the work an academic does is best described as the endeavour of a scholar. Being an academic, a scholar, in Angela's words, is therefore connected with asking questions, being curious, pursuing more questions and making "people uncomfortable potentially" (Angela). All of these statements show the emotional element involved in these academics' identity work. Emotion work and the role of emotions within higher education is not well explored with emotions and academia often seen "as incompatible entities" (Bloch, 2002:113). In an environment of competition and productivity academic identity is also understood and performed somewhat differently, as we will see in the next section.

Academic identity in the neoliberal academy

When asked to make sense of their academic identity many research participants highlighted the relevance of contractual details. Contractual conditions and job insecurity were key concerns, especially for early-career academics:

> Being employed on a business support contract, that seems to make all the difference. Like, you know, you seem to be kind of, I don't know, two different categories, either academic staff or business support staff
>
> Kate

For Kate, being employed on a business support staff contract resulted in questioning her personal identity as an academic. Having finished her academic qualifications and continuing to contribute to knowledge through research activities and publications for her signified that she was an academic. In practice, she felt that her work as business support staff was not recognised as academic work, especially as her contractual conditions do not embed scholarly engagement and research work. Feather's (2010) research involving lecturers at further education colleges delivering higher education business programmes highlighted that scholars or practitioners are not academics, but that the combination of conducting research, teaching and publishing papers makes an academic. Interestingly, the lecturers at the further education colleges also consider themselves as less academic and more as interpreters of academics' work, as due to workload issues these lecturers do not engage in the scholarly activities to the extent that "academics" would do. The description of "business support staff" was more commonly used within the context of further education than in higher education institutions. For all of the research participants, however, the principle was the same: in academia there are hierarchies and pecking orders of contracts:

> As I'm not a university employee I don't have an academic email address or access to internal events or meetings, so it can be hard to feel part of the community. Some people do not even count me as an academic: a popular online magazine refused my pitch for an article purely because I'm not employed at a UK institution.
>
> (Blog post[11] written by a participant in my study)

This participant's narrative exemplifies the power-relationships resulting from structural constraints within academia (Luthar and Šadl, 2008). Instead of being able to engage with others in academic debates, the participant talks about being excluded and not being able to break through glass-ceilings. The above excerpt also shows the tensions and contradictions between the public image of academic identity, the role and relevance of employment details and one's personal affiliation or feeling. For early-careers academics on temporary or hourly-paid contracts, in particular, these discrepancies relate to and are enhanced by the precarious situation they find themselves in. Where there once was tenure and permanent employment, academics, especially those new to academia, are now employed on a greater range of contracts, including on fee-paid and temporary basis. Academia is now characterised by increased job insecurity and worsening working rights, particularly for those early-careers academics (Blix et al., 1994; Tytherleigh et al., 2005; Watts and Robertson, 2011). The narrative of Alison is probably the best example to demonstrate the ambivalence early-career academics experience. Alison is a young, early-careers academic who has completed her PhD and successfully published journal articles and books. Alison is confident and comfortable with who she is within academia, and she clearly identifies as a successful academic. However, this academic success as a popular seminar leader, speaker and published author is at odds with her employment situation. At the time of writing she held an unpaid, visiting lectureship at a UK university, which at least allowed her to have an institutional email address and access to library. She regularly applied for paid research or teaching positions:

> I have been told that it's like I should apply for jobs that are, like, you know, nine months in a small town in Wales for basically minimum wage and that I should do that, and I should, if I really wanted to be an academic, that's what I should do 'cos that's the sacrifice you make. […] So it's like, yay! Applying to not be paid, woo hoo! I put in an application this week and doing another one tomorrow, and doing one the week after, 'cos who needs weekends? […] I work like my *guts* out, you know, *long* nights, pushing through the fibro, like getting it done because it's

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[11] Blog post available at: https://www.theguardian.com/higher-education-network/2016/apr/08/im-not-employed-but-please-recognise-that-i-am-an-academic

> important for me to do a good job and yet, if I weren't married, I couldn't like I couldn't pay rent
>
> Alison[12]

Alison quite vocally provides a sarcastic description of the employment search, but then her situation is truly upsetting:

> I'm angry and I'm sad because I'm really good at my job, like I am genuinely good at this, but that doesn't get any financial recognition, and money at a certain point is important; I don't want to be a millionaire out of academia, but I wanna be able to pay my rent, and at this point, given how good I am at it, like what the fuck is going on?
>
> Alison

Alison's narrative reflects what has been identified as the typical experience of younger academics, who feel unsuccessful and inauthentic (Archer, 2008b). In the current dominant performative context early-career academics compete with and against established staff members in excellence exercises whilst struggling to establish themselves as legitimate contributors to the institution (Archer, 2008b; Blackmore, 2015). Alison's precarious working context is unfortunately not unique. From the full study with 28 participants 48% are in temporary and/or hourly paid employments, with two participants even being unemployed. Many of the academic participants in this study quite eloquently highlighted the precariousness of academic employments as an issue. Participants talked about their work being very individual and individualised, but at the same time the early-careers and mid-careers academics fight for recognition within their community of scholars. The recognition in this case is not so much the publication and the academic recognition, but the recognition as a contract-holder.

The changing landscape of higher education has left traces within individuals' understanding of their position in academia with academics' narratives dividing into three categories: regressive, progressive and stable (Ylijoki and Ursin, 2013). In the regressive storyline, academics understand the values as problematic and therefore interpret academia as deteriorating. With progressive storylines academics interpret the neoliberal university as opportunities for growth and development, whereas the stable narratives are neutral and situated between the two extremes (Ylijoki and Ursin, 2013). The narrative of participants in this study is one of regression which is performed as accepting the role as the contemporary academic. For them, working

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[12] Evidence for the precarious contracts in academia requiring individuals to push themselves to the limits (mechanism (i) as per the introduction).

as independent researchers on a self-employed basis or following temporary and hourly paid contracts does not mitigate the academic achievements and research work. In practice, they are caught in the dilemma of conforming to the institutional values and norms whilst trying to actively shape their work and employment (Collins, 2008).

As we saw earlier, what makes an academic is linked to research work and engaging in research activities. These may not necessarily be large, prestigious, funded projects, but can also be simple systematic enquiries into personal practice or systematic approaches to learning about something new. For participants, the definition of academic work, however, was less clear-cut and not simply divided into the teaching element on the one hand and the research element on the other. In reality, due to cost-cutting measures academics' workload has changed and increased drastically. Academics are now involved in administrative tasks such as the creation of module validation documents, the compilation of programme reports or standardised handbooks, the monitoring of student progress and the designing of a curriculum that fits the university branding and increases its marketability, which feeds back into marketisation and consumerism. Through the reduction of administrative staff academics experience more pressures to take on administrative duties (Winter, 2009). Strategies to widen participation also contribute to increased workloads, as students entering higher education are weaker and so require more informal, tutorial support (Friedman, 1995; Merrill, 2001; Taris et al., 2001). In the course of conversations, participants specified teaching as student-facing work, teaching-related activities and to some extent administrative or regulatory aspects of work that are connected with teaching:

> When I used to teach, preparing lesson observations when they come up, and they call for OFSTED inspections and things like that. Actual request actually pressed on your time. When you just... your job becomes so big they have for more and more timing, and especially after work.
>
> Kate

Participants talked about teaching, marking, providing feedback, offering tutorials and support sessions and about attending meetings to discuss teaching-relevant developments within modules and programmes, such as marking moderation and standardisation meetings, programme development meetings and away days. The individualisation and fracturing of the teacher-research relationship (Barnett, 2003, 2005) coupled with the diversification of job specifications results in higher numbers of academic staff being employed on a contractual basis (Hey, 2001; Reay, 2004).

When participants were asked to consider what working life in academia was like, many of them talked about exactly that: precarious contracts, job insecurity and lack of recognition for academic work and research, especially when their contractual conditions referred to business or professional work. They talked about feeling under pressure to succeed and overcome the difficulties of contracts and the competitive environment in academia.

> I feel that I am under pressure to perform especially academically with the writing and the outputs. The teaching is a joy and that's like being back in the restaurants and hospitality, where you give energy and energy comes back, and it's a very natural environment for me to be in. I love it; there's no other word for it […] I don't feel pressured to be up and on in the classroom environment, but in the rest of the environment at work, where it gets into the academic publishing and outputs, yeah, I do feel it.
>
> Yasmin

Despite their experiencing precarious conditions and a pressured environment, participants emphasise their position of privilege when asked about academic identity and being an academic.

Privilege, autonomy and flexibility – the false friends in academia

Throughout the conversations, participants often referred to the privilege of academia and that it is impossible to be an academic without having been privileged in some form or other in their lives. Participants consider academia as worth striving for (Bauman, 2008) and so being an academic in itself is seen as a privilege:

> I mean, in fairness, academic life is possibly better at, is probably one of the better places to be, than lots of other jobs. Because of the flexibility. I didn't have to, you know, really negotiate to leave today at half-past two […] here's a sense in which, you know, it's tempting to sort of moan about academia and then you remember what every other work place is like. Yeah, yeah, that's why I prefer working here.
>
> Hanna

Participants explored at great lengths the role academia plays in their lives, and for them, being an academic allows for flexibility. This flexibility is particularly relevant in relation to adjusting to and accommodating life with fibromyalgia (see chapters 6 and 7 for more detail on academics with fibromyalgia). For example, in comparison to non-academics within academia, such as professional services staff, as well as in comparison to non-academics more generally in the wider society, the academic has got the privilege to work flexibly. The flexible working arrangements may relate to part-time positions, but also to the opportunity to start the working day later, to catch up on work over the weekends or in the evenings, as well as to work remotely rather than in an office on campus. For the participants, academia allows the flexibility to autonomously and freely choose the mode of work and as such working in academia is generally equated with being privileged and lucky:

> I mean, I'm quite lucky in that, you know, we're not a student facing department, so although I'll do a bit of teaching, it's not like being in some of the other departments where you are constantly just email upon email upon email from students, you're trying to teach, you're trying to do research, you're trying to respond to all the students; and I don't have to do that and I think I think that means that my workload is more manageable, when some of my peers who are working at least seventy or eighty hour week, now there's no way that I can do that but because I'm in a department that is a research unit it's just a very different type of academic department compared to say, law or psychology, and politics, those sorts of things.
>
> Amy

Sutton (2015) as well as Ylijoki and Ursin (2013) explore the freedom and flexibility academics enjoy within their work. In practice, freedom and flexibility represent a major advantage of working in academia, but at the same time are an equally major drawback. More nuanced discussions highlight that freedom and flexibility embody a form of control (Henkel, 2005a). In Bauman's (2008) terms belonging to a community requires balancing a certain sense of security and safety against the loss of freedom and autonomy. Belonging to the academic community means to be amongst like-minded individuals and as such offers a sense of security and safety, but there is "a price to be paid for the privilege" (Bauman, 2008:4). Being part of a community means individuals lose freedom, autonomy, the right to assert themselves and to be themselves. In this sense, flexibility of work is not enabling but a means to maximise labour contributions as cheaply as possible (Lovin, 2018). Professionals in other fields also take home their work and continue engaging in work-related emails or other activities when they are no longer in work. However, it is easier to lose sight of barriers and borders between one's work and one's life in academia where the working hours are flexible and where the work satisfies the need to learn and to find answers:

> So you might have days when you work in twelve hours non-stop because you don't want to let go, and there are other days you might not even be able to do any thinking. So, I do think the flexibility, where it is an advantage, it also becomes a disadvantage because there are no boundaries.
>
> Dana

Dana's exploration of flexibility in its negative form demonstrates its destructive potential. Indeed, formalised measures of performance and productivity have led to general availability in academia. Work after working hours or at weekends, voluntary attendance or participation at the expense of holidays or at financial costs have become entirely normalised. The work flexibility offered at academic institutions results in the need to demonstrate "heroic stamina" (Beretz, 2003:52) to work at all times. Consequently, academics who resist the perpetuation of such expectations are labelled as under-performing (Shipley, 2018). Academics need to find their places on the continuum between freedom and institutional authority, between knowledge and marketisation (Sadler, 2011).

Participants not only talk about privilege in the context of flexibility, but also in comparison to the wider public. As we have seen from the debates of what constitutes academic identity and the contractual conditions of the contemporary academics being an academic means being privileged in that not everybody would be able to sustain a life without regular income. A quantitative analysis from this study supports the view that privilege is required to be able to financially afford a career in academia. At the mid-career stage, only two out of the eleven participants, thus 18% did not have an open-ended contract at the time of interviewing. Amongst the early-career academics, the reverse is true, as only two out of fourteen participants had an open-ended contract. This means 86% of the early-career academics did not have an open-ended contract. The early-career academics therefore would have certainly experienced increased pressures and stresses. These figures compare to 66.2% of academic staff on open-ended contract across the higher education sector (Advance HE, 2018). It is particularly concerning that those who are in part-time employments, thus overall earning lower incomes, are more likely to be on a temporary, fixed-term or hourly contract. 50.9% of academics employed part-time are on fixed-term contracts (Advance HE, 2018). Many research participants highlighted how they grew up in a privileged position that allowed them to study and develop a career in academia. In fact, even when considering the potentially adverse circumstances research participants find themselves in, academic work and working in academia for them is still a privilege. For the participants therefore being able to continue to pursue an academic career in itself is a symbol of privilege:

> I, I'm, I've definitely been able to become white, middle-class privileged from a working-class background […]and when I'm talking to other people, I do realise that, what a privilege it is to be in this situation, whereas a lot not people I know that have problems do not have that, you know, there's the debt spiral
>
> Bernie

> in some ways I come from a high achieving family, I'm one of the low achievers probably in my family's context, my, and I come from an upper middle-class family in India
>
> Dana

This understanding that working in academia is a privilege and that they belong to some elitist group within society results in participants placing additional pressures on themselves as emotions perpetuate discourses of domination and power in organisations. "Emotions of shame, fear and guilt lead women to exercise self-control and self-exclusion and thus contribute to their own domination" (Luthar and Šadl, 2008:250). The academics in this study feel that they need to prove themselves for their own sake and for the sake of their families to do justice to the privilege they are entrusted with. For example, in an already quoted statement Alison talks about not being able to pay rent without her husband's income. Her privilege of being married and financially supported may mean that she is under the self-imposed pressure to succeed. In effect, academics conform to and have internalised values of workaholism (Fassel, 2000), which has been described as an "addiction that [Western societies] praise, value and brag about" (Gini, 1998:18). For many participants being an academic is not necessarily related to having an academic identity or merely having a position in academia. Working in academia and being an academic is considered a lifestyle choice:

> [I am] fully established. Fully established. I'm not doing anything else. There is no plan B, I have no alternative CV sitting in a drawer. I don't look at other jobs. I used to do that. I used to do that, when my PhD was really awful and I thought, I'm struggling so much now, how could I possibly take on a career, but I don't want to do anything else. I don't want a plan B, and I don't tell myself the plan B, otherwise I'll just give up. […] Different job? No.
>
> Sian

> I enjoy I like what I'm doing, it's like having a work-kind of hobby all rolled into one. Umm, I can't see me wanting to move on to from doing what I'm doing
>
> Bernie

> I would just say that at that point in time, roughly a year ago, maybe last summer and I was reaching, I had reached a point where my funding was up and so I had to kind of decide what to do next and, after some fits and starts, I currently work as a librarian. So, I work as a librarian in an academic institution and it's nice because I just get to be a practitioner while I'm at work […] that's what I currently do, so my, the current hat I

> wear is "academic librarian". Oh, I love being a librarian it's what got me into this whole weird lifestyle anyway.
>
> Angela

> I think it can be a lifestyle.
>
> Amy[13]

These statements demonstrate that certain elements of working in academia are often romanticised (Lovin, 2018). Although they are aware of structures and norms, academics still feel they are autonomously deciding to embrace the academic lifestyle. Instead of understanding academia as an exploitative labour market that is particularly difficult to penetrate for young women, they still view it as a lifestyle and a labour of love (Coin, 2018). The academics in this study have fully internalised the views that have prevailed for several decades, that "the most admirable thinkers within the scholarly community […] do not split their work from their lives" and that "scholarship is a choice of how to live as well as a choice of career" (Mills, 2000, 126f). As a consequence, the academics in this study are not considering a different profession as a career option.

Character traits of academics

As part of the identity box project participants were asked "how do others see you?". The brief to this question was phrased in such a way that participants were not to ask significant others or friends for their opinions, but to consider how they themselves thought that others would see them. The answers in response to this question provide insight into and understanding of participants' underlying characteristics and personality traits:

> They view me as bullet proof. […] So, like for my friends, I am the one people go to, I will fix it. And by fixing it, it's that I will listen to you, and I will help you have your emotions and we will talk about it and I will be I will pick up the phone.
>
> Alison

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[13] Evidence for how academics must reconcile the tensions of internalised external values and personal expectations (mechanism (ii) as per the introduction).

> The things that I have heard people say about me are things like "tough cookie" I get that quite a lot "funny" apparently and "good at giving advice" and really someone who's got a lot of stamina, and integrity, which is nice, and "faithful" that's come up.
>
> Amy



> Hubby would see me as being the strong type, the organizer, the person that gets things done, and the loyal type but he would also say that I am not easy to live. With the people I do work for, tend to be those that will see me as like being their knight in shining armour or the font of all knowledge or all things SEN [special educational needs] they come straight to me. […] but then if you're on the opposite side of me, so like, say the local authority, they may see me as being a bit of a prickly thorn. Definitely a thorn in their side. So, it's, perhaps a bit Marmite. Some people will be embracing me for the knowledge and skills that I have and see them as a strength, and other people are frightened of my knowledge and skills and see me as a complete pain.
>
> Bernie

> Well organised, well-organised, I get that a lot, well organized and they think I'm quite calm under pressure, because I don't have a temper outside of my house, I don't have a temper and mostly in my house, I don't have a temper. […] Pedantic. My husband, my husband called me pedantic, right. Things must be correct, I must, wrong things may not continue in my life. Everyone must know that things are factually correct, and if something is factually incorrect, I must move on.
>
> Sian

In the conversations, the participants quite openly linked their thoughts of how others saw them to why they were then successful in becoming and being academics. There seemed to be a general consensus regarding the kind of person who works in academia, thus is or becomes an academic. For participants, academics are high-achievers and have high expectations of themselves:

> [In a discussion with a superior] I said "I've been thinking about changing this" and he said "there's that Yasmin that we all know; you make more changes", and I thought he was going to say "you make more changes in a semester than everyone else makes in a year", and he said "you make more changes in a month than the rest of us do in ten years"
>
> Yasmin

> In a way you could probably argue that everybody who's working in academia as an academic is probably more likely to be a high achieving

> person than somebody who is, I don't know, sitting at a checkout till of a supermarket. […] I think I do have a mindset like that, that I feel like there is still more to be done, still more different things to be done, and I just get caught into that […] Definitely, I am, I am a perfectionist. I don't like - although I will say to people "Why are you a perfectionist? It's okay, just needs to be good enough". In my own life I don't do that and I just have this, this thirst for new stuff, more stuff.
>
> Dana

Being high-achieving, having high expectations, paying attention to detail were commonly discussed as positive traits. Through having high expectations, it is possible for academics to strive for more knowledge, produce better research articles, to contribute to the academic community, and so to feel validated in their identity and their work. Participants talked about the relationship between their character traits, academic work and their identity and how these are all interconnected:

> I like having purpose, and I like what I do, and I like having that sense of being independent
>
> Amy

> Academic identity correlates with perceived locus of self-esteem. Mine can be a little shaky, therefore I have an external locus of "academic identity".
>
> Erica

There was clearly openness around having high expectations, being pedantic and potentially having a low self-esteem because they are not meeting those high standards set. Participants also considered traits they might have and how these may be the prime determinant for their being successful in academia. Perfectionism and perfectionist tendencies were discussed in generic terms and generally seen as a positive characteristic. When they were probed more specifically and directly about being perfectionist, participants emphasised the difference between perfectionism and having high expectations:

> If I were perfectionist, I'd like never leave the house without my hair and makeup being done. I would never forget a birthday, or a birthday card, my room would not be the mess that it's in. And it should, you know, be, but my room wouldn't be that messy, you know, self-presentation would be paramount. No. I just I'm a nerd, I'm a giant nerd, and I spent my whole life being a nerd, and I know lots of things, and incorrect facts must not be allowed to continue in the universe. It's just about facts.
>
> Sian

Existing research into perfectionism in connection with health and wellbeing highlights that perfectionist traits play a significant role in psychological disorders (eg. Flett and Hewitt, 2002; Frost and DiBartolo, 2002), but also moderate health behaviours and thus promote wellbeing (eg. Bieling et al., 2004, Stoeber and Otto, 2006). At this point in time, the link between perfectionism and physical health is less well developed (Sirois and Molnar, 2016). However, considering the close relationship between mind and body as well as the fact that conditions such as fibromyalgia sit on the cusp of the psychological, somatic and physical, the consideration of how perfectionist traits impact psychological as well as physical health seems natural.

Models of perfectionism are diverse. Following the traditions of Freud for example, researchers see perfectionism as a uniform and unitary concept so that a person is or is not a perfectionist. A second school of thought revolves around Hamacheck's (1978) understanding of perfectionism as multidimensional and multifarious. The discrepancy here lies within the disciplinary views of perfectionism as clinical and a stable trait versus seeing it as fluid and changeable. By interpreting perfectionism as multifarious and multidimensional Hamachek made it possible to hone in on particular elements, such as frequency of perfectionist thoughts or domain-specificism. People may be perfectionists in one area of their lives and not in others (Matte and Lafontaine, 2012). This allows for deeper engagement with specific elements and components to perfectionism, which in turn helps forge and understand definitions of perfectionism. Generally, perfectionism is understood as setting and pursuing unsuitably high and unreasonable standards along with a disproportionate focus on achieving these unfeasible standards and self-evaluation that is overcritical (Frost et al., 1990). This definition forms the basis of today's biopsychosocial understanding of perfectionism that combines perfectionist strivings with perfectionist concerns and other-oriented perfectionism:

> PS [perfectionist strivings] refers to the propensity to set excessively high personal standards that are often unrealistic in nature and to demand nothing less than perfection from the self. […] PC [perfectionist concerns] includes extraordinarily critical appraisals of one's own behaviour, chronic harsh self-scrutiny, excessive preoccupations with others' evaluations, expectations and criticism, and an inability to gain satisfaction even when one is successful in an endeavor. […] OOP [other-oriented perfectionism] measures the extent to which individuals rigidly demand perfection from others in an exacting and entitled way and are being highly critical of others. (Sirois and Molnar, 2016:8-9).

Sian sees perfectionism as stable and clinical, a character trait that infuses one's entire life and livelihood. As such, she conceptualises her own striving for success not as a sign or symbol of perfectionism, but merely as that, striving for success. It does not occur to her that she may demonstrate signs of "domain-specific" perfectionism, the kind of perfectionism that does not necessarily manifest itself in all aspects of her life. And that therefore, it may well be her perfectionist strivings and concerns that exacerbate mental and physical health. What is interesting to note, is the convergence between what makes an academic in the participants' views and what it means to have fibromyalgia. Participants do not exclude a link between their being academics and being diagnosed with fibromyalgia. Van Houdenhove et al. (2001) highlight that typically those diagnosed with fibromyalgia are more action-prone and overactive, which in turn fits perfectly well with participants' description of what makes an academic. The data in this study also highlighted that participants inextricably linked academic identity and their selves and that they continued to focus on academic work and achievements. These factors strongly reflect the characteristics of workaholics, who are prone to external referenting, unable to relax, self-centred, isolated and perfectionist (Fassel, 2000:27-38). These character traits, in turn, are also recognised in individuals diagnosed with fibromyalgia (Van Houdenhove et al., 2001). It therefore stands to reason that academics may be workaholics and fibromyalgia a coping mechanism for the internalised values.

Sian's emphatic declaration went further, when she openly dismissed links between her character traits of being a nerd and pedant to her life with fibromyalgia. Sian adamantly argued that throughout her life her friends and family had always considered her a perfectionist, whereas she had not had fibromyalgia symptoms throughout that time:

> I think it has a hundred percent physical cause. So, I don't think I'm doing anything that sets me up for fibro at all. You know, the perfection, perfectionism thing is something other people have said about me my whole life.
>
> Sian

At no point does it occur to Sian that fibromyalgia could be the physical manifestation of years of over-exerting, pushing herself and pursuing or succumbing to her personal perfectionist traits. Through rationalising and interpreting their experiences, individuals have highlighted the role the somatic and psychological play in fibromyalgia, for example, when they refer to the deterioration of symptoms at particular life-or career stages (eg. p.156ff.). Indeed, the impact of somatic and psychological issues on an individual's experience of their body and bodily symptoms is long-documented (Wahler, 1968; Pennebaker and Skelton, 1978; Mayou, 1991). In their work relating to work stress, Wainwright and Calnan (2002) identify four potential models for explaining what they term the modern epidemic of work stress, which see work stress and ill health as the employees' resistance against their employers.

Being a perfectionist, having high expectations and being a high-achiever means that academic work does not stop at the end of a nine-to-five working day. In the words of Dana, the brain work continues and an academic may continue or even start new projects in the evening after a full day's work:

> The brain doesn't function like that; it doesn't function 9:00 to 5:00, it will happen when it will happen.
>
> Dana

This tendency to strive for doing more and being high-achieving is ever-present, and spills into other areas of life. For academics, being successful and highly functioning also related to being high-achieving and successful in dealing with fibromyalgia. Some participants spoke directly in those terms about their managing fibromyalgia, whereas others referred to being well adjusted or having learnt well. In all cases, the participants took pride in being high-achievers:

> He [General Practitioner] sort of said to me, and he even sent me a letter titled "Professor XXX" and "it was good to meet with you", and he was, basically, I can't remember whether it was in the letter or he said personally, but "my most; the highest achieving Fibromyalgia patient I've had"
>
> Dana

> I'm quite lucky to be like quite high functioning […] I can see that I am one of the most high-functioning in the group in terms of like career, in terms of the kind of like battles that I have to fight […] so, you know, I can walk to that clinic
>
> Alison

Using Simmel's (1950) and Parsons' (1970/1964) understanding of illness as a corporeal expression of tensions and strains, the relationship between academic identity, academic work and fibromyalgia becomes more salient. I will discuss what it means to have fibromyalgia in today's neoliberal academia in detail in chapters 6 and 7. Suffice it to say at this point that academics do realise that there is a link between their working environment and their symptoms, but that they do not recognise academia as the cause for fibromyalgia.

Concluding thoughts

In this chapter I showed how the participants in this study view being an academic in relation to the stereotypical images prevailing in the public discourse, before considering the role and relevance of qualifications in accessing the academic community. Academics work on their self-identification, identity and self-image at a personal level. Actively constructing, defining, redefining one's identity is a complex, "cognitive and emotive process" (Fitzmaurice, 2013:622). Emotion work therefore becomes part of and integral to identity work (Winkler, 2018). And yet, the participants' interpretation of academic identity is strongly influenced by images and depictions that are generally available from personal experiences, depictions in media and social media (Feather, 2010). Academic participants are part of the set of beliefs and values within institutions and disciplines. How an individual academic identity is experienced, depends largely on the academics' understanding of their personhood, their personal relationship with others and their conception of roles and responsibilities within the wide range of academic activities (Clegg, 2008). Becoming or being academic is an active process of reconciling or indeed resisting to reconcile autonomy, authenticity and values with the success criteria audit of the neoliberal university (Archer, 2008a, 2008b; Henkel, 2005b).

A key consideration relating to the relationship between identity and work is the level of an individual's conformity and internalisation (Haslam et al., 2000; Tyler, 1999). The difficulty lies with grasping and identifying the difference between external, outward behaviour and internal, private thoughts. In higher education, this dichotomy has been identified as a binary between apparent conformity and actual conformity (Stormer and Devine, 2008). Different levels of conforming behaviours have been identified: compliance, identification and internalisation (Piaget, 2013; Vygotsky, 1980). At the level of internalisation, individuals have integrated external values to such an extent that they represent a new behaviour and new personal values. It is at this level that individuals will perform activities without external controls and without seeking to impress others (Kelman, 1958). Once these norms and values are continually referred to, reiterated and enforced, they become established (Butler, 2011). The auditing culture within higher education is one example for consistent iteration and enforcement leading to establishments of norms (Canaan, 2008). In Scott's (1971) terms norms represent social action statements of which behaviours should or should not engage in. Values, by contrast, refer to an individual perspective of dreams and desires, and as such represent the personal endeavours and commitments. In effect, however, norms and values are interrelated in that societal norms need to be valued at an individual level for them to become established overall (Scott, 1971).

Academics are bound by personal values and social norms, which they internalise through their moral commitment to the academy (Scott, 1971). As such, academic identity, working in academia and the specific characteristics and personality traits of academics can be seen as manifestations of internalisation processes (Parsons, 1970/1964). For academics, working as an academic represents privilege, autonomy and flexibility, although having freedom and autonomy does not mean they can do what they want (Bauman, 2008). Additionally, flexibility is destructive in that it normalises constant availability on the one hand, and exclusion from specific tasks on the other. The academics' core character traits of being perfect and high-achieving reflect and are reflected in the pressures of striving for teaching and research excellence. Participants in this study emphasise the importance of being an academic and working in academia, despite being aware that they succumb to structures and rules as we will see in detail in chapters 6 and 7.

6. Academics making sense of fibromyalgia

As we saw in chapter 4 concepts like illness narratives (Frank, 2013) and biographical disruptions (Bury, 1982) are helpful lenses to explore the lived experiences and individuals making sense of life with fibromyalgia amongst non-academic women. The variability of fibromyalgia makes it difficult for individuals to develop a sense of new normal or to understand fibromyalgia as a temporary biographical disruption, and so non-academics adopt an attitude of combative acceptance. In this chapter, I demonstrate that amongst academics the process of understanding and coming to terms with fibromyalgia is different. I argue that for academics making sense of fibromyalgia happens in two forms: as an academic, scientific, objective, cerebral activity and as an experiential, personal, emotional journey. Through the scholarly and emotional meaning-making process academics understand fibromyalgia as a holding diagnosis. I further contend that, in reality, academics' scientific level of engagement with fibromyalgia is pseudo-objective or quasi-scholarly in nature, and that their narrative is one of resistance against processes of marginalisation (Ware, 1999). In chapter 4, I highlighted some of the processes related to making sense of life with illness, such as identity continuity (Llewellyn et al., 2014; Wolfenden & Grace, 2012) and normalisation (Sanderson et al., 2015; Sanderson et al., 2011). This chapter shows that academics with fibromyalgia realise at scholarly and emotional levels that their academic identities and sense of self are at risk and so actively counteract, resist and transform that dominant discourse (Raddon, 2002).

The role of society and cultural environment within the context and understanding of illness and illness narratives is well documented (eg. Kleinman, 1982, 1986, 1992, 1995; Good, 1992; Ware, 1992, 1998, 1999) in medical anthropological and sociological discourses, and increasingly within the medical realm (Hadler and Greenhalgh, 2005). Within these conceptualisations, illness is seen as constructed at three different levels, as it is embedded with cultural meaning, but also defined at an experiential level and shaped by the medical discourses (Conrad and Baker, 2010). Illness symptoms which individuals experience are felt as sensations, but also experienced at an emotional, embodied level as learnt responses to conventions (Trigg, 1970). In this sense, illness symptoms are physical manifestations of societal ills and cultural influences (Kleinman, 1986) or a lived experience placed within a society or culture (Ware, 1998). In line with this sociosomatic understanding of illness, experiences of physical pain in fibromyalgia are also a manifestation of emotional pain, stresses and traumas (Guignard, 2013). Through the expressive body's (Williams and Bendelow, 1998) manifestation of pain, individuals' experiences are validated and become "real". The physical pain can be explained more easily to oneself and to others, and as such represents a protective mechanism that allows individuals to avoid dealing with the underlying, emotional issues. In effect, the bodily expression of pain is in lieu of the individual's verbalisation of pain (Guignard, 2013). How individuals report and respond to pain is shaped by cultural and societal conventions (Kotarba, 1983). Indeed, the entire illness experience is a social experience that impacts and is impacted by individuals and their relationships to others (Kleinman, 1995). Any illness experience therefore needs to be seen in the context of the social. Ware (1999) developed a conceptual model for a social course of chronic illness based on the experiences of individuals with chronic fatigue syndrome (Figure 6.1).

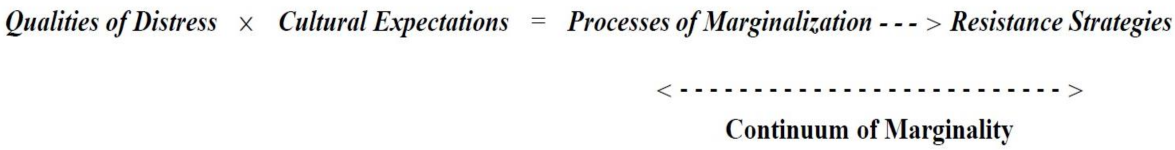

Figure 6.1: Social course of chronic illness (Ware, 1999,

In Ware's (1999) terms the qualities of distress experienced at an individual level combined with cultural expectations, societal norms and conventions result in processes of marginalisation. Individuals are faced with delegitimation or delegitimization of their illness experiences, with limitations to their activities and thus to their role performance, with financial consequences and social isolation. In order to prevent this marginalisation and being pushed to the marginal edges of their social group, resistance strategies are employed. Ware (1999) describes preserving and re-making the lifeworld as two groups of resistance strategies amongst people diagnosed with chronic fatigue syndrome. Further resistance strategies include educating others (Wahl, 1999; Link et al., 2002), distancing oneself from the illness or condition (Weinstein, 1983), trivialising the condition (Estroff et al., 1991), strategic avoidance of particular situations and conversations or defiance in view of the inevitable (Riessman, 2000), which are all simplified in a model describing resistance behaviours as strategies to deflect versus challenge or confront (Thoits, 2011). Such behaviours do not necessarily need to be public, formal, intentional to be interpreted as resistance (Collins, 2002; Ortner, 1995; Scott, 1990, 2008), and in some instances actors do not even intend to signify resistance (Hollander and Einwohner, 2004). For those with chronic fatigue syndrome resistance is commonly performed as maintaining existing activities, even at the expense of experiencing symptom aggravation or pacing themselves through cutting down on what are considered as less important activities (Ware, 1999). Resistance amongst the academic participants in this fibromyalgia study is performed differently. My contribution to original knowledge in this chapter lies in my identification of these four forms of resistance amongst the academics with fibromyalgia.

In the section "The scholarly understanding of fibromyalgia" I outline how academics attempt to make meaning and seek sense in their diagnosis through researching the condition. I show that as a result academics know about the contested nature of the condition, the connection between the psychological, physiological and somatic, but also about issues around and consequences of classifications and categorisations. I outline that this scholarly activity of seeking understanding extends to individuals being aware of the roles medical professionals play in validating and legitimising the illness experience, and the roles the academics themselves are enforced to play as good patients. I further demonstrate that through these research activities academics gain awareness of processes of marginalisation and stigmatisation and so employ four different kinds of resistance strategies. (1) As a first strategy, academics incorporate societal expectations and norms into their life-stories. Instead of using the contested fibromyalgia diagnosis, academics revert to conditions and explanations that would be socially more acceptable. (2) The second strategy is the re-making the lifeworld at a cerebral level through redefining reality and creating a new, socially acceptable reality. (3) Linked to these first two strategies, academics further resist the processes of marginalisation by actively rejecting the fibromyalgia diagnosis. I emphasise that academics' scholarly and cerebral engagement with fibromyalgia is, however, embedded in individuals' actual illness experiences and felt and lived emotions, with academics often not realising how bound they are in societal norms and existing discourses around illness as a "problem to be fixed" and that in this sense, the scholarly understanding of fibromyalgia cannot be separated from the emotional and experiential. In the section "Understanding fibromyalgia at an emotional level" I tend to that specific level of analysis and sense-making. I show that the predominant emotions in relation to the fibromyalgia diagnosis are ambiguity, confusion and uncertainty and that for the academics the diagnosis explains and validates their experiences. I outline that within this validated experience with and of fibromyalgia academics hone in on the permanence of fibromyalgia even in phases of remission and despite their scholarly and cerebral rejection of the diagnosis. I demonstrate that in having and dealing with fibromyalgia on a permanent basis, the condition takes on a relative quality, so that academics compare the "before and after" fibromyalgia or the "with and without" fibromyalgia, but that ultimately academics begin to doubt their own experiences, the realness of the condition and even, themselves. At the same time, I show that academics do not indulge in the potential excuse the fibromyalgia diagnosis may provide, but instead push through difficult times and bad days, thereby engaging in the fourth resistance strategy: (4) active and pro-active countermeasures to assuming the sick role. I conclude that unlike the non-academic women academics cannot find any positives in and cannot get anything out of having fibromyalgia. In the subsequent section "The female fibromyalgia body" I demonstrate this lack of a silver lining. I use the theme of the female body with fibromyalgia to demonstrate that for academics fibromyalgia takes on an all-encompassing, negative presence and permanence. In this section I highlight how individuals struggle to conceive and how for two academics this failure to conceive results in even more ambiguity, confusion and negativity around their bodies. I show that the wish to become mothers is in itself a strategy of resistance, as the women refuse to lose out on normal experiences because of fibromyalgia. But I further highlight that the failure to conceive and the fears of how to physically cope with pregnancy, birth and having a baby result in emotional stress and distress. With this section I exemplify how the academics' scholarly, cerebral sense-making and their experiential, emotional levels of understanding outlined in the previous sections are inextricably linked with one another.

The scholarly understanding of fibromyalgia

When questioned about their understanding of fibromyalgia, research participants drew on their scholarly curiosity and academic knowledge. Participants had generally engaged with some form of research into fibromyalgia, its aetiology, symptoms, prevalence and forms of treatments. As such, they were fully aware of the contested nature of the diagnosis and the fact that the condition sits on the cusp of psychological, somatic and physical. This kind of understanding and learning about fibromyalgia is a scientific, objective, cerebral activity. The careful reading, exploring and researching represent academics being academic about having fibromyalgia:

> [From reflection I could see] what fibromyalgia is or what chronic pain and chronic fatigue are and how I interpret them. I am myself I'm personally interested in the idea that they are – and I don't mean this to sound overly psychological, because I do believe that it's a very physical thing – but that there is some kind of maladaptive response to stress, and

> that these flare-ups have been kind of my body sending me the message "this is too much".
>
> Hanna[14]

At this analytical level, Hanna and other academics understand fibromyalgia as a classification for a condition that integrates physiological, psychological and social meanings (Kleinman, 1986). In this academic, scholarly meaning-making and engagement with the condition participants remove themselves emotionally from their personal experiences with fibromyalgia. Instead, irrespective of their professional fields of study, they approach understanding fibromyalgia from sociological, medical anthropological, psychological points of view. Hanna, for example, works within software development and computing. Without wanting to sound "overly psychological" she makes the kinds of connections that demonstrate that fibromyalgia is understood as a field of study beyond her own. This cognitive process (O'Connor et al., 1990; Lewis, 1989) reflects the meaning-making process described as "finding a positive purpose for a negative event" (Fife, 1994:310). Being able to find meaning, in Hanna's case to academically connect and infer, allows individuals to extend and confirm their sense of self (Reed, 1991).

Their scholarly endeavours in making sense of fibromyalgia is also exemplified in individuals' detailed knowledge of classifications of diseases. Some participants knew that the relevant International Classification of Diseases code clearly identifies fibromyalgia as a condition related to the musculoskeletal system and connective tissue within the group of the unspecified and otherwise unclassified disorders. For academics, therefore, the code describes fibromyalgia as a disease, but as a condition that is still categorised as unspecified and unclassified. This detailed understanding leads to individuals interpreting the condition as difficult to place and ambivalent, an interpretation that is compounded by the scholarly debate around validity and usefulness of the fibromyalgia classification (Ehrlich, 2003; Hadler and Greenhalgh, 2005; Wolfe, 2009). Consequently, the process of being diagnosed and provided with that all-important classification of a specific illness is also met with ambivalence. Diagnosis is important as it provides a name and categorisation for the disabling symptoms individuals experience, whilst also reassuring them there is no terminal illness underlying the symptoms:

> I still would rather know […] well, I don't want anything sinister to be wrong, so it's better to have that.
>
> Jackie

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[14] Evidence for how the mechanisms (i), (ii) and (iii) relating to the relationship between academia and higher education as per the introduction are reflected upon.

> [O]nce I was diagnosed by a rheumatologist it all made sense and as far as feeling about it, it varies by day, it really does, it's, I have mixed feelings about it, not always great, you know.
>
> Angela

These statements show the reassurance gained from the diagnosis in that the condition is not life-threatening. At a rational level of understanding academics feel they need to attribute meanings to the condition, and they do that through engaging with the diagnosis. Receiving the diagnosis is therefore considered as helpful as a validation and as an enabler for access to health care and treatment options. This is particularly because it is proven that an individual's ability to make meaning of an illness through receiving a diagnosis is key in fostering self-care and so coming to terms with the illness itself (Toombs, 1987; Baker and Stern, 1993). However, due to the way fibromyalgia is presented and interpreted within the medical professions and scholarly treatises, academics view the diagnosis with cynicism:

> I mean it's a very strange sort of mental dance that you do when you go for these tests, because obviously you don't want them to find something terrible, you don't want to be told ah you've got stomach cancer or something, but there then there is always that element of you that wants something.
>
> Hanna

> I still would rather know […] well, I don't want anything sinister to be wrong, so it's better to have that, but on the other hand […] So more and more people seem to have it, or be told they've got it and is it just a cop-out by the doctors? Well, we don't know what's wrong with you, so therefore you've got that.
>
> Jackie

The participants describe the process of diagnosis as a medical professional's attempt to negotiate different pressures. This interpretation mirrors the outcome of Broom and Woodward's (1996) research into the relationship between medical professionals and their patients with chronic fatigue syndrome. Broom and Woodward (1996) found that general practitioners sometimes consciously withheld information or diagnostic labels, as they were concerned to reinforce self-fulfilling prophecies amongst their patients and thereby potentially doing more harm. For the patients, diagnosis represented reassurance. Not having a diagnosis and therefore not receiving constructive help led to feelings of distress, anxiety and not being listened to. Lack of information and having had diagnosis withheld resulted in distrust for the medical professionals on the basis that they may have missed more serious conditions (Broom and Woodward, 1996).

Academics also want reassurance, but are critical of doctors, who they see as gatekeepers to legitimise illness experiences (Freidson, 1970:237-240). For academics, the medical professionals are bound by medical discourses, which in the case of fibromyalgia are not easily discernible. Academics are aware of the roles that they and their medical professionals take within the doctor-patient relationship and understand the concepts of the sick role (Pilowsky, 1978; Parsons, 1951). Within the scope of their reflections in relation to the process of diagnosis academics highlighted the responsibilities attached to a medical categorisation or diagnosis. In line with their understanding of the sick role, for the academics the fibromyalgia diagnosis comes with responsibilities, such as the responsibility of being a good patient. Being a good patient means being compliant and agreeable to treatments and of cooperating with the health care professionals.

> This is the first time I've been in a proper pain clinic, so that's what, twelve years it's taken me to get into the room. […] It's very affirmative seeing other people in the room of a variety of cultures, races, men, women, different sort of pain, and that's really great, but that's kind of it so far. So, I'm going and I'm doing, I'm being a good patient.
>
> Alison

Although the cerebral understanding of the sick role may be experienced as liberating (Broyard, 1993), for academics in this study it was not. Academics see engaging in treatments and cooperating with health care professionals as a necessary step to access the actual and actually relevant courses of treatment. This particular interpretation highlights the limitation of academics' scholarly endeavour in relation to fibromyalgia. Academics understand that it is the doctors' responsibility to provide legitimacy (Freidson, 1970), that the diagnosis enables the patient to be exempt from ordinary responsibilities, but that instead the patient is obliged to get better (Parsons, 1951). The participants even critiqued the roles we are all performing within the norms of society, and that by following these conventions and rules we are perpetuating this role division. The academics seem to miss that they themselves are bound within a biomedical view of their condition. At a rational level, they understand the social (Merskey, 2008) and psychosocial factors (Eich et al., 2000) in relation to the meaning and experience of fibromyalgia. Yet, they seek out the medical professionals' support to alleviate symptoms, thus to "fix the problem". In this sense, their understanding of health is grounded in the expectation that they be free of symptoms (Baumann, 1961). The academics feel that they are seen as difficult and problem patients, which they tie back to having fibromyalgia, a contested and contentious diagnosis. In their logic, they would not necessarily be able to get referred to the kinds of treatments they would potentially benefit from, if they were seen to be uncooperative. They think that by complying with the pain clinic schemes, for example, they are good patients and worthy of consideration for further developments and treatments. They do not take notice of their continuous pursuit to achieve the state of absence of symptoms as problematic:

> I think you don't get referred places, or it's much more kind of referred back to you because you're a problem patient. But if you say "well no, you suggested this and I've engaged with that, and you can see I've paired up for those things, however, now this [a symptom] is my problem", you get further in the game that is actually getting treatment.
>
> Alison

Being a good patient also means to look after oneself, to manage the fibromyalgia symptoms, to control bodies and emotions (see chapter 7 for more details). Through the scholarly engagement with the condition and its contested nature participants clearly make sense of fibromyalgia as a holding diagnosis, not an actual diagnosis. Having experienced years or even decades of medical tests and appointments, and often having been diagnosed with localised pain conditions, tendonitis and the like, fibromyalgia is merely one more label amongst a list of ailments, which does not drastically change or impact the management of the symptoms or the course of treatment on offer:

> [T]he label to me is irrelevant because I don't change and my condition won't change whatever you decide to name it.
>
> Bernie

> I got to the point when I was diagnosed with fibromyalgia and I just thought okay it's another diagnosis.
>
> Amy

One participant stood out in her attempt of coming to terms with the contested nature of fibromyalgia. When probed on her thoughts around fibromyalgia as a physical manifestation of psychological disorders, she considered how "real" the illness is and what the public rejection of fibromyalgia as a "real" condition would mean:

> People said that [being imagined and unreal] about PMS [premenstrual syndrome] and the AMA [American Medical Association] said that about homosexuality too and they were wrong, you know, they were wrong… As a feminist scholar particularly, I take umbrage at science knowing what it's talking about, it often does not and nobody can embody our experience of ourselves our bodies, our selves quite literally with fibro. And that's adorable, that they think it's just psychological symptoms

> because, you know, try being up all night because your spine feels like it's on fire and your head is exploding, that's pretty visceral, I'm going to go out on a limb and say that's pretty real.
>
> Angela

This statement is another example for academics' pseudo-scientific engagement[15] with fibromyalgia. Angela, whose primary field of research is information studies, appears knowledgeable about medicalisation processes (Conrad, 2007; Busfield, 2010). Although she does not expressly discuss the risks or benefits of medicalisation, she demonstrates awareness of the role societies and organisations play in the construction of medicalised conditions (Rose, 2007; Conrad, 2007; Busfield, 2010). In what appears to be a rational approach, she uses this knowledge to construct an argument and provide evidence regarding the real-ness of fibromyalgia. She fails to see that her argument around the legitimacy of fibromyalgia is embedded in and based upon her experiential understanding of the condition, and as such represents an emotional process of making sense. Although the label provides them with a framework to make sense of their experiences and explain themselves to others, the women worry about stigmatisation and marginalisation through prejudice and lack of understanding in formal and informal contexts in their everyday lives. Without their realising, the academics' rationality and logic are "undermined by the emotions, feelings, moods, and *semi*conscious thought" (Kotarba, 1983:198). In order to overcome the risk of being marginalised, individuals revert to resistance strategies (Ware, 1999). Resistance here is the incorporation of cultural expectations and social conventions into personal life stories. This is achieved by describing their condition through using additional or alternative explanations for their symptoms. For these alternative explanations, academics link back to their learnings about fibromyalgia from scholarly engagement. They use biomedical interpretations from literature, such as central sensitisation, over-firing of nerve-ends, hypermobile joints and collagen dysfunctions, as well as the introduction of an entirely different illness, which they may not necessarily have been diagnosed with, but which is more commonly understood, such as arthritis:

> I guess I am still very aware that there are many people out there who are misinformed, who think it's not a real illness, who would do a quick

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[15] The choice of words here may be perhaps stronger than originally intended, but was needed to express the inherent difference in the academic participants' scholarly work and their engagement with and around fibromyalgia. In their everyday academic work the participants ensured they would be reading contradictory and alternative publications to substantiate an argument or idea, whereas when it came to fibromyalgia they had chosen biomedical sources, such as guidebooks on how to overcome fibromyalgia symptoms.

> Google search […] I don't want them to think that I'm lying, I don't want them to think that I'm making it up and I don't want them to judge me for it, so I am quite happy to say that I have arthritis because that seems much more real and tangible.
>
> Yasmin

> I was diagnosed with Ehlers-Danlos syndrome. It's a connective tissue disorder whereby collagen isn't formed correctly […] the most obvious sign is a lot of double-jointedness and that hyper-mobility puts strain on the ligaments and things around your joints […] it seems to me that the problems that Ehlers-Danlos causes put your body under so much strain repeatedly over the years that that develops into a chronic pain and fatigue disorder; but if I'm filling out a form and it says, you know "do you have any medical conditions?" I will put down Ehlers-Danlos rather than fibromyalgia.
>
> Hanna

> It's Central Sensitization Syndrome [...] Central Sensitization Syndrome is much more about my nervous system than fibromyalgia, and it was a malfunction in my nervous system where my nerves are forever all in a heightened state of alert, so if I have surgery, or I knock myself, or something like that, it can be misinterpreted if you like as pain, which then won't go; which is why I get a lot of tingling and pins and needles.
>
> Amy

> [T]hey diagnosed me with, like, in 2003 with associated fibromyalgia from the leg length discrepancy. It was diagnosed so late, it's already caused damage to my spine, my hip and so on.
>
> Kate

The resistance displayed here is a form of re-making the lifeworld, which is not entirely explained in the social course of chronic illness (Ware, 1999). In people with chronic fatigue syndrome re-making the lifeworld manifests itself in the form of pacing strategies, the reduction of activities or the intensity with which activities are performed (Ware, 1999; Charmaz, 1997). The re-making is embodied and bodily. The participants in this fibromyalgia study are re-making the lifeworld at a cerebral level through redefining their reality and creating a new, socially acceptable reality. This form of re-making resembles the normalisation processes (Sanderson et al., 2011; Sanderson et al., 2015) linked to maintaining identity continuity (Wolfenden and Grace, 2012; Llewellyn et al., 2014). Where it differs, is that academics in this study do not embed their understanding of fibromyalgia into their lifestory and their beings. They incorporate society's understanding into how they make sense of the condition at a cognitive level. How strongly academics have internalised society's values and understanding of illness is evident in their personal interpretation of chronic conditions. Participants talked openly about being prejudiced and having biases against conditions like fibromyalgia. Their attitude towards fibromyalgia is such that they reject the contested fibromyalgia diagnosis:

> I did fight against the diagnosis. I didn't want to accept it, I didn't want to believe that they're actually...because it's so like ME isn't it? And those things. You don't want to believe that, well I didn't really want to believe I've got that because I didn't think that was me.
>
> Jackie[16]

This active rejection of the diagnosis represents another resistance strategy as a technique of information control (Goffman, 1990/1963) instead of admitting to and accepting the fibromyalgia diagnosis, which would be experienced as a threat to identity and sense of self. Academics' reluctance to accept a diagnosis that may feel uncomfortable is not unusual and represents a process of negotiation, what Madden and Sim (2016) refer to as negotiated order within the diagnostic process. Kokanovic et al. (2013) report that the process of diagnosis is often a balancing act between individuals' understanding of their experiences, their self-acquired knowledge from internet sources and their acceptance of what may be a stigmatising and stigmatised condition. The participants in that study accepted that they needed help, and yet did not feel comfortable to being treated with anti-depressants (Kokanovic et al., 2013). The individuals in that study are caught between the experiences in their own bodies, cultural meanings of conditions and the experiences within the wider society (Kleinman, 1988). The issue for these individuals is that this society demands for the "self-esteemed", "confident", "happy" personality and that deviating from this perfect picture is considered as "not normal" or "wrong" (Furedi, 2004).

Academics are not so much trapped between their personal own bodies, culture and society. They are fully entrapped by their concern for outwards appearances. This theme will be explored in detail in chapter 7. Suffice it to say at this point that academics are reluctant to use the fibromyalgia diagnosis in order to explain their experiences to others within their social network, because they considered the diagnosis too difficult to explain and the condition too difficult to understand. So, where the causes of fibromyalgia did seem to matter were in the context of conversations with others. In the words of the participants themselves, their academic minds prevented them from fully understanding and accepting

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[16] Evidence for how academics must reconcile the tensions of internalised external values and personal expectations (mechanism (ii) as per the introduction).

fibromyalgia as a diagnosis. For them, a physical or psychological cause that has some demonstrable effect on the body and manifests itself as pain was much easier to grasp than the elusiveness of cognitive dysfunctions that seemingly appeared out of nowhere. In truth, the academics' engagement with fibromyalgia is not an entirely scholarly undertaking. It is a cerebral activity on their part to grasp and make sense of the condition, but their choice of readings and critiques highlights that the focus of their scientific, objective exploration remains firmly embedded in their personal experiences.

Understanding fibromyalgia at an emotional level

Despite their attempt to engage with fibromyalgia as a scholarly activity, and despite their attempt to seeking deeper knowledge and understanding involved in trying to learn about fibromyalgia, in reality, the academics cannot detach themselves from their everyday experiences of and with fibromyalgia. They do make sense of their experiences on a more direct, personal and emotional level based on their bodily and embodied sensations. At a personal and emotional level, participants feel it difficult to come to terms with a condition that is not clear-cut and commonly accepted or widely understood. Participants struggle to make complete sense of the label and their experiences. In studies relating to women with fibromyalgia this struggle has been described under the theme of "fibromyalgia as the choreographer of activity and relationships" (Söderberg and Lundman, 2001:621) or as loss of dignity (Söderberg et al., 1999). For women having fibromyalgia means to experience transitions in life that are essentially minor and gradual, but in sum amount to drastic changes to lifestyle to account for the "imbalance between the women's will to do things and their lack of strength" (Söderberg and Lundman, 2001:626). The difficulty of coming to terms with a condition is particularly pronounced at onset (Charmaz, 1995; Galvan, 2005; Nettleton et al., 2004). What academics in this study said about their experiences with fibromyalgia and being diagnosed demonstrates the complexity of coming to terms with a condition more generally on a personal level. The overarching sentiment is one of confusion, uncertainty and ambiguity. For the women, the fibromyalgia diagnosis validates and explains their symptoms and thus helps them understand their physical and emotional experiences; experiences, which for some participants have lasted for decades:

> I could go back as early as my 20s. I'm in my 40s now but I would say as maybe as long ago as 20 years ago, maybe more, and it would explain, it would explain a lot, but I would say when did they, when did they get

> more pronounced and announced re-announced themselves severely? Probably in my mid-30s, roughly.
>
> Angela

At this emotional level, the diagnosis represents a validation of experiences that does not require or warrant for further engagement at a scholarly level. Academics do not necessarily worry or take note of the cause of fibromyalgia. They just merely accept the fact they are sick and as such feel permitted to engage in life in whichever way is suitable and feasible for them. Unlike the non-academic participants who withdrew from employment in order to incorporate pacing as a coping mechanism (see chapter 4), most academic participants ultimately decided to actively live with fibromyalgia, and to get on with life irrespective of and in spite of the fibromyalgia diagnosis.

> I think you learn to live with the condition. I was being asked yesterday, "how has it affected you?" and I really have to think hard, how has it affected me? Because you forget, because you've learned to live with it, and have strategies to deal with what's happening.
>
> Dana

This kind of understanding is different from the scholarly engagement we saw earlier. This is due to the fact that fibromyalgia is contentious and mysterious and as such does not allow for imbuing or making meaning of the condition (Madden and Sim, 2006). Making sense of fibromyalgia at this personal level refers to the two interconnected dimensions: self-meaning and contextual meaning (Fife, 1994). In constructing meaning of the condition, individuals must be able to make sense of the self as persons who interact with, respond to and are shaped by the roles they play within their personal context (Fife, 1994). This requires constant evaluation and re-evaluation of the perception of self, being, becoming, body image in relation to the relationships with friends, family and colleagues (Fife, 1994). The participants' academic mindset means that participants engage with and are generally aware of theories around health and illness, the reconstruction of selves and the development of new identities. Indeed, for them, the process of making sense of fibromyalgia is predominantly built around personal relationships and social networks. Participants regularly compare themselves and their experiences to those of others within as well as outside academia, as well as to their own pre-diagnosis or pre-illness status. In this sense, fibromyalgia takes on a relative quality (Charmaz, 1997). Whilst they describe their sense of self as affected initially, for most participants the journey from the first symptoms through to the diagnosis with fibromyalgia is relevant for how they make sense of the condition. Participants are getting stuck in and getting on with life with fibromyalgia, but also explain the qualities of their distress (Ware, 1999), when they talk about what the reality of living with the symptoms feels like:

> I'm never without the pain. So, but when it's really bad at work it's, I have my medication. I always make sure I have some in my drawer, some in my bag, I'm never without it. I would make sure that it's there; and then the coffee as well. I have like cafetière with really strong coffee and I love the smell, just to keep me kind of, motivated.
>
> Kate

> I get very tired, the pain is one thing but it's the knock on effect that has on every area of my life really.
>
> Amy

What fibromyalgia is and feels like to the academics is, however, best exemplified through the objects they used to explain and describe life with fibromyalgia:

> A backpack.
> Because obviously fibro in its classic symptoms is across the shoulders and across the hips.
> And when I went to see the GP after 15 years of it. It was because I had had enough of carrying that heavy weight of a backpack across my shoulders as well as obviously the sleep. But the tablets removed that weight, that pain you get from carrying a heavy backpack and I upped the medication once. So, I mean I started on it when my son was 15; he's now 23, and I think I upped the meds, fairly recently, maybe a couple of years ago and we started on a lower dose so I wanted that room to manoeuvre. So, you know, I'm only going up if I have to. And that is when that backpack starts, I'm aware that that's backpack's there. It's not going, that weight, I've got the arm and shoulder pain. But the backpack if I was on video camera, you'd see me massaging my shoulder joint quite a bit. If you know once that backpack remerges, I will be looking at upping the meds again.
>
> Bernie

A cactus.
In terms of it being really scratchy and horrible, and not wanting to go near it, all those little things sticking out. That's what made me think of it. And because of sensations, to feel like a cactus scratching you, and that's I guess what made me think of it.

Amy

A spider web ink stain on some paper or some fabric.
Doesn't really matter what that bit is, but that idea of, kind of like, ink is purple, and it's that idea of like its one point, but then it fractures everything and actually when you look at; you know, it's not worse it's just different, but bits of it are ugly, bits of it are kind of deeply beautiful.

Alison

A stretched out old grey t-shirt but that's crumbled up.
So, I've got the different parts of the description for different reasons. So, the old T-shirt was for two reasons. One it's like something you've had forever. You know you don't even know where you got it from, but it's always been around. It's moved with you from house to house, type of thing. It's probably something where it's something where you tried to throw it away once before and couldn't, or you tried to get rid of it. I picked the sort of a soft cotton T-shirt and grey because the soft and colourless is kind of the way that having fibro feels like, right. It's not a stabbing pain like appendicitis and it's not, I don't know anything hallucinatory like a paranoia or something. It's just this dull thing. But I guess I crumpled it up because like a crumpled-up piece of paper and a bin, I was trying to push it into a corner and forget about it, or crumple it up and throw it away. Rather than something you care about which you would fold nicely and will put on display, put in a frame or something like that.

Sian

Through the objects, participants emphasise the permanence of fibromyalgia. They explain how the illness fluctuates and how symptoms move and change, but ultimately, their experience with fibromyalgia is shaped by its permanence, even in periods of remission. Fibromyalgia therefore is less of a biographical disruption (Bury, 1982); it is more likely experienced as an intrusive illness (Charmaz, 1997), an illness that the individual needs to pay consistent attention to and that becomes part of life. As we have seen, academics actively deny the condition and construct its non-existence. As such, the academics do not allow for fibromyalgia to become wholly intrusive, although the reality of fibromyalgia including its flare-ups and unpredictable aggravations mean that the illness can never be completely out of individuals' minds. Despite the permanence that academics describe, the fluctuation in symptoms and severity coupled with the contested nature of fibromyalgia, also leave their marks on the participants. Some participants talk about doubting themselves, and being unsure regarding their diagnosis, whereas others talk about the body/mind split, in that the body would be more capable than the mind or vice versa:

> I think at times it can feel like a battle between my body and mind, cause my mind can feel very active and good and my body does not at all, and it's really unhappy, the more I try and do the less happy it becomes so it can feel like a battle.
>
> Amy

> I've been doubting whether I've even got fibromyalgia, but then other times, I get this wham of tiredness.
>
> Jackie

> It's almost like having the imposter syndrome times two or squared, you know, that it's; you have the regular imposter syndrome about being a writer and an academic and all that, but then I also have the imposter syndrome from do I really have an illness? Is it really real? Is it?
>
> Yasmin

When considering the question "What does life with fibromyalgia feel like?", participants quickly turned to the practical day-to-day management of fibromyalgia symptoms and the navigation of the health care, access to treatments, the management of their public selves in academia and thus questions of disclosure (see chapter 7 for more details). What was on the participants' minds first and foremost, however, was the impact that living with fibromyalgia has on work and career. In practice, academics largely follow the pattern of good and bad days with periods of activity and rests (Charmaz, 1997). Although there are times where participants say they are more productive or sociable, their bad days and flare-ups mean that overall, they feel they are held back in what they could achieve without fibromyalgia:

> It does mean being held back or slowed down […] I think if I hadn't got fibro, oh yes, I would have gone up the academic chain quite quickly.
>
> Bernie

> I could have done much more, I could've done much more. […] There was a vacancy for lecturer on the disability studies course and I could have applied for that […] I've had the school ask me, sometimes, ask me whether I would maybe cover a few sessions, maybe, and teach or cover a module for a semester […] I had to turn them down unfortunately and I had to say that I was flattered […] but that I had enough work to do […] but I didn't want to admit really, to them, that I wouldn't have the energy to do it […] I regret not being able to apply for that. And I regret not being able to teach a module, not being able to commit
>
> Kate

> If somebody gave me a magic medicine right now that would stop the fibro. The next ten years of my career would look unbelievably different from the last ten years. If you looked at my CV, of what I'm able to achieve, just how slow I am versus other people […] I know how to play the game, I know all the things that they do. They just have four times as much as I do and I just can't do that much work. I just I don't have it and erm, if someone magically gave me a medicine that would take that block away and gave me ten years out the gate to see what I could achieve, you know. Wind me up and watch me go because then is probably the only thing in the way right now, because of the stamina.
>
> Sian

> I think that is the biggest thing; that is stopping me from doing my PhD; it is the absolute terror that I am going to have brain fog when I have to do my viva.
>
> Yasmin

Participants are acutely aware of the difference between what could and would have been, thus their virtual social identity (Goffman, 1990/1963) and what is, their actual social identity (Goffman, 1990/1963). For academics this discrepancy between what is and what could be is a source for negative emotions, such as sadness and disappointment, but also anxiety and shame. In this sense, fibromyalgia makes academics discreditable (Goffman, 1990/1963:14). Although the women do not explicitly talk about Goffman's theoretical treatises of stigma and spoiled identity (1990/1963), they do emphasise how they employ strategies to cope with this discrepancy between their virtual and actual social identities (Goffman, 1990/1963; see chapter 7 for more details). Whilst they acknowledge the impact of fibromyalgia, participants are concerned that the diagnosis of fibromyalgia does not become a self-fulfilling prophecy (Broom and Woodward, 1996) or an excuse for being less productive or entirely unproductive at certain times. As we have seen, Yasmin highlights brain fog as a concern especially when it comes to a viva examination. Indeed, cognitive dysfunctions are seen as amongst the most intrusive of all fibromyalgia symptoms (Mease et al., 2008). However, in the conversation Yasmin also emphasises her thoughts around blaming fibromyalgia or using it as an excuse for not engaging with specific tasks or responsibilities:

> Part of me then automatically starts giving myself a hard time saying "Don't, you know, you're taking that as an easy way out", and then it's like, to use rude language, "Well, fuck me, this ain't easy, you know, it's not, it's not easy". So, on the one hand I see that as a little bit of a cop-out, but on the other it is very real that I have had to slow down what I do.
>
> Yasmin

The academics in this study highlighted that fibromyalgia stopped them from achieving as much as they could, but were not willing to pace or give up on their academic work and academic life. At an emotional level, academics seek out the legitimacy to assume the sick role (Parsons, 1951) and to withdraw from the academic rat-race. The academic engagement, the knowledge around the sick role, and indeed, the importance of academic work for their sense of self (see chapter 5) mean that they are not allowing themselves to indulge. Instead, they push themselves through difficult periods and bad days, potentially overcompensating for their perceived shortcomings. This active and pro-active countermeasure to assuming the sick role needs to be seen as the fourth resistance strategy amongst academics with fibromyalgia. Non-academic women with fibromyalgia are able to situate themselves within their experiences of losses and gains, leading to the combative attitude described in chapter 4. For academics, there is no silver lining or positive in the negative that is fibromyalgia (Fife, 1994). The lack of a silver lining is best exemplified in the consideration of the theme "the female body".

The female fibromyalgia body

For some women a key concern of living with fibromyalgia meant managing their female bodies. When asked to reflect upon the fibromyalgia experience participants highlighted the difficulty of being a woman with fibromyalgia in a male-dominated environment. Not only are they women, but they are women with an illness or disability. Indeed, the experience of fibromyalgia was strongly related to and connected with the experience as a woman with fibromyalgia being the female condition. At the time of interviewing, two participants were actively trying to conceive and had been for quite a while. Both women had already consulted doctors and were considered for fertility treatments. Both women had considered in great depth the relationship between fibromyalgia and their failure to conceive, to such an extent that they had found their personal, quasi-scholarly explanation:

> When I think of the effects of fibro on me, so, pain, fatigue, brain fog, let's call them those three things none of those is related to having a baby. I mean there might be some third factor that I don't know, let's say chronic inflammation, so that would be one. If I had my inflammatory markers measured regularly and if I could match a diary of fibro symptoms to trying to have a baby plans to inflammatory markers, I put a thousand pounds in an envelope that they're related. For sure. […] I'm sure that there's a relationship there that's not a coincidence.
>
> Sian[17]

In the conversations around conception, it becomes quite clear that fibromyalgia once more interferes to such an extent that the women cannot live "normal" lives.

> I definitely thought I would have had a baby by now.
>
> Alison

Sian's and Alison's sentiments around failing to conceive is not unfounded, as women with fibromyalgia are more likely to have reproductive health issues (Shaver et al., 2006) and other gynaecological, hormone-related diagnoses (Østensen et al., 1997; Østensen et al., 1983). In relation to fertility, 20.6% of women with fibromyalgia have issues compared to only 13.4% of women in the general population (Shaver et al., 2006). The higher levels of infertility are ascribed to the wider issues around health status (Shaver et al., 2006) but also to altered sexual behaviours amongst women with fibromyalgia (Yilmaz et al., 2012; Tikiz et al., 2005). The intimate relationship with her partner and her sense of self as a woman were the primary concern of the impact of fibromyalgia on her female body for Yasmin. Due to her pain levels of having fibromyalgia she often struggles to physically engage with her partner. Pain and the resulting contact-avoidance because of the pain combined with depression, fatigue and side effects of medications all contribute to higher levels of sexual dysfunction amongst women with fibromyalgia in comparison to healthy controls (Bazzichi et al., 2012; Ryan et al., 2008; Orellana et al., 2008). Yasmin explains how to her fibromyalgia results in a loss of sexuality and femininity:

> It does, it does interfere with my libido and with my sex life. It's not that flash because I just, you know, when touches pain. That's like, uh let's not go there either. I have a very understanding partner so that's good but it does still, I do still feel, I do feel guilty about having this illness.
>
> Yasmin

This statement encapsulates the women's experience of fibromyalgia; an experience that is characterised by symptoms like pain, brain fog and fatigue, which has a

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[17] Evidence for how academics must reconcile the tensions of internalised external values and personal expectations (mechanism (ii) as per the introduction).

significant impact on their daily lives, their work and careers, but also their emotions. It is that specific link to the emotional that leads to women with fibromyalgia struggling with sexual desire and arousal, which in turn results in avoidance of sexual contact and intimacy (Prins et al., 2006; Kalichman, 2009), which is also typical behaviour for women with other chronic conditions associated with pain (Kralik et al., 2001; Kralik et al., 2003; Hordern and Currow, 2003; Knafo et al., 2011). Sexual behaviour and infertility are, however, not the only concern around the female body. Both women, Alison and Sian, are very conscious of the consequences of pregnancy in relation to fibromyalgia.

> Pregnancy and fibro, I think that the way he [General Practitioner] was saying it, just, like, it amplifies how bad your fibro already is; and also I'm gonna feel like crap all the time, and you get a tiny human and you don't ever sleep, so that's, you know, again there's no end-point.
>
> Alison

> I'm more scared out of my mind of the effects of pregnancy on my body and what life after, and what labour and life after delivery is going to be like, you know. On the one hand, do I have an increased tolerance to pain, because I'm in pain all the time, so maybe labour will be a breeze, right? On the other hand, if I can't even handle, you know, sitting in a desk for a couple of hours to work on a very intense project, what the heck is it going to be like carrying a 20-pound lump that can't stand up, around for a year. Just the physical demands of caring for another person, washing someone, dressing someone, feeding someone and carrying someone. Running after them to make sure they don't kill themselves, over and over again until they go to school. I don't know if I can do it. It's not stopping me trying. I'm going to be an excellent mother, it's something I've wanted my entire life and we want, you know, we want it now. But I'm not afraid of having to ask for help and, and family help and hired help and just telling people what I can and can't do, but I just don't want to be tired mummy. I want to be fun mummy, I want to be on and playing on the floor mummy. I want to be, come to this thing after school with me.
>
> Sian

The concern of pregnancy and motherhood being too much for them is valid, as women with fibromyalgia are more likely to miscarry (Wadsworth et al., 1995) and if they do come to full term, they are more likely to require extended sick leave in addition to experiencing higher levels of fatigue, pain and depression resulting in needing more support physically and emotionally to cope in the post-delivery period (Østensen et al., 1997).

Where motherhood in academia is discussed, literature tends to focus on the problematic impact of motherhood on career prospects and the struggles of women to balance academic work with the mothering home-life (Armenti, 2004; Faulkner, 2012; Nikunen, 2012). Only more recently, has there been an effort in exploring the joyous, empowering aspects of motherhood in academia (Huopalainen and Satama, 2019). The statements from Alison and Sian, however, highlight the distressing and worrisome emotional impact of the relationship between working in academia, having a baby and fibromyalgia. But there is also a physical element involved, in that both are having to cut back on their medication in order to foster the best conditions for fertility treatments and the least possible effect or consequence of tablets and medication on the unborn, as of yet still to be conceived baby. Alison summarised this conundrum best, when she said:

> I've had a lot of like GPs basically telling me that, I'd like poison the baby, the foetus, because of the drugs regimen I'm on, or just be like, there's a lot of like quite aggressive stuff; either getting pregnant would [makes quotation signs] "sort me right out", as one GP put it, or "don't get pregnant because you'll poison the foetus".
>
> Alison

For both women, motherhood is an important stage in their planned life course and something they are both looking forward to, especially, as they both feel they and their partners would make very good, loving parents, despite the challenges that fibromyalgia would present. For women like Alison and Sian, motherhood represents a narrative of resistance against the prevailing position that being a good mother and a successful academic are irreconcilable (Raddon, 2002). Simultaneously, resistance here is against the marginalisation brought on by and through fibromyalgia. Alison and Sian are not willing to be different and othered as women who are mothers, but want to be mothers just like others who do not have fibromyalgia.

For Yasmin, having remained childless is now rationalised with the argument that she would not ever have wanted children as she could not picture herself living with fibromyalgia and reconciling that with children of her own:

> It [having fibromyalgia] did have a small part to play in my decision not to have children, but I don't think I would have had children anyway. And I believe that there are enough people in the world and that I'm happy with my role of working with young people rather than necessarily procreating; and that's, that's both that. I never wanted a child to go through the pain I had as a child.
>
> Yasmin

What unifies these three women's experiences is the emotional impact of dealing with questions of femininity, sexuality and childlessness. All three women referred to the vicious circle of emotional distress and physical pain exacerbating one another to the extent that the fibromyalgia symptoms more generally are aggravated. Their sense of failure for not yet being a mother, for not being able to cope with pregnancy and motherhood, or for not producing offspring manifests itself in physical fibromyalgia symptoms, which in turn creates further emotional stress. This emotional distress is compounded by the pressures and responsibilities they and others feel are placed upon them.

Concluding thoughts

In their attempt to make sense of a life with fibromyalgia, academics draw on their emotional and personal experiences as well as on their scholarly curiosity. The resultant narratives of fibromyalgia are best described using Ware's (1999) concept of a social course of illness. Fibromyalgia is associated with experiences of bias and stigmatisation (Goffman, 1990/1963), which are particularly severe before diagnosis because the variability and inconsistency of the symptomology cast doubt on the realness of the illness experience (Asbring and Närvänen, 2002). Knowing about the risk of being stigmatised results in the academics actively seeking to resist the marginalisation process on the basis of their condition. Academics resisting and employing resistance strategies represents nothing less than stages three – learning to cope – and four – learning to pass – in the moral career of the discredited or discreditable (Goffman, 1990/1963). The way academics perform resistance differs from the resistance strategies of those diagnosed with chronic fatigue syndrome (Ware, 1999). The four forms of resistance identified in this study are (1) the incorporation of cultural expectations and social conventions into personal life stories, (2) the re-making the lifeworld at a cerebral level through redefining reality and creating a new, socially acceptable reality, (3) active rejection of the fibromyalgia diagnosis and (4) active and pro-active countermeasures to assuming the sick role. Academics perform their resistance at both, the scholarly, academic level and the personal, emotional level. They are overall reluctant to relinquish their academic work and continue with their ordinary activities pretending they are not ill. During the course of the study there were participants, who were becoming too ill to continue in their current positions and roles. However, they were fully set upon continuing academic work and managing their illness and work by scaling back on hours and taking on slightly different positions. They were not willing to consider alternative careers or non-employment, which was an option for non-academics (see chapter 4). It may well be this attitude towards holding on to academic work that leads to their quasi-scholarly engagement with the condition. Engaging as an academic means to critique and question; and the participants do indeed critique and question the label, the diagnosis, the responses of others, but also their personal experience, their emotional responses. However, academics do not realise the pseudo-objective and quasi-scholarly nature of their endeavours to make sense of fibromyalgia and that they cannot truly separate the cerebral from the experiential. For individuals the discrepancies between the public and the private (see also chapter 5) as well as between their past experiences and the present state-of-affairs constitutes emotional pain (Frost, 2003). As emotions are expressive and communicative (Van Kleef, 2016), this emotional pain requires emotional labour in order to alleviate it. If emotional pain is not counteracted through active intervention strategies "toxicity can build up to the point that it can be contained no longer and finally erupts" (Ward and McMurray, 2015:88) and as such turn into a physical, corporeal manifestation (Katz, 2001). If we understand emotions as a basic physiological manifestation (Simmel, 1950), then conditions like fibromyalgia become "one way in which the individual can react to the "strains"" (Parsons, 1970/1964:259). Emotion work in this sense is not entirely harmless (Morris and Feldman, 1996). Illness itself then is a form of resistance that interconnects personality, the sum of all norms and values internalised through socialisation, with organism, an individual's physiology (Parsons, 1970/1964). Therefore, societal constraints and expectations placed upon women aggravate their situations and symptoms. Women are expected to take on more caring and tutoring responsibilities in the workplace (Quinsee and Hurst, 2005; Merrill, 2001) in order to meet student expectations and provide excellent student support. However, where women seek to meet societal expectations in relation to motherhood, mothering and motherhood within academia are seen as problematic and irreconcilable (Raddon, 2002). Where non-academics grapple with losses through fibromyalgia but also find silver linings of gains (chapter 4), academics' responses to the condition are predominantly negative. Instead of the non-academic women's cerebrally or emotionally accepting fibromyalgia whilst still looking to get better or overcome the condition, academics with fibromyalgia reject and deny the condition to resist stigmatisation and marginalisation. With the cerebral and emotional understanding of fibromyalgia as a manifestation of a combination of psychological, somatic and physical triggers and factors, participants interpret fibromyalgia as a disabling holding diagnosis. And although they specifically emphasise how they do not care about the psychosomatic nature of the condition, the participants find it easier to use alternative diagnoses to explain their illness experience.

In effect, two trends are at play here: on the one hand, the academics' moral commitment to the academy leads to their internalisation of academia's values of performance and productivity. These values are continually reinforced through academics' fear of isolation or pronounced change in status (Scott, 1971) and result in fibromyalgia as a corporeal manifestation of external pressures. On the other hand, academics refuse to accept and give in to the sick role (Parsons, 1991/1951), and continue to resist the processes of marginalisation and stigmatisation that are usually associated with mental or somatic illnesses (Parsons, 1970/1964). Whilst I discussed internalised values in the context of academic identity in chapter 5, the themes of isolation and managing fibromyalgia as a condition in academia is the focus of more detailed analysis in chapter 7.

7. Having fibromyalgia in the neoliberal academy[18]

It emerged from chapters 5 and 6 that participants have internalised and perpetuate traditional and commonly applicable values associated with the wider society in general and the higher education sector in particular. In this chapter, I explore the research participants' lived experiences of working in academia and how academics view the interrelationship between working in academia and fibromyalgia. I argue that the state of affairs of neoliberal universities (Canaan and Shumar, 2008) and the internalisation of public and private values of being an academic (see chapter 5) cause tensions and emotional dissonance, which are inscribed in and become manifested through the bodily experience of fibromyalgia, so that symptoms become worse and individuals in academia more ill.

Demands of the universities mean that academics are continuously required to carry out high quality research, acquire relevant research funding and produce reputable research publications (Abouserie, 1996; Watermeyer, 2015). This is in addition to teaching, tutorial commitments and consistent engagement with the public to ensure long-term research impact (Watermeyer, 2015). The universities' subjection to consumerism is further compounded by government initiatives that link student fees to institutional achievements such as research outputs or teaching excellence. Measures to ensure that targets are met and that courses retain certain credibility include the introduction of benchmarks, frameworks and criteria. These policies and initiatives resulting from the demand for accountability lead to managerialism and bureaucratisation within higher education (Winter, 2009; Waitere et al., 2011). Paradoxically, universities are under pressure to perform and demonstrate high levels of achievement, but at the same time concede to massification of higher education (Harris, 2005). The pursuit of excellence is crucial if an institution is to gain higher status and a better reputation across the higher education market, which in turn attract more students, more staff and more funding. Excellence therefore leads to prestige, a relational value against which institutions measure themselves (Blackmore, 2015). For individuals, working in a prestigious institution is motivation to increase productivity and quality of their own work to input and contribute to the institution's collective prestige (Blackmore, 2015).

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[18] This section draws on my published article: Brown, N. (2019). The embodied academic: body work in teacher education. In: Leigh, J.S. (ed.). *Conversations on Embodiment across Higher Education: Teaching, Practice and Research*. London: Routledge, 86-95.

The internalisation process at play results in individuals experiencing increased pressures to perform and conform. It is therefore not surprising that stress-related illnesses, burnout or mental health conditions are on the rise amongst university staff (Abouserie, 1996; Taris et al., 2001; Opstrup and Pihl-Thingvad, 2016; Darabi et al., 2017). While burnout amongst academic staff remains under-researched the application of burnout descriptors (Maslach and Jackson, 1986) demonstrates that emotional exhaustion is higher amongst women with younger staff being particularly vulnerable to burnout (Watts and Robertson, 2011). The reason for these discrepancies may be that the roles of early-career academics include more interpersonal interactions with students and therefore a higher workload regarding tutorials (Quinsee and Hurst, 2005) and pastoral support (Merrill, 2001), but also higher stress levels due to students' apathy and lack of engagement (Friedman, 1995). Dealing with such situations, personal experiences and feelings requires academics to undertake emotion work (Constanti and Gibbs, 2004).

I show that through using their scholarly mindset for critical reflections and analysis, academics are fully aware of the impact of working conditions and experiences of academia on the severity of fibromyalgia. Academics consider the pressures linked with and responsible for the aggravation of their fibromyalgia symptoms, and yet, the academic work is an intrinsic part to being and still seen as an aspiration. I argue that how academics manage their fibromyalgia bodies represents an attempt to reconcile the many tensions experienced in academia – competition, precarity, the fractured academic identity and sense of self. I show that this process of reconciliation requires the academics with fibromyalgia to undertake active and continuous bodywork.

In contemporary sociological discourses bodywork is commonly seen as the paid work on the bodies of others (Twigg et al., 2011), and as such largely concerns research in nursing, health care and social care contexts. Others may not necessarily use the term bodywork when they consider the work done on bodies, such as hairdressing, massage or tattooing (Black, 2004; Sweetman, 1999). For some bodywork in Twigg et al.'s (2011) conceptualisation also includes work that may be less prestigious, such as that of sex workers (Sanders, 2004) or undertakers (Howarth, 2017). Twigg et al. (2011) acknowledge that their definition of bodywork is narrow and that the boundaries of bodywork are not necessarily definitive. After all, they claim to focus on "bodies that are alive and, typically, awake to some degree" (Twigg et al., 2011:173), but then do include the work of undertakers. A systematic literature review has shown that existing sociological research into and on the human body largely focuses on four aspects:

> (i) the work performed on one's own body, (ii) paid labor carried out on the bodies of others, (iii) the management of embodied emotional experience and display, and (iv) the production or modification of bodies through work (Gimlin, 2007:353).

In Gimlin's (2007) elaborations (i) is best evidenced in body practices undertaken to change and modify one's existing body; (ii) is the work described by Twigg et al. (2011) for example; (iii) relates to individuals' attempts to remain professional and maintain a specifically expected exterior despite and potentially masquerading their personal, emotional experiences, for example; and (iv) corresponds to the actual, physical impact and effect work may have on one's body. What is less prominent and often deliberately excluded in research projects cited is the link between body, self and identity. That work influences and impacts on the body, as is reported in Hochschild's (1983) work on flight attendants, is recognised. It is also acknowledged that work on the body helps individuals express their selves and identities, as for example through tattoos (Doss and Ebesu Hubbard, 2009). Yet, these definitions do not include the kind of bodywork required to handle or manage the body. Mauss (1973) describes a form of managing one's body as body techniques, which for him are "ways in which, from society to society men [sic] know how to use their bodies" (Mauss, 1973:70). The techniques of the body in Mauss's (1973) sense remain descriptive rather than providing a framework for understanding the way body techniques are mediated and the meanings that are inscribed in them. As such body techniques provide the descriptive foundation in defining bodywork. However, the concept needs to account for the overlaps between emotional labour and manipulation or active management of the body. Because, what if the experience of one's body makes it difficult or even impossible to play out the socially constructed and expected bodywork? Individuals will still seek to present a coherent image of their selves (Goffman, 1990/1959). In Goffman's (1990/1959) terms those with chronic illnesses seek to align their own ill bodies with the ingrained image of what healthy bodies and beings look like. They actively produce a public, front-stage persona, they "manage" their bodies in the sense that they are "working on their bodies" or "working their bodies". Widening the definition of bodywork to include "the work performed on one's own body" and "the management of embodied emotional experience and display" and then embedding this wider-ranging definition into Goffman's (1990/1959) work on the presentation of self, allows for an analytical framework that helps understand how individuals deal with the impact of illness and cope with deviant bodies. Bodywork in this sense is part of the postmodern project of identity, with the body becoming a tool for the purposes of staging identity and roles. My original contribution to knowledge in this chapter therefore lies in my reconceptualization of bodywork in relation to how academics deal with and manage their fibromyalgia bodies.

I use this chapter to demonstrate bodywork in the context of the research on academics with fibromyalgia which I reconceptualise as (a) the management of the fibromyalgia body, the deviant body, thus the management strategies employed in order to be able to fulfil the role as an academic and embody academic identity; (b) the management of the academic body as a public and private identity; and (c) the individual's work on and with the fibromyalgia body to make sense of one's self, whereby this final aspect incorporates physical, material bodily interventions as well as emotional labour involved in this process.

I commence this chapter with the section "Managing fibromyalgia symptoms" where I outline how academics have learnt to manage and alleviate fibromyalgia symptoms and which strategies and illness routines (Charmaz, 1997) they employ. I further highlight how the illness routines and coping mechanisms represent the later stages of the discreditable person's moral career in dealing with processes of marginalisation and stigmatisation (Goffman, 1990/1963). I show that for the academics these strategies have two purposes in that they support their physical wellbeing and experiences of well-ness within their illness whilst also reinforcing participants' academic identities. In the section "Academia making illness worse" I focus more specifically on the relationship between the contemporary higher education context and the illness experience for academics with fibromyalgia. I show that academics have internalised values of academia to such an extent that despite neoliberal universities bringing with them higher levels of job insecurity and competition, academics still see higher education and the academy as an environment worth striving for. I further outline that as a consequence of that deep internalisation individuals accept worsening working conditions, longer working hours and more demanding performance criteria in relation to productivity. I demonstrate that academics are fully aware of the link between these external factors and their personal illness experience, and of the academy aggravating their symptoms. However, I also show how academics emphasise that ultimately working in academia is not the cause for their condition. I use the subsequent section "Managing the public and private self" to detail more clearly how academics engage in processes of information control (Goffman, 1990/1963) and careful management of their presentation of self (Goffman, 1990/1959). I show that academics distinguish between symptom management and bodywork in the private realm and in the public life of academia, in many instances avoiding the use of adjustments that for them represent stigma symbols (Goffman, 1990/1963). At the same time, I demonstrate how bodywork and managing the fibromyalgia body are inextricably linked to emotion work and the management of one's own as well as others' emotions with workplace jealousy being particularly problematic in the neoliberal academy. This leads to and into the section "Considerations of disclosing fibromyalgia in academia", where I focus on how academics weigh risks and benefits of disclosure. I show that academics know that disclosure results in some processes of protection and allows to access support systems but that in a higher education section that is already highly competitive academics are concerned with the impact of public disclosure on their contractual positions. I further outline how academics also experience disclosure as a private event in that it means to be committed to and accepting of a diagnosis, the potential risk of being stigmatised and seeing oneself as weak and a failure. I conclude that academics require their colleagues to have an awareness of their physical conditions for support and to potentially find allies amongst colleagues and line managers, but that non-disclosure is a tool for self-preservation, information control and impression management (Goffman, 1990/1959; Goffman, 1990/1963) within the competitive environment of the contemporary neoliberal university.

Managing fibromyalgia symptoms

Having fibromyalgia means to consciously counteract pain, mental health issues and cognitive dysfunctions. Throughout their illness experience, most participants have learnt to manage their bodies and have developed strategies to better cope with the fibromyalgia symptoms. This is achieved through medication (Baker and Barkhuizen, 2005), but also through alternative means, such as massages and homeopathy (Ashe et al., 2017). Interestingly, where symptoms were concerned, the conversations and visual representations predominantly revolved around experiences of pain, tiredness and cognitive dysfunctions. Issues such as irritable bowels, allergies and intolerances, or feeling hot and cold were mentioned, but did not seem to be serious enough to warrant explorations. Individuals merely listed symptoms (see Appendix D) to demonstrate how strongly fibromyalgia affected them. The general message regarding fibromyalgia was to seek to alleviate pain early on. One participant created a series of photographs demonstrating this active management of the body. Strategies for pain management included medication, the application of heat or ice packs, support structures, such as height increases on laptops or lumbar support for chairs, or support stockings and wrist support:

Figure 7.1: Photographs demonstrating strategies to manage fibromyalgia symptoms

The above photographs represent the first level of bodywork academics undertake to manage symptoms. By applying heat packs, creams and the like, academics with fibromyalgia effectively do work on and to their own bodies in order to manage and control their deviant bodies. Individuals become experts in listening to their bodies (Bates, 2019), recognising their limitations (Juuso et al., 2011) and developing a routine around the failing body (Charmaz, 1997). Participants did not speak explicitly about expectations in relation to the body within academia, but they did implicitly when they referred to situations where their bodies failed them or where they described how the consciously manage and manipulate their bodies. In many cases, participants talked about avoiding pain wherever they could, for example, through getting up and stretching or varying activities from sitting down to moving around. In Charmaz's (1997) terms they have developed a way of life that incorporates the illness routine into their everyday activities. This is further exemplified in the strategies academics use to deal with as cognitive dysfunctions. For participants, the issue with brain fog is that they cannot actively work towards avoiding it and therefore they need to employ strategies to deal with potential situations of brain fog occurring suddenly. The strategies for brain fog are largely employed on a private level through taking copious notes, maintaining detailed records or through alternating more difficult with some lighter, mundane tasks:

> I've just adapted to learning to do other kinds of work tasks. So, I get brain fog but then I do things like file my expenses, or plan my, plan my next research trip, or change my syllabus for the fall term, or, erm, you know, tidy up my papers and my references system or do a, awful lot of email and conference planning and stuff. I just do other low-level tasks and then, if I notice that I'm starting to make mistakes or I'm incredibly slowing down, then I stop. […] I never really have a problem when other people are around. I take good notes and, you know, I participate really in meetings.
>
> Sian

> I wouldn't manage without it [keeping records], so we're insisting. We are holding onto the paper records because we have in there everything. We print out every single correspondence with them [students]. All the paperwork is in one place so you have the whole story, so it doesn't matter if my other colleagues saw the student or myself you know, it's all there in the file. So, it helps me with my memory.
>
> Kate

Employing such illness routines has two purposes for the academics: they manipulate their bodies to promote physical wellbeing as well as to reinforce their academic identity. In effect, academics engage in conscious manipulation and management of self (Goffman, 1990/1959) through information control (Goffman, 1990/1963). Naturally, dealing with symptoms includes the emotion work needed to come to terms with a failing body, and as such is part of identity work more generally, as the body represents the event of becoming (Budgeon, 2003). A body truly is the inscription of self and identity and as such signifies belonging or otherness (Weedon, 2004). In the context of this research, managing the body takes on an even higher priority in order to meet and fulfil internalised expectations, values and norms. It is this pressure to fulfil internal and external expectations that lead to academia aggravating fibromyalgia.

Academia making illness worse

The difficulty of living with the chronic condition fibromyalgia is coupled with the competitive environment of having merely a few positions available, which are then most often contracted as fixed-term or on zero-hours. The combined force of these factors results in academics feeling under even more pressure to perform and be productive in order to contribute to the institutional good (Blackmore, 2015; Lewis, 2008):

> I feel that I have to fight that [fibromyalgia] at work; and to work harder at it to perform the same as other colleagues. I don't want to show that it [fibromyalgia] interferes.
>
> Kate

> I feel under pressure to make sure my work is of the good standard, you know, or even, or even better, to cover me for when I'm in a period that it's not. So that if, I guess, over time no one would notice, right.
>
> Sian[19]

What these statements show very clearly is that the pressures to perform and be productive may not necessarily be stemming from external forces only. As was explored in chapter 5, academics have high expectations of themselves and display perfectionist tendencies. The pressures that academics feel exposed to and impacted by may therefore well be a manifestation of internalised norms and values (Kelman, 1958). In the context of this research academic work and being employed in academia represents the personal perspective that leads to academics committing to excessive working hours, worsening working conditions and being available at all times. As such, their personal standards, their high expectations and perfectionist traits are the material manifestation of value-orientation (Parsons, 1991/1951). The individuals' moral commitment to norms (Scott, 1971) and their value-orientation (Parsons, 1991/1951) are evident in academics' regularly comparing themselves to an imagined picture of what other colleagues would or would not do:

> I know there are people who would, if, if someone had a deadline, they would put in more hours and they would mainline the coffee and the heavy metal music and push through until it's done and I can't do that. […] I can't sit in the chair and use the, that mouse much, I can't come in to work every day. I can't get washed and dressed and commute and come into work every day. I can't start work early and stay late, every day, and my brain works, I, you know, I'm not watching cartoons and reading Women's Wear Daily or something, my brain is working, but my body can't do it. I can't produce, so.
>
> Sian

This view of being comparatively less productive or unproductive is ingrained in the academics' psyche and mind. On the one hand, participants like Sian use the comparisons to help them identify areas for improvement and further development

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[19] Evidence for working conditions in academia requiring individuals to push themselves to the limits (mechanism (i) as per the introduction).

in order to compete against others within the academic environment of precarious contracts and to succeed in their scholarly work of developing original contributions to knowledge. On the other hand, for people with high expectations and perfectionist tendencies such comparisons lead to feelings of inadequacy, falling short and ultimately, feelings of failure (Lovin, 2018). The increase in status academics may potentially experience when they are productive and successfully contribute to the knowledge society is offset against the cost of experiencing personal failure instead of achieving higher status, thereby further reinforcing unreasonable standards (Scott, 1971). Having fibromyalgia compounds matters further. In order to manage fibromyalgia symptoms most effectively, academics embrace the flexibility part-time work offers, but the flexibility that is so hailed results in academics feeling excluded. Participants expressed that working part-time leads to not being able to engage fully, which in turn, precludes specific positions or roles and thus, specific career-prospects:

> I cannot commit to full-time job. […] If you want to work part-time, you're on those sessional hours contracts, so you're never in the position to become management, you're never going to be in the position to create influence, you're never in the position to develop your own CPD.
>
> Bernie

Due to their nature of being inquisitive and critically analytical, most academic participants had considered the relationship between their working environment of academia and fibromyalgia. Without explicitly referring to the "institutionalization of institutionalized individualism" of higher education (Parsons, 1982/1977:329), for most participants, academia is an environment that fosters competition and as such creates additional pressures on individuals. In this context, fibromyalgia is understood in its somatic quality. Fibromyalgia in this sense is the body's expression of an academic's inability to fully perform the tasks attributed to the academic role (Parsons, 1970/1964). Although in the participants' view academia does aggravate their condition, they do not blame academia as a cause or trigger for the development of the condition in the first place:

> I don't think fibromyalgia is a by-product of it [academia], but I do think it probably sometimes means that I push myself when I maybe shouldn't have pushed myself.
>
> Dana

> I think, it [academia] possibly sets the stage for stress-related illnesses, or maybe other ones like, I guess, there's chronic fatigue syndrome, adrenal fatigue like there's all sorts of—and I don't think it's an accident that

> some of us are developing these you know in in the in the academy particularly during the PhD process.
>
> Angela

Indeed, many participants referred to specific stages within their academic career as being particularly impactful in relation to the severity of their symptoms. For most, the time during doctoral research was particularly significant:

> I think with the PhD I just thought, "Do you know what? This is horrible, but I will get through it". I mean it did definitely make me worse. There's no doubt about that; the pain levels compared to when I started the PhD, compared to where I am now, have definitely gone up, definitely got more symptoms. I ended up having something like six surgeries in my final year of the PhD. Now, I don't think that's a coincidence. I think the PhD really just made everything worse. There's no doubt about that.
>
> Amy

> I think that certainly my general health was worse and my mental health was worse some point in the middle, when I was doing my PhD, and I didn't have any job security.
>
> Sian

Although participants made the connections between their health concerns, decreased wellbeing and increased severity levels and variety of symptoms and their doctoral studies, they did not see an option of addressing these links. None of the participants seemed to have reflected on which aspects of the doctoral studies would cause the added pressures and anxiety, whether this was to related to supervisory relationships or feelings of isolation, for example (Collins and Brown, forthcoming). On the other hand, this kind of reflection may have been seen as futile. After all, as chapter 5 shows, the doctoral qualification is the required "currency" to enter academia; and there would be no way around this other than "pushing through". These experiences result in academics being disillusioned and distressed (Davies and Petersen 2005), at loss, in crisis and alienated (Beck and Young 2005).

What does become evident, is the in-depth critical reflection that individuals engage in, in order to make sense of their experiences. The best exemplification for this kind of critical reflection comes from Hanna who talked about the consistent pattern in her life that sees her taking on a role, pushing herself to the utter limits, which then results in her body crashing leading to long-term absences and her resignation; only after extended periods of recovery, is she then able to pursue a new role:

> I realised it [pattern] before now; I don't know if I realised it at the time. It's more something that, when I had that extended period of incapacity, I

> had a lot of time, maybe too much time, to reflect on how I had ended up, where I had ended up, what factors had led me there […] and the patterns that were reoccurring and the pattern of, of working in a very intense way and, you know, putting myself under intense pressure, and then, kind of, you know, collapse, collapsing, crashing, and literally, physically running away, in the sense of, you know, going to a new place.
>
> Hanna

In addition to the difficulties academics with fibromyalgia face, Hanna's story also highlights the intensity with which individuals involve themselves in their academic lifestyle. This admission to and consideration of intensity again begs the question of whether it is the academic environment combined with personal character traits that enables and fosters the context for fibromyalgia and similar illnesses. At the time of writing, Hanna had had yet another long-term absence from work and having delayed the start of her doctoral research twice, had effectively dropped out of the PhD studies, although she continued to work within an academic setting. In her view, she would be able to continue to take on research positions and contracts, but would not be able to establish herself as an academic. She felt she would have to choose between a successful, meaningful academic career and maintaining independence and quality of life in view of her deteriorating health. It is this kind of context that individuals talk about when they consider the relationship of fibromyalgia and academia:

> It should never be that someone has to choose between an academic career and their health, that is absolutely disgusting. But I think, there are similar arguments, aren't there, around childcare, having children: do I choose between that or the academic career. It is a culture and it is not a very nice one.
>
> Amy

As this statement shows some participants talked about expectations and normative and normatised standards within academia. They describe the working environment of academia as male-dominated and more conducive to and appropriate for men (see chapter 5). This negative attitude towards the working atmosphere in academia relates to the masculine, strong, competitive (Hey and Bradford, 2004) reinforced through the new managerialism in higher education (Waitere et al., 2011; Deem, 1998, 2001; Deem and Brehony, 2005). In the current gendered discourses of the neoliberal universities, men are engaging in real work, whereas women are forced into lower paid or unpaid positions that involve caring and nurturing duties (Lovin, 2018). Some academics openly highlighted their scholarly and personal interest in feminism and their feminist worldviews underpinning their interpretations of what happens in academia. Others, however, who did not necessarily relate to a feminist identity, still pointed out the differences between disabled men and women, with those at the intersection of disability and femininity finding it more difficult to work and live within academia. For them, these are pressures women have to contend with in the white-male-middle class academia (Read et al., 2003; Shipley, 2018), and which also impact their symptoms and the severity of their illness. As a consequence, managing the deviant body takes on an even more important role. However, managing fibromyalgia and the fibromyalgia body is closely interlinked with the management of the academic body as a public and private identity.

Managing the public and private self

For many participants, continuing their roles in academia is intrinsically linked to who they are and how they see themselves in their actual and virtual social identities (Goffman, 1990/1963). The public picture they therefore present is heavily edited. Academics thus manage their stigma through information control (Goffman, 1990/1963) to protect themselves from becoming even more vulnerable:

> I'm quite active on Instagram and Facebook and stuff, but I don't I, you know, I don't post up anything about having a shit day, ever. My Instagram is just cakes and gardening and cats and, and, you know, knitting and it's just nice stuff. […] I think that's really common, particularly with something like Instagram, you know, it's, it's about visual, and it's about, it's, it's about presenting your life in the best way, in the best light […] it's a very, very narrow version of what's happening.
>
> Hanna

Attachment to family means to be forced to protect others from the realities of the illness experiences. It is quite understandable that individuals would not want to upset friends and family by highlighting how badly ill they are. At the same time, not divulging the full extent and all details of the illness experience means that academics do not need to open themselves up to criticism. However, another consequence then is that colleagues are also unable to see how ill the individuals truly feel; particularly, when individuals like Hanna pretend that everything is fine, that they are well enough to bake a cake or do some gardening. Hanna's statement exemplifies how individuals engage in front-stage and back-stage behaviours (Goffman, 1990/1959). Hanna's public persona, on social media but also at work, is such that it conceals (Goffman, 1990/1963) the impact fibromyalgia has on her. The strategies she uses to manage her symptoms are largely hidden and invisible: pain medication, hot baths, Epsom salts, the use of massage and Tens machines. In the private sphere, she immerses herself in her illness (Charmaz, 1997), whilst in the public realm of academia she uses her body to enact the academic she aims to be (Goffman, 1990/1959). The bodywork here reminds of the emotion work describing the balancing act between "feeling and feigning" (Hochschild, 1983:90; see also Brown and Collins, 2018) with the body here being used as a tool to bridge that gap. It is this particular element of bodywork that leads to feelings of isolation, in that individuals experience a distance between themselves and others (Råheim and Håland, 2006). The process of immersion in illness itself leads to individuals withdrawing into themselves in order to make sense of and deal with their illness experience (Charmaz, 1997). Additionally, through immersing in her illness, Hanna loses touch with the academic environment and work projects, and so becomes isolated further. However, coming back to work after some time in isolated sick leave is also laden with anxiety. Appearing too well makes colleagues become untrusting and suspicious that the illness may after all not be as bad as Hanna has made out. If she presents herself as very ill, however, her return to work is postponed, which leads to further imposed isolation. The answer for many is to largely avoid social interactions in order to evade situations, where they may have to explain themselves (Armentor, 2017). Returning to work after a prolonged absence also requires additional bodywork and emotion work. Jackie, for example, was required to adjust to having had her work tasks and responsibilities changed in her absence:

> All I know is that the worst year, I didn't have any responsibilities, which didn't help me. I felt I was just given marking to do. I felt like I was just being pushed to one side. […] It's almost like I wasn't there and therefore I didn't have a value. It's so bizarre.
>
> Jackie

Jackie expresses very clearly the emotional upheaval and isolation she experienced on the basis of the alternative provisions that were put in place during her absence. For Jackie as indeed for others, long-term absences represent a turning point in their moral careers as discredited and/or discreditable persons (Goffman, 1990/1963) in that the absences emphasise more drastically the difference between their own beings and those of their colleagues. However, in addition to the emotional isolation experienced, participants also feel physically and literally isolated. Being moved into a specific part of a building, or being assigned particular work spaces or offices can mean that individuals are quite literally removed from the majority of their peers. Managing the body is therefore not merely a social or personal matter, it actually is materially spatial, too, resulting in physical isolation, as well as emotional.

> So, I don't have an office. […] It's a desk dedicated just for me, but it doesn't have any balls, because I'm not permanent staff.
>
> Sian

> I feel so incredibly isolated--I have no idea how most others have dealt with their issues in the workplace.
>
> Patricia

Many participants explain that immediate supervisors, line managers and colleagues often offer sick leave or working from home as an alternative to coming to the office, especially when pain or chronic fatigue are too difficult to deal with. What happens in practice, however, is that those with fibromyalgia isolate themselves by staying away from the joint academic space. Not being physically present means they are not in meetings and therefore excluded from networking and making connections.

> I mean I'm supposed to be on a sort of phased return but, umm, which doesn't really exist for PhD students, you know, it's kind of hard. You're either, you know, particularly at the place that I'm based, you're either in or you're out.
>
> Hanna

Retreating from the physical space of academia therefore coincides with a withdrawal from the cognitive space of thinking and accumulating thoughts. They are on their own in their homes and private environments. In order to counteract this isolation, participants do take a fairly active part in social media networks and online support groups. Participants enjoy the sense of community and connection they can feel, and yet, they can continue to manage their online image, in Goffman's (1990/1963) terms their virtual social identity, and representation of what is happening carefully, as we have seen in Hanna's case at the beginning of this section. Where the relationship with colleagues and line managers works in avoiding that sense of isolation and lack of value, is usually in a context where the colleagues or line managers themselves have chronic conditions, and who are therefore in the same potentially vulnerable and worrisome position of being discreditable or discredited persons (Goffman, 1990/1963):

> My advisor [research line manager] is also chronically ill, which is really crucial here, she was understanding to a point, I think, in ways that most advisors might not be, because she could empathise. Then there were days where I would have to forgive her flares, you know, especially if she would like forget things, or you know, we all do this, would get foggy, and I would understand, you know, like "you didn't read my email because you had an ocular migraine" for example.
>
> Angela

Conversations around the relationships with students, colleagues or line managers also highlight the impact disclosure or non-disclosure may have on developing these relationships further. On the one hand, disclosure allows discreditable or discredited persons (Goffman, 1990/1963) to form a bond and in-group of members with similar experiences and therefore provide a safety net, as is evidenced in Angela's statement quoted above. On the other hand, the participants in this research also related to colleagues potentially being uncomfortable in empathising and knowing how to deal with someone who has a chronic condition, but they also highlighted how issues around disclosure impact relationships at a much deeper level:

> I get up from meetings a lot and I need a desk near the bathroom. […] I have physical accommodations at my desk. I have working practice accommodations with Flex-time and flexible location. I have working time accommodations with you know, full autonomy, erm and in, independent working and not, not needing permission, for stuff or a reporting structure. So, I have things that help me.
>
> Sian

When participants look after themselves and employ strategies towards avoiding or pain and brain fog, they take clear decisions on what they do in the public or the private realm. Additional support materials, such as ergonomic chairs and stands, use of dictation software products and the like require careful consideration. The participants talked about how such tools and implements were helpful, and how they used them in their own homes to actively manage and deal with their "deviant" bodies. And yet, they did not use them within the public sphere of the academic office, specifically within those that are designed as shared or open-plan spaces. Despite their usefulness for the individual, these adjustments represent stigma symbols (Goffman, 1990/1963) that will impact the process of careful information control about the academics' discrediting condition. Where academics are using specific tools, gadgets and support materials, they do so, knowing that their colleagues will feel differently about them and that they will stand out:

> So, the only thing. I think we talked about this in the last interview, is I have a special chair. With a mesh bottom and a sort of lumbar support and every bit's adjustable. I have a height adjustable desk. I have a SAD [seasonal affective disorder] lamp and I have an ergonomic, sort of, footrest.
>
> Sian

Signs of adjustments, such as different kinds of chairs, lamps, specialist equipment, computer software programmes and the like, quite openly prove difference in treatment of those who are ill compared with those who are not. In times when most academic staff owned their personal offices these differences may not have played out as openly as they do now in open-plan environments and hot-desking suites. As has been observed in other workplaces (Oldfield et al., 2016), many institutions joint offices and open-plan constructions result in increased contact amongst colleagues so that direct comparisons between one another's work, conditions and adjustments are possible more easily. By being granted the extra office in order to prevent sensory overload and at the same time to allow for the personal management of breaks during the working day, the individual is quite obviously treated differently, and in the eyes of colleagues "better", leading to workplace jealousy that is commonly reported (Vecchio, 2000; Dogan and Vecchio, 2001). This is particularly relevant in instances, where individuals may not necessarily have full knowledge of an individual's special needs due to a complex condition. Managing one's personal needs in relation to the bodily experience of fibromyalgia ultimately leads to having to deal with one's own and others' emotions:

> But to be honest, it sounds cruel but I don't think my colleagues think about me at all. […] I don't think they're like super jealous that you know. I mean they see it because I work in an open plan office, they like my tools, and all of them just look at it for the extra productivity that can be generated through it.
>
> Sian

The introduction of a backrest to ease back and neck pain, for example, coincides with experiences of shame, embarrassment and guilt (Goffman, 1990/1963). It is shameful and embarrassing that someone much younger than others would need a backrest. In the event of individuals being granted special working spaces, and potentially even separated and own offices. The feelings of shame and embarrassment extend to guilt, in particular as institutions generally are struggling for spaces:

> That's the whole thing with fibromyalgia [being ill, but not looking ill], because I've got my own parking space at work now and they did come to me and say, oh do you still need it, and I'm going, I do.
>
> Jackie

In that sense, disclosing or not disclosing a condition to colleagues can become a bargaining chip within that competitive environment of academic status and impact. The consequence for many participants therefore is to undertake the bodywork and the managing of their symptoms in private only. The public-facing managing strategies are around restructuring workdays, reorganising workload or merely pushing through. Ultimately, the connection between disclosing fibromyalgia and developing a social network is complex. Not disclosing the condition openly, but taking measures and steps to improve working conditions may cause mis-trust and jealousy amongst colleagues. But then again, opening up about having and living with the condition requires those with fibromyalgia to make themselves vulnerable, which, in turn, requires them to put trust in their colleagues.

Considerations of disclosing fibromyalgia in academia[20]

Declaring a disability, chronic illness or neurodiversity is not only a matter of succumbing to social oppression and control. Ticking the "I am disabled" box is a statement and commitment. By underwriting a disability, the academic has to be confident and comfortable with identifying as a disabled person. Illness and disability trajectories are often experienced as journeys of acceptance, particularly if these illnesses or disabilities occur later in life or appear suddenly. The proportion of staff in universities declaring health conditions or impairments rose from 2.2% in 2003-04 to 3.9% in 2012-13 (HESA, 2017). However, 16% of working age adults (GOV, 2014), and nearly 13% of undergraduates have a known disability (HESA, 2017). Considering these statistics, there is a stark underrepresentation of disabilities, chronic conditions, invisible illnesses and neurodiversity amongst academic staff.

Where hidden or invisible conditions like fibromyalgia are concerned, individuals have a choice to disclose, pass or conceal (Goffman, 1990/1963) and therefore more control over their identity (Kundrat and Nussbaum, 2003). The decision on whether or not to disclose fibromyalgia is closely linked to academics' personal attitude towards the condition, and as such rests on a number of factors. Age plays a particularly important role in this connection. Individuals who are older or who within their personal life-span have more experience with illnesses tend to cope better with managing issues around their conditions and the broader concerns of disclosure (Kundrat and Nussbaum, 2003). Before being able to publicly announce and stand by an illness, the person needs to have come to terms with the condition at a very personal level first. Being ill with fibromyalgia for some participants was very strongly connected with the feeling of being held back and slowed down (see chapter 6). This emotional response to fibromyalgia also determines how participants act and react towards others knowing about their condition. Participants generally consider fibromyalgia as disabling and are not shying away from considering themselves as being disabled or referring to fibromyalgia as a disability.

> For me a disability is something except for which you would be able to perform at full capacity and participate fully, in your, in your life, however

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[20] This section draws on my published article: Brown, N. & Leigh, J.S. (2018). Ableism in academia: Where are the disabled and ill academics? *Disability and Society*, 33(6), 985-989.

> you want that to be. […] Mine is a thing that reduces my potential performance and that needs accommodations to bring me up, to the level of everybody else. No, I think, I think mine's a disability.
>
> Sian

And yet, having lived with fibromyalgia for a long time and attempting to make sense of the condition does not necessarily mean to have accepted and fully come to terms with it to such an extent that a public disclosure is acceptable. To be confident enough to tick the "I am disabled" box means that this person would have accepted his/her dysfunction, disability or illness, a rather advanced stage in the moral career of a discredited person (Goffman, 1990/1963), as it means learning to accept chronic illness, neurodiversity or disability as a normal experience of life or even as an asset, an outlook on disability that is at odds with internalised ableism:

> I think I would disclose if I needed any reasonable adjustments, or if I could put those in place I would not disclose maybe, it depends, it depends. I know now that I couldn't go for a full-time teaching post, lecturing post, because I wouldn't have the stamina. Unfortunately. And that's very sad to have to say that or admit that.
>
> Kate[21]

In addition to this very personal interpretation and understanding of disability, a public disclosure brings further risks. Academics, specifically early-career academics, worry about the consequences of being identified as someone dealing with health issues and conditions. In an environment where temporary, as-and-when contracts are more prevalent than permanent, tenured positions, employees are concerned about job insecurity. Individuals fear that by admitting to health conditions or disabilities they may be worsening their chances for employment. For them, the rewards of passing (Goffman, 1990/1963) are greater than the consequences of disclosing. Some participants told of examples, where they had shared their diagnosis with colleagues whose lack of understanding had led participants to change their views on disclosing and to generally hold back:

> What I've found interesting this year is, I've had three students come to me telling me they've got it [fibromyalgia]. And it was really interesting, when I said I understood because I had it, and they said, but you're so full of energy, how do you keep going? Because they'll sit in lectures and then say, I've got to leave, and I'll go home, and they won't see me go ooh [does flopping exhausted action].
>
> Jackie

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[21] Evidence for how individuals refuse to accept the sick role and engage in a resistance narrative, as outlined as mechanism (iii) in the introduction.

> I've told four people at work that I have fibromyalgia and I think, two of them kind of understand.
>
> Yasmin

Whether or not academics choose to disclose their disabilities and illnesses is, in practice, a risk-benefit analysis of consequences associated with the specific concern or issue. In order to access support, workplace adjustments, potential financial benefits and allowances, academics do need to disclose their conditions. Another potential benefit of disclosing a condition is the opportunity to have an ally and companion, someone to share the same identity with (Defenbaugh, 2013). However, disclosing more commonly means being categorised as a non-deviant within the normed and normalised society, which in turn leads to being stigmatised (Goffman, 1990/1963). Within academia it is this stigmatisation that causes particular concerns. Invisible, less known or contested conditions are dismissed as a fabrication, malingering, and as an act of a fundamentally lazy or overwhelmed worker seeking validation. Considering such strong views, the act of disclosing automatically links the personal and private to the public. Participants talk about how disclosing fibromyalgia as an illness or potentially as a disability could result in an increased risk of being stigmatised and discriminated against; particularly, as fibromyalgia itself is a contested condition and not widely understood or accepted. At the same time, this risk is weighed up against the potential support and help they would receive.

> I now do put in that I have a disability, because, well, I mean with, with that sort of thing it's because I might need access to some form of service.
>
> Bernie

> Well I'm always honest about it, so for example I submitted a grant application on Monday and there was the equalities disabilities monitoring form and so in a box it said, you know, "do you have any special concerns" and I'm always honest, and I put on there, you know, multiple chronic medical conditions that require accommodations, so I don't hide it in terms of submitting my work.
>
> Sian

The decision about whether to disclose or to hide a condition is therefore an act of self-preservation, information control and impression management (Goffman, 1990/1959, 1990/1963), thus identity work. For most participants, disclosing to colleagues and immediate line managers did not equate to disclosing to the university at institutional level; and they felt more comfortable with completing the monitoring and disability review forms than with explaining themselves to colleagues:

> They [colleagues] can't help me, you know, so it's basically, like, why would I want a pity party. There's nothing they can do, they can't take my work from me, they can't give me any less work, they can't do my work for me, they can't give me the career progression that I want, erm, with the record I have, without it there is no such thing as a mitigating circumstances form, for career progression erm, and people don't have an ability to forget what you tell them. They will just constantly be asking me how am I feeling, and, you know, how are you doing and I don't want to talk about it with them if they can't help me.
>
> Sian

Sian's words in relation to what colleagues can and cannot give her exemplify this cost-benefit analysis. She does not want her colleagues to feel pity, commiserate her and potentially focus on that illness of hers more than on practical work and solutions. A "pity party" would have a serious impact on her academic identity, how she sees herself, but also how others within academia see her.

As we have seen in chapter 5, being an academic means more to individuals than a mere profession or role. For the participants, being an academic is a lifestyle choice that allows them to indulge in their personal curiosity and thirst for knowledge. In this sense, disclosing the fibromyalgia would be seen as an admission of weakness. It is this element of weakness that also determines the tendency towards not disclosing fibromyalgia. For some participants, considering themselves as ill or disabled is a self-fulfilling prophecy and the beginning of a downward spiral of failure that will be more difficult to escape. Therefore, instead of admitting defeat the academics push themselves through episodes of illness, pretending that everything is fine:

> Some days I have no idea how I've got to the end of a lecture because you put so much energy into it, especially on those days, when you've got more and more tired […] I do sometimes get to the end and think, I don't actually remember the last part of the lecture, but we got there.
>
> Jackie

> People see me as being able, and yeah, they see the image I portray; they see me as being able and energetic and mostly on and up.
>
> Yasmin

In the conversations, participants highlighted that even once they have personally come to terms with being ill, the disclosure of that illness in academia is still contentious. Attitudes and expectations in relation to productivity and ways of working are such that deviation from that norm is practically impossible, especially in an environment where precarious contracts and job insecurity are rife:

> I don't think you can, you can like openly disclose.
>
> Kate

> You're breaking protocol because you're being vulnerable, personal and interpersonal, and intrapersonal; and you're asking for something different, you're asking to be assisted, you're asking for help, you're actually displaying the need for assistance, which is really not welcomed all the time, and actually it's irritating.
>
> Angela

> There are kinds of disabilities that are easier to disclose, that have different kinds of stigma that do affect work place politics, so I think it is, I'm not at all talking about the lived experience, but I think it is easier, say, you'd get a better reaction if you're a woman and you say "I have breast cancer", than if you say "I am a woman and I have", I don't know, "borderline personality issues"
>
> Alison

Many participants discussed disclosing to colleagues and the university in relation to and connection with their contractual conditions. Participants on fixed-term contracts or on support staff or teaching fellow contracts were less likely to disclose their fibromyalgia diagnosis. The question around when people were told of, found out or knew about her life with fibromyalgia prompted Dana to contemplate her privileged professorial position:

> Most people only know about me having Fibromyalgia once I became a professor. […] It wasn't a conscious hiding of it, but it might have been unconscious. And also remember, it also goes with the research because before that research was "fibromyalgia's a psychosomatic disorder", so did you want people to think it's in your head, and things like that**;** or is it the influence of research then in the last four or five years talking about, you know, neurological conditions or sort of, sort of biochemical sort of aspects of it. So, I don't know whether it's the, having that professor identity, or something, or it is to do with the research is now, if you like, validating my experience as not just being in my head, but having a physical cause. […] I remember when I, or we had HR paperwork being reviewed and we were renewed and we were being asked to update them, and I put about Fibromyalgia and one of my colleagues, I don't know why he knew that, said "Are you sure? Are you sure you want people to know that?"
>
> Dana

Dana goes on to explain that she had eventually come to terms with the diagnosis on a personal level and is now using her privileged position as a professor to advocate for and support others with fibromyalgia. Her moral career has taken a turn towards being a professional within her group of the discredited (Goffman, 1990/1963, 38).

For her, fibromyalgia is now no longer only an illness she has to deal with, but is also the focus of her research and public engagement activities. In her own words, she is now in a position where she can indulge in more freedom and flexibility:

> If I don't have a class, and if I'm not well, if I decide I'm going, not going to start work at nine o'clock, I'll start at 12 o'clock and I'll carry on for my, whatever number of hours I want to work, or I can work from my bed, so I'm in pain, but my brain's working, so I'll work from my bed. I can do that.
>
> Dana

Other participants, especially those in early career stages, find being ill in academia taxing and demanding. In their views, getting the balance right between work and private life is often difficult because academia is experienced and interpreted as an all-encompassing lifestyle choice and identity. Participants therefore regularly refer to their emotional experiences, and managing their self-worth and feelings of isolation. Being diagnosed with a chronic illness is in itself life-changing and isolating (Charmaz, 1997; Frank, 2013). But then, the feeling of not being able to be completely open, honest and transparent about the body's needs and therefore the adjustments required also leads to a wide range of emotional responses. Participants express their experiences and feelings of isolation and having to work through their needs by themselves, especially, if they have not disclosed their condition to those around them, and so they have to deal with their illness on their own and thus become even more isolated:

> At the moment I just feel like I'm just a, a mess. I feel like, like, people are avoiding me from my course, maybe not deliberately but they're just, they're so busy and involved with what they are doing. And I think extended illness of this type makes people very uncomfortable. They, they don't know what to say, they don't know what they can do. It's not like an acute illness where they can come and visit you with a bunch of flowers and, you know, you're in bed looking all poorly and then next week you're not so bad and then the following week you're back in the office. I think it's very confusing for other people and, and, yeah, I think it makes them feel uncomfortable, and I feel like people who were very supportive, say, six months ago, the last, this last spell of illness since March, I've hardly heard from them at all, not seen them, so I do feel a bit abandoned. And, and, you know, I, I have made an effort to keep in touch with people, it's not that I've put myself off, I understand that they're really, I mean, they are insanely busy, they could, you know, they're in the midst of their PhDs, but it's, I do feel a bit hurt.
>
> Hanna

> You know, and then the really annoying part is that when I do want any social interaction or I want to go and see people or talk about ideas nobody has any time for me, right.
>
> Sian

Thought processes around disclosure therefore relate to physical, material manifestations as well as emotion work. In effect, individuals analyse and calculate whether disclosing the condition is a risk worth taking. Individuals are more likely to disclose their health concerns if they feel that disclosure facilitates continued employment and explains absences or conditions (Butler and Modaff, 2016). Women with fibromyalgia have also been found to be disclosing more likely when fluctuating work commitments or changes in work relationships occur (Oldfield et al., 2016). The difference between the general public and academics is manifested in the dimensions of disclosure. Non-academics choose to disclose illness and impairments, to provide information about the contested illness or to selectively reveal invisible impairments (Oldfield et al., 2016). The academics' disclosure dances (Oldfield et al., 2016) remained on the level of selectively revealing through conscious information control (Goffman, 1990/1963).

Concluding thoughts

In order to understand what it means to have fibromyalgia in academia, higher education must be seen in the context of the processes towards increased marketisation, internationalisation and bureaucratisation (Hussey and Smith, 2002; Tilak, 2008; Gewirtz and Cribb, 2013). Against this backdrop fibromyalgia emerges in its somatic quality as a physical expression of pressures and emotional pain (Frost, 2003). Through their ability to critically reflect and analyse academics identify the working conditions as a contemporary academic in the neoliberal university as a source of aggravation for their fibromyalgia symptoms. However, academics themselves do not interpret the academy as a source or cause for the condition in the first place. Instead, working in academia continues to be romanticised (Lovin, 2018) and is still seen as worth striving for and so, the participants' focus lies on managing their emotions and bodies.

In dealing with fibromyalgia academics employ a specific form of bodywork that combines strategies for managing symptoms with emotion work. This kind of bodywork manifests itself in three forms: (a) the management of the fibromyalgia body, the deviant body, thus the management strategies employed in order to be able to fulfil the role as an academic and embody academic identity; (b) the management of the academic body as a public and private identity; and (c) the individual's work on and with the fibromyalgia body to make sense of one's self, whereby this final aspect incorporates physical, material bodily interventions as well as emotional labour involved in this process. The emotional components of this bodywork are closely linked with issues around disclosure. Disclosure is complex in that three core conditions need to be met.

Firstly, the person with the diagnosis needs to have reached a state of personal acceptance. As an individual the academic with fibromyalgia needs to learn to accept that there is something "wrong". It is perhaps easier to accept an illness than to accept disability, but then it is not so easy to accept an illness that does not have an outcome unlike cancer for example, where the narrative is one of heroism (Frank, 2013); heroism for those who fight and survive, but also for those who are brave knowing that they cannot survive.

Secondly, those with a fibromyalgia diagnosis need to experience acceptance at their workplaces. The culture at the workplace must be such that individual differences are accepted and understood. Conditions like fibromyalgia are not met with the right levels of understanding. For example, a visible disability requiring wheelchairs, walking canes and guide dogs is more easily understood than disabilities that cannot actually be seen. "But you don't look sick" is commonly heard.

Finally, in order to be able to fully disclose the fibromyalgia diagnosis, an academic needs to be sure that there will not be any repercussions. In reality, many academics, especially those with hidden disabilities and illnesses experience discrimination in one form or another – not necessarily as a malicious act, but because of lack of understanding (Brown and Leigh, 2018). As society is discriminating in that sense, academics with fibromyalgia worry that their workplace will be equally discriminating if it becomes clear that they have health needs, and so, they end up not disclosing their condition. With this in mind, the disclosure issue is really about how comfortable academics are within their own skins. Disclosure therefore needs to be discussed as a personal, private event as much as it needs to be considered as a public event.

Disclosure issues therefore need to be viewed through the lens of ableism (Campbell, 2009), in that we all compare ourselves to the norm, which tends to be the concept of someone who is perfectly able-bodied and able-minded. This image is further reiterated through medical technology and pharmaceuticalisation that allow for enhancement of the normal. But normal nowadays is not the naturally developed body: it is the body with a six-pack, or perfectly aligned teeth, it is the body that goes the longest without sleep and remains productive at all times of the day (Shilling, 2012). These new "norms" are not necessarily achievable and achieved even through external means, but this is what we measure ourselves against.

When disclosure is considered within the public realm, it tends to be discussed in the context of stigma. As we have seen, the participants in this study may not have talked openly about stigma. However, although people "are normal" and "look normal" stigma plays a role in fibromyalgia. Academics with fibromyalgia have got an opportunity to navigate their image and control if and how much they would like to divulge of their condition, thus their "otherness" (Goffman, 1990/1963). Their bodies do not openly display their issues and are not inscribed with any stigmatising features (Goffman, 1990/1963). This is obviously a concern because academics with fibromyalgia are therefore treated as normal in relation to productivity and effectiveness although they may not be able to meet these high expectations due to their bodily limitations. At the same time, this means that they may pass and not be subjected to stigma (Goffman, 1990/1963). The general awareness and understanding of fibromyalgia are so limited that the brain fog does not tend to come up within the everyday interactions with others. Participants have brain fog and suffer from and with it, but it is a personal experience, not a public one. The stigma comes through the use of adjustments to make life easier, such as the walking aids, wrist supports or back rests, which all represent stigma symbols (Goffman, 1990/1963). Academics with fibromyalgia are therefore hyper visible and entirely invisible at the same time (Mitchell, 2001). These themes of disclosure, managing the fibromyalgia body and being invisibly ill are explored further in chapter 8.

8. Fictionalised analysis

In the previous chapters I highlighted how academics make sense of their academic identities, their experiences of and with fibromyalgia and of negotiating fibromyalgia in academia. However, there are key elements missing that remain untold in these previous chapters.

Throughout the research process participants shared difficult situations, narratives of discrimination, ableism and stories of grievance procedures and tribunal panels. In many cases, individuals were concerned that they would eventually be subjected to non-disclosure agreements (BBC April 2019a, b), and so were particularly keen to have their voices heard. The precariousness participants experienced in these times meant that they were even more acutely aware of their vulnerability, should they be identifiable. Participants also worried about the reaction from colleagues, family members and friends, as in many of the narratives, the social networks around the story-tellers were implicated as unsupportive, distrusting, lacking understanding and empathy. In those narratives, colleagues, family members and friends were responsible for the deterioration of working conditions and the exacerbation of symptoms. And yet, the participants wanted to share their experiences and regularly commented on the importance of not being silenced, but making their voices heard loud and clear. They wanted to tell their stories publicly under the caveat that they as individuals not be recognisable and recognised. I was entrusted with intimate revelations and emotional outpourings with the expectation that they would lead to better understanding and increased awareness, but without harming the individuals' professional development, career opportunities and personal relationships.

When participants asked me to guarantee their anonymity, I realised that many sections of the interviews could not be shared in the conventional, academic format. At the same time, I needed to make sense of the wealth of experiences I was entrusted with, and so instinctively I started to create characters and developed stories around them. Gradually, the characters became my companions and they spoke to me when I was driving or I dreamt of them when I was asleep. Some of the situations described in the stories happened, others felt like they did or as if they could have. In line with the ideology of thinking with stories (Frank, 2013) and using writing as a method of inquiry (Richardson, 2000, 2003) I used the story-writing process to help me better understand my data. As the author of the short story cycle, I merely collected, arranged, revised, rearranged and then told a new version of what

I had heard (see Appendix E for the full short story cycle). What all characters and stories have in common is that they are thoroughly embedded in the research data.

The more I immersed myself in interpretive and arts-based qualitative research I not only learned about but started to embrace crystallization (Richardson, 2000) as a methodological framework and process (Ellingson, 2009). In effect, crystallization is writing or analysing in different forms and media to illuminate data (Ellingson, 2009, 2017) and extrapolate meaning that would otherwise stay hidden or forgotten because researchers do not consciously bear in mind that knowledge production is socially constructed and impacted by conventions (Ferguson, 1993). Engaging crystallization in research means to recognise that all methods of data collection and analysis are flawed with no individual approach being superior to others (Ellingson, 2009). Consequently, developing and employing a range of methods through the process of crystallization allows researchers to tend to different kinds of truths and experiences:

> not to evoke a sense of empathy, cultural insight or deep significance, but to confront us with the *radical specificity* of living a life … in the sense that life is lived in the flows, multiplicities, and provisionality of each moment, event, emotion (Sotirin, 2010, n.p., section 6).

Writers of fictionalised accounts as are common in narrative research, evocative (auto)ethnography, creative nonfiction and other forms of artistic research-practices rely on the three pillars of structure, characterisation and literary tools (Leavy, 2016) to tell a coherent story. This artistic approach towards dissemination through fictionalising data allows for research to become transformational (Leavy, 2015), expressive and evocative (Barone and Eisner, 2012). Sotirin (2010) and Ellingson (2009) do not argue against these kinds of writings, but emphasise that researchers need to engage with the radical specificity of experiences, thus the otherwise subjugated and marginalised (Ellingson, 2017). In an arts-based analytical process data cannot be moulded along figments of imaginations, but need to draw out and represent their complexity. Tending to radical specificity in this sense reflects a deeper engagement with "unfamiliar connections and relations that move both beyond and against the familiar storylines" (Sotirin, 2010, n.p., section 7) and "cultural clichés" (Ellingson, 2017:178). Evocativeness, expressiveness and transformation are not intentional but natural by-products of readers engaging with similarities and differences in experiences and "think[ing] beyond the dominant, the familiar and the common" (Sotirin, 2010, n.p., section 7). The arts-based research movement has produced many such accounts, dramatic and poetic explorations with more or less intentional commitment to the social justice project and varying degrees of emphases on evocativeness, expressiveness and transformation. Sense Publishers support and maintain an entire social fictions series publishing books that explore and support the teaching of sociological themes, but are also advertised as stand-alone readings for pleasure. Authors in that tradition do not usually provide an analytical, interpretative commentary, and while they do draw on artistic forms of expression, such as literary devices, they tend to closeness to and clarity of data rather than allow form and aesthetics take priority. In line with these publications, I present in this chapter the first and last stories of the story cycle to stimulate reflections and initiate debates in relation to the "untold" fibromyalgia stories. The full story cycle including the stories not presented in this chapter are detailed in Appendix E, alongside an exploration of how the stories will told further to highlight the characters' development.

"Calm waters" presents the impact of cognitive dysfunctions, perception issues and fatigue that are associated with fibromyalgia. The goldfish in the bowl of water is a commonly used metaphor amongst people with fibromyalgia as a short-hand explanation for why individuals may find it difficult to follow conversations or streams of thoughts. "Dead in the water" summarises individuals' struggle between wanting to have their stories told and shared, but at the same time wanting to protect their identities for fear of repercussions. "Blood is thicker than water" is the story of Tricia who is an early-careers academic on an hourly paid contract and who is the first in her family to become an academic (see chapter 5). John, the mid-career academic in "A fish out of water" is the symbolic embodiment of otherness: as a man he has been diagnosed with the predominantly female and feminine condition fibromyalgia and he has entered higher education from a further education career path (see chapter 5). "Come hell or high water" explores the difficulty of receiving a fibromyalgia diagnosis and at the same time highlights the physical and emotional impact of trying to conceive (see chapter 6). In "Treading water" Mary is a typical academic who cannot adjust her lifestyle to the expanding health issues. Her husband means well and wants to help her, but does not fully understand that for Mary pacing herself would mean compromising and giving up on her academic identity (see chapters 5 to 7).

All of the themes explored in the stories are reflected in the analysis chapters 5 to 7. However, the short story cycle allows for tending to the radical specificity (Sotirin, 2010, n.p., section 6) of individuals' experiences. For example, in Sam's story the theme of conception is not only highlighted as a medical issue in relation to fibromyalgia, it is also explored in relation to its emotional impact on the individual. Similarly, Tricia's story also offers the reader internal dialogues and innermost feelings, in this case in relation to becoming or being an academic. My focus on and commitment to the radical specificity (Sotirin, 2010) is best explained with the title and subtitles used in the short stories. With the exception of "Come hell or high water" the story titles are direct quotes from interviews. I merely went with the water theme, created the one title I needed to encapsulate Sam's experiences and consciously entitled the story cycle "Ripples and waves". "Ripples and waves" naturally fit with the water metaphors and similes, but the title also highlights how actions have consequences, thus causing ripples or making massive waves in the lives of individuals and the people around them. The interconnection between the stories and links from one character to another emerged organically, when I tried to find means to represent that many of my participants knew each other and of each other, even if in public they never openly talked about their issues with health and disabilities.

Ripples and waves

Calm waters

All things considered, I do think of myself as a writer.

I have always written – diaries, blog posts, letters, emails, texts, scrapbooks, poetry, fictionalised accounts and short stories. I have even been part of reading and writing groups to learn more about the craft of writing; and I have read about reading and writing, and reading and writing well.

But how can I sustain that writing life if I am tired?

My body is too weak to even hold the pen, let alone move it across the page. And that is despite the pens already being of the "disability kind", pens that are meant to help old people because they are losing their fine-motor skills to grip or pens that are meant for toddlers who have yet to develop their fine-motor skills to grip.

I can perhaps overcome the challenges, perhaps with the help of a computer sprawled over my lap or a Dictaphone and other recording devices, where I can pretend to have those all-stimulating conversations with my academic self.

But even if I'm somehow able to overcome the physical barriers and to bypass my body's weaknesses, what about my brain? I'm simply too tired to hold and record the conversation.

My brain is brimming with ideas, but all I can feel is the goldfish bowl that is my head, where the goldfish-ideas just wait to be caught; and I am not able to do that because as soon as I grasp at the goldfish the entire water bowl tips to one side with water lapping up at the sidewalls of the bowl. Of course, I follow that thought, reach for it, only to miss it again because the water sways the goldfish to the opposite side of the bowl. All I do is worry. I worry that my dizziness and tipsiness are visible to others. And I worry that the waves of the water will splash over on one side of the bowl washing the good, red goldfish-ideas out of my brain altogether.

What do I do?

The answer is, I don't write.

I rest to try keep the waters calm and the goldfish in the bowl.

Dead in the water

Full of anticipation, I approach the café after lunch on that sunny day in March. It has taken a long time to get this meeting set up. Karen and I have been in regular contact for over a year by now, but we have never met in person. She has always put off meeting me "for real". I am eager to hear her full story. From our private messages I know a lot of what has happened to her, and really want to have her contribute to my research. As I enter the café, I notice a number of tables having been taken. I become acutely aware how little I know Karen although I know so much of her. I know that she doesn't like air conditioning. The cold air blowing directly onto her makes her muscles seize up. I know she hates noisy environments. I know that the noise of the baristas handling the coffee machine will make her lose her train of thoughts and forget her words. I know that the direct sunlight will make her vision turn fuzzy. I know that the combination of the noise, the light and cold air will make her tighten her muscles, grit her teeth, clench her fists. I know that she needs to be near the toilets, in case she suddenly struggles to swallow and needs a private space to retch.

And yet, I don't know what she looks like.
I am asking myself, "Do I really know Karen? Or is it that I know about her struggles because I know what life with fibromyalgia feels like?"
I let myself fall down comfortably on the sofa in the corner off the self-service counter. From this vantage point, I will see her enter the café but we will be away from the cold air and the noise as far as possible. Karen will be here any minute.

Five minutes.

I am slowly starting to wonder if this will happen at all. Karen has often missed and rescheduled skype calls and phone conversations.
She was uncontactable for several weeks around Christmas; and she avoided longer conversations in February.

Ten minutes.

Recently, she seemed keener than ever to share her story, but her responses were largely one-liners like "I'm sorry I've been so flaky" or "I can't think about it" or "I know I should probably turn this into a paper but lack the stamina".

Fifteen minutes.

Karen is a senior academic, a professor, and renowned in her field.
Karen lost her job.
Karen was sacked.

She was appointed on the basis of her successful publications and the potential boost she would bring to the department for the next research exercise. She was under pressure to perform and conform. She did; and yet, she did not.

Twenty minutes.

She continued leading on her research and producing articles for publication. But she struggled with the pace. She was required to produce more, faster, of higher quality. Brain fog and pain interfered with that work, and she complained about the lack of reasonable adjustments. That was uncomfortable. She became uncomfortable.
Then she was let go.
That was five years ago.

Twenty-five minutes.

She has been out of employment ever since. After all, who would want to employ someone who is "uncooperative" and "incapable"? But what is going to happen to her and with her? As someone in her mid-sixties she finds it difficult to relaunch a career.

Thirty minutes.

Ping.
I look at the message that just arrived in my inbox. "Hi. I'd love to tell my story on my own terms and in my own time (if I live long enough). But I've been told I'm not allowed to make public comments that may be interpreted as critical of my university. They offered me a lot of money to leave at one point. I refused to sign any papers on the grounds that I had done nothing to lose my job."

Karen is not coming.

9. The reality of research with creative methods[22]

After the presentation of the research findings in chapters 4 to 8, I now offer an evaluative reflection regarding the research process and its particularities due to the use of creative methods. In relation to the overall thesis argument in this chapter I focus on issues of methodology and lessons learnt from the new field instrument of identity boxes. After a brief introduction to lessons around the correct use of language, I turn to an exploration of the reality of using identity boxes. I argue that the use of creative methods requires considerations that are different to more commonly used interview approaches. Existing literature considers and promotes the employment of visual, sensory and embodied methods (Pink, 2013, 2015; Ellingson, 2017; Kara, 2015) or arts-based approaches (Leavy, 2015, 2016, 2017; Barone and Eisner, 2012). Research publications employing less conventional methods also briefly refer to the methodological innovation (Bates, 2019; Gauntlett, 2007; Nind and Vinha, 2016; Orr and Phoenix, 2015), but do so tentatively and do not focus on the participants' creations as a form of data but on the participants' contributions to interviews and surveys. In the section, interruptions and disruptions I highlight how researching academics with fibromyalgia as someone who has fibromyalgia has been shaped by the condition. My contribution to original knowledge in this chapter lies in the detailed, critical, reflective analysis of my arts-based approach. What sets my method apart from many other creative research methods is that I view the outputs and creations, the objects and the identity boxes themselves as data. I contend that the data generated through those processes represent individuals' deeper reflective work (Panjwani and Brown, 2019; Brown, 2019b, 2018a, 2018b; Brown and Leigh 2018), but that the entire process is more demanding and complex due to the commitments required from individuals, and that the use of arts-based, metaphorical representations leads to ethical and moral considerations that more conventional methods do not. I conclude that the most beneficial and advantageous aspect of this research was openness towards all forms of expression, so that participants could genuinely communicate how and how often they wanted to.

The correct language and terminology

The previous chapters showed how the academic participants in this research made sense of academic identity, their work in academia, but also their experiences with

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[22] This section draws on my published article: Brown, N. (2019). Emerging researcher perspectives: Finding your people: My challenge of developing a creative research methods network. *International Journal of Qualitative Methods, 18*, 1-3.

the fibromyalgia diagnosis. Throughout this sense-making process academics engaged in a scholarly debate and considered their experiences on a personal level but through a somewhat academic lens. It is this scholarly and academic endeavour to reach understanding that has led to the all-important debate around terminology and language. The importance of language and terminology was highlighted in an informal conversation at a very early stage of this research project, when I spoke to a participant about being a fibromyalgia patient, but corrected myself to say a person diagnosed with fibromyalgia:

> Nicole: So, one of the questions relates to how you feel as a fibromyalgia patient, I mean, a person diagnosed with fibromyalgia.
> Patricia: I'm not a person diagnosed with fibromyalgia, or a patient. I am a sufferer.

Within the wider discourse around illness, disability and neurodiversity language and terminology are a hotly debated topic. There are advocates who would like to see language to reflect that the person is more important than the person's disability, for example. On the other hand, however, there are specific groups advocating terminologies used to reflect the person's identity that is encapsulated in language. According to this debate, it should therefore be unthinkable to say "the disabled" or "the handicapped", but would be desirable to use "the Deaf" or "the Autistic" (Sinclair, 2013). Language here is seen as a powerful tool to convey thought processes. A person using a wheelchair, for example, would primarily want to be seen as the person rather than the disabled person (Ward and Meyer, 1999). This interpretation is closely aligned with the social model of disability (Oliver, 2013) that sees disability as a barrier imposed by society and its members. On the other hand, proponents of the use of "the Deaf" or "the Autistic" are generally advocates of the affirmation model (Swain and French, 2000). For them, being ill, disabled or neurodiverse is not a negative, non-normal experience. Instead, they embrace their illness, disability or neurodiversity as part of their identity. In this sense, offering a hearing aid to those who are deaf is an affront as their identity, the inherent experience of being deaf is taken away from them (Leigh, 2009). Similarly, the term "patient" is charged with connotations and reminds of a person's passivity and victimisation within the medical realm, as patients are objects within the doctor-patient relationships, whose experiences are validated by doctors and who are supposed to endure treatments prescribed to them. Most participants in this research had very clear thoughts about and were very precise regarding the terminology they used and they wanted to be used. Even if most participants did not express their preferences as clearly as Patricia had done, the most widely-used terminology around fibromyalgia was to do with suffering:

> I go through phases of this, and so therefore, I must be lucky, that I'm not one of those people that suffers all the time but, no it comes and goes.
>
> Jackie

> I have just seen [a tweet] which reminded me that I had not responded to your DM [direct message]. Please accept my apologies. This is the way it is with FM sufferers, or at least me. I have been going through a very bad patch for about the last 8 months or so.
>
> Patricia

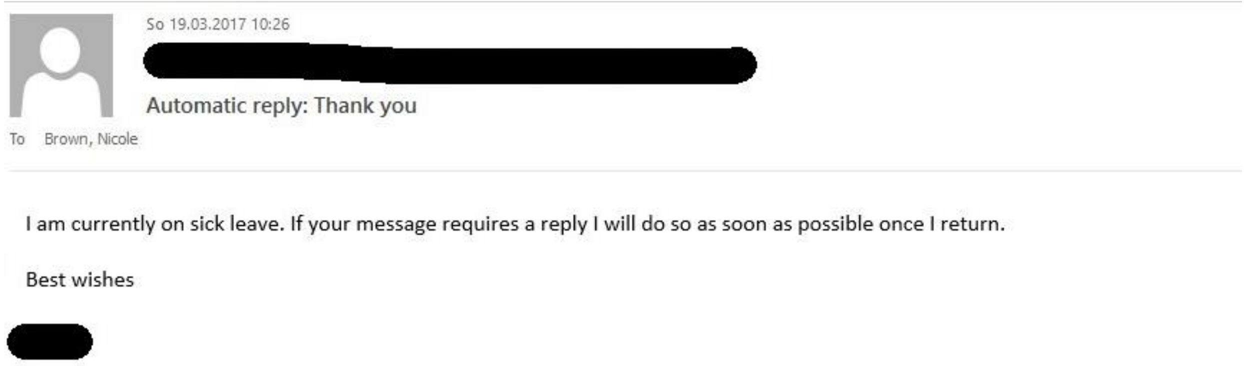
> One of the, my colleagues, she was talking about fibromyalgia, she was talking about how she was suffering […] I said I feel the same.
>
> Kate

> Did we really need to talk to pain sufferers? Like, yes, also pain sufferers is a really problematic term [thumbs up sign]. So there has been a fair amount of political juggling.
>
> Alison

The kinds of language participants and I have used throughout the project was therefore largely agreed upon on an individual basis. After all, not only are these terms politically and culturally charged and as such represent signs of oppression and victimisation, they also encapsulate personal experiences and feelings in relation to being ill. The above cited conversation highlights very clearly how politically correct language may sometimes be inappropriate exactly because it takes away that charged connotation. With fibromyalgia the concern around the right use of language and terminology is even more complex, as fibromyalgia is badly understood and therefore not clearly classifiable as an illness, disease or disability. Overall, all participants described fibromyalgia as a disabling condition, although most were reluctant to refer to themselves as disabled.

Interruptions and disruptions

Throughout the process I encountered interruptions and disruptions to the data generation and analysis stages. Due to the variability of fibromyalgia academics drifted in and out of participating in the research. They were keen to tell their stories, share their experiences and be heard; but, the reality of life with fibromyalgia and pressures of academic work led to flare-ups and complications, which in turn resulted in the increased need for pacing. Within the hierarchy of academics' priorities, the participation in my research was therefore often the first thing to be abandoned or cut back on. During the course of my study two participants interrupted their PhD studies, one participant decided not to continue her PhD studies and forfeit her scholarship, and three further participants contemplated reducing working hours and working loads accepting diminished salary. Out of office messages were a constant reminder for the fluctuation of illness and long-term absences:



So 19.03.2017 10:26

[redacted]

Automatic reply: Thank you

To Brown, Nicole

I am currently on sick leave. If your message requires a reply I will do so as soon as possible once I return.

Best wishes

[redacted]

But I, too, encountered flare-ups, and periods of increased pain. Mostly, I was able to maintain composure and it would not impact the conversations with the participants so that they specifically asked about my health status:

> And so, what about you? Do you have it as well? And is that why you started to look into it?
>
> Jackie
>
> Nicole
> I never asked but, if I may know (dont worry if you cant answer) do you yourself suffer from fibromyalgia?
>
> Carmen

In all honesty, being able to maintain public face and composure was only possible because many of the conversations happened in writing by email. Indeed, Carmen's query started a whole conversation around my being ill, carrying out research and balancing work with the doctorate and family commitments:

> From Nicole to Carmen:
> Dear Carmen,
> I saw your message earlier, but was rushed, so didn't want to reply straight away. The short answer is yes, I do. The full story is somewhat longer, but I was initially diagnosed in 2003. However, I didn't accept the diagnosis and so continued the journey from doctor to doctor, until in 2012 I was diagnosed again. This was the point where I started accepting the diagnosis. But with hindsight I showed the first signs of fibromyalgia when I was a teenager, so probably around 1990. So, yes, I have a long story myself. Feel free to ask away.... 😉

> From Carmen to Nicole:
> Hi Nicole, thank you so much for sharing your stories
> I appreciate it
> And well done to you that you have worked hard so far for your phd and other things in your career
> I just........ I've been finding the phd hard as I'm ill a lot
> I have constant headaches, sore throat, fatigue and fever
> And its just..... people around me start to adapt with my pain I think as I'm always ill
> And like with panels and examinations etc its done after 8 months, 1 year etc and its just that my 8 months seem to be different than a healthy student's
> As I am not capable of 8 hours a day of work, for example
> And in the end my PhD is assessed by my thesis
> And not say my thesis and the situation where I'm working on my thesis with this illness
> Sometimes I feel like its a huge struggle cause I cant work as much as other people in the way that I have limited time and energy
> Thats why I asked
>
> From Nicole to Carmen:
> I fully understand. And it doesn't come easy for me either. I am usually asleep by 10 pm, and don't do much after 8 pm actually. For me the worst thing is the brain fog, which really upsets me. But I am ill a lot, too.
>
> From Carmen to Nicole:
> I'm just worried that I won't finish my PhD, I think

On the one hand, this conversation disrupted the natural flow of the interview and we ended the conversation on a leisurely note, only to take up the interview on another occasion. On the other hand, these interruptions demonstrate the reality of being a researcher and trying to work through an illness. Similarly, there is ample evidence throughout all interviews of how individuals, including myself, started struggling after a certain amount of time, finding it difficult to focus thoughts, not being able to prevent brain fog from setting in:

> [Pause]. Right. I tell you, tell you what Alison, I'm starting to struggle now. Umm, umm, I mean, I think it's been roughly an hour anyway, that we've been talking. If it's okay with you, I'd, I'd like to ask you back for a another chat, 'cos I, I've actually written down a, a few questions, and I've got a few questions that I want to, to ask, but I really, I'm starting, I know that I'm starting to, yeah, not be able to focus
>
> Nicole

> Sorry Nicole, I'm fucked, I'm really tired. Lost my train of thought, going to lie down for a second, yes.
>
> Hanna

> Thank you for changing it this afternoon, but I, I slept for 12 hours when I got, because I got back yesterday [from an international conference]. I was, I was so behind and, I appreciate you being able to adjust it.
>
> Jackie

Once I had coded all the data and had gone over all of the interviews, there was one particular conversation between Angela and myself, which epitomises the severity and immensity of the task of balancing work and life with an illness, of carrying out research and maintaining a relatively normal work schedule whilst having fibromyalgia:

> Nicole: And at the same time to be very, very honest, I'm finding myself, that I'm now starting to struggle to make the connections that I need to make [laughs]
> Angela: Oh no. Okay, yeah, it's hard when you're focusing.
> Nicole: I'm coming to the limits of my concentration span, I think.
> Angela: I understand, yeah. I totally get it. I do. Believe me.
> Nicole: It's really frustrating 'cos em, yeah, it's lovely to hear you talk, and, and it kind of makes a lot of sense, of the things that you say in it, and I, I get the drift of, you know, like, some jobs being more, sort of, related to status and reputation, and therefore not as welcoming or accommodating to people like ourselves basically.

Some of the interruptions were also signs of minds drifting off, but at the same time a way for the participants to engage me in their personal environments, as I highlighted in chapter 3 within the section of ethical considerations:

> I don't mind [wearing a headset and standing out from other colleagues]. [Waves]. Sorry, I'm just waving to some, my neighbours. [Laughter]. But I don't mind wearing a headset, in fact I think it's great.
>
> Jackie

> There was a couple of years really of doing sort of small courses. I did Spanish course, I did a course in soft furnishings in curtain making. I made these curtains, I'll show you my curtains. They are pretty good curtains. See? Look, those curtains there [moves the screen round to show curtains].
>
> Hanna

Figure 9.1 provides a visual snapshot from a skype call with one of the participants. In the middle of the conversation, Jackie remembered that she had prepared her diary, as she wanted to share particular images with me. The photograph depicts the moment where she got up to retrieve the diary from a bookshelf.

Figure 9.1: Still image taken from a skype call between Nicole Brown and a participant

It was situations like these that made the research process particularly difficult, where positionality was concerned. I was constantly trying to distance myself from my own experience as an academic with fibromyalgia in order to not become known as "the fibromyalgia patient", to not be leading in my questioning and to maintain objectivity regarding the thoughts and experiences of others. However, through engaging with the participants on such a personal level, being shown around the house, meeting colleagues, friends, husbands and partners, I felt drawn into the participants' world in a way that I feared would disrupt my analysis and my understanding of what was happening.

Reality of using identity boxes[23]

Working with participants who are chronically ill is naturally very difficult. The participants are keen to have their voices heard and their stories told, but the research process may be having a negative effect on them because of the additional demands and extra pressures placed upon them.

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[23] This section has been published in the article: Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology,* 1-15.

What was interesting for me was that I had not entirely understood the enormity of the creative tasks until I started the analytical process and coding. I was keen to minimise any detrimental impact on the participants by choosing openness and flexibility in relation to the research process, but I had underestimated the physical and emotional engagement and commitment I had asked for.

Across all phases of my fibromyalgia research, 35 participants took part in the identity box project, of which 15 completed all five tasks. The participants who did not complete the tasks did not do so because their personal, health circumstances had changed to such an extent that they decided to withdraw from the research or to provide data in alternative formats. Depending on the participants' personal circumstances and how long participants took for each task, the projects took between 5 and 15 weeks. The project's flexibility meant that participants' personal circumstances and fluctuating health conditions could be catered for flexibly, as participants could respond to the tasks whenever they felt most comfortable. The individualised approach of opening up to participants' ways of thinking and working impacted and indeed enriched the data. In addition to the identity box and interview, participants provided series of photographs, song lists, poems, extracts of diaries as well as personal musings and reflections. The identity box project therefore required more commitment on the part of the participants than for example a single interview or survey. This commitment was one of time and effort for the reflective process and the physical collection of the objects, but emotional commitment and engagement were also required.

> I'm happy to help with the project, and I think it's important and I know how hard it is when people drop out at different stages in multistage research.
>
> Sian

> Well, I'm getting a little bit teary on that [objects]. It also affects me, normally I can, no, normally I can't; sometimes I can pick when it's going to come, often, when there's too much stimulus it really tips my brain fog over-the-edge.
>
> Yasmin

On a practical level, participants had to get a box organised, had to then find objects in response to questions, move those objects into the box, take photos and email those through before repeating the process. In many instances, the objects that needed to go into the box were of such personal meaning that participants either regularly used them and so needed to consistently them in and out of the box for the duration of the project; or participants did not feel comfortable putting their prized and valued objects into a box with other less important items. It was almost as if putting the important, personal object into a box with others, less relevant ones devalued them:

> I have tons of other giraffes throughout my home and I've got a lot of giraffe print strewn about. The truth is there wasn't much I could bear to place in a box. Everything is sort of feng shui'd in a way the soothes me. Prob a little crazy to say I would have a hard time parting with.
>
> Lily

The emotional, physical and practical commitment was particularly poignant with one participant, who had very recently had relatives move into her house. As is rather common after house moves, there were still many items in boxes, and indeed in storage. So, whilst she was keen to complete the project and whilst she was really engaged with the concept of material and metaphorical representations, she could not really bring herself to deal with boxes and physical objects.

> The, the questions won't bother me, it's about actually the stuff, because and I'm having a lot of trouble with stuff in my house at the moment. My mother, my grandmother moved in with me. […] So now we live in a multi-generational household and she just brought too much stuff, and so my house is overflowing, for someone who likes, you know, tidy desk, tidy mind, it's quite stressful already. So just have to find things and use them, and to talk about things again, I think it would have been the limit.
>
> Sian

This leads into another relevant aspect: the role of emotions within the identity boxes. Whilst the above discussion demonstrates emotional engagement and therefore the deep-level thought processes involved in the identity boxes, there is a concern about this, too. From a researcher's point of view, it is important to get to the meaningful, personal level of participants' thoughts and ideas, but potentially neither the participant nor the researcher are prepared for this unleashing of unrecognised emotions. This is particularly important to consider when working with participants who may not necessarily be used to reflective practice in the context of their everyday life. As a researcher I have not received formal coaching or counselling training, but I can build on my experience as a teacher to support participants with their emotions in interviews. In this project using the objects for the identity box, the participants were on their own during the process of reflecting and selecting objects. They did not have the immediate, personal contact to provide the safety of dealing with the emotional impact of the activity. The emotional impact of the reflective process is best exemplified with participant Sally, who dismantled her identity box as soon as the project was finished:

> I actually dismantled it the minute that I sent you the final photograph (laughs); I didn't want to look at it. [I felt] relieved, relieved that it was over […] it's just one of those things that was a lot harder than it should have been, and I was so grateful to have finished it.
>
> Sally

What needs to be said, here though, is that many participants, and indeed Sally experienced the identity box as therapeutic and cathartic. Although Sally dismantled the box as quickly and as soon as she could, she was one of the participants who described the experience of creating the box as most transformative.

> Before we started this project I was completely fine with the idea of having fibro, I thought I was accepting of myself as a person. […] but now looking at the objects, thinking about what I put in the box, I'm probably more fake because I'm always fighting, but then if I were to put things I the box that reflected the true me, I wouldn't know where the start. Yeah, I just need to cut myself some slack and find out who I am.
>
> Sally

To Sally, the process demonstrated that there was more to her, and that she needed to find out more about herself, especially in relation to the illness experience. She talked about not being true to herself before the project because she had thought she was a down-to-earth person accepting the position she was in, when through the project she realised that she was fighting against the illness after all. For other participants, the process foregrounded that there was more to them than just the illness, that despite the condition there was still a person that had always been there and that still had a lot to offer and give back.

Some participants enjoyed the project because it tied in with the advice given to them about managing fibromyalgia: keeping a diary. However, in practice, diary-keeping or journaling through writing regular entries is not sustainable for many:

> I don't really have a diary or any sort of mental record. Maybe I should have done. […] I'd write like one page and then I'd go, well this is so much I don't need, and I had about three or four notebooks with beginning starts, and unless I wrote them and burned them, unless I did it as like a, you know, cathartic exercise, and burned them I wouldn't do any reflections.
>
> Sue

The participants therefore saw the potential of the identity box as a more accessible alternative to maintaining a diary or journal. To them, the project almost represented a time capsule of their experiences at this specific point in their lives, and they could see potential in re-running the project at different times in their lives to see and track personal development and changes:

> [Repeating the project in a few years] would be great experiment, no, just, just to be even waiting just six months and try it again to see how much you've changed.
>
> Lisa

Another important aspect in connection with the use of the identity box project was the engagement in reflective practice itself. Where reflections and reflective practice are concerned, written entries are often descriptive and not as analytical as they could be (Fook et al., 2006) and diary keeping and journaling tend to be focussed on and limited to specific areas of life, such as specific events or happenings on the day (Thompson and Pascal, 2012). However, as part of the identity box, participants' views become broadened, widened and deepened. This is because they are trying to go into themselves, see themselves and think of how others see them. The view becomes a lot more holistic and the reflections deeper, often to the extent where the reflections became meta-reflections:

> I'll look over this [the questions for the identity box task] again and get back to you soon. I always keep a diary so I'll utilise it.
>
> Carmen

Through the identity box project participants considered the entirety of their experiences and reduced that entirety to its absolute essence in order to be able to find a representation of that experience in response to a question. In effect, participants applied phenomenology by going "to the things themselves" (Husserl, 2001/1901), although they may not necessarily have been used to or trained in reflective practice and phenomenological analysis. As a consequence, participants became more consciously aware of and in tune with their emotions and feelings. They were able to identify and work through them, which – as stated above – was experienced as unsettling, transformative and cathartic at the same time.

Despite the physical and emotional demands placed on the participants and the commitment required from them, the fifteen participants who completed the project highlighted how carrying out the identity box project gave them a sense of purpose. This sentiment of purpose through the project was particularly prominent amongst those participants who were on long-term sick-leave or no longer working at all. Participants who undertook the virtual alternative equally confirmed their positive experience through the reflective practice. It could be argued that it was not necessarily the identity box as a method, but the research itself that provided that context for the sense of purpose. Being house- and bed-bound with limited social relationships meant that participants felt they were burdens to their partners, families, friends and colleagues at work. Being part of the research was seen as a productive, though limited way of giving back to the wider community.

> I feel proud […] I feel like I'm fighting, like I'm potentially gonna help make someone's life better.
>
> Sally

Participants may initially have had altruistic reasons to be part of the research, but through the process they were able to engage in social contacts: directly with me and indirectly through the installation in the art gallery. The participants' sense of purpose developed further with the reflective practice of the objects, as they started to realise that they were more than their illness, and that they were still important links in the social structures of their immediate and extended families. In her identity box, Lisa represented that position of hers with the glue, as she binds the family and holds family members together. Through participating in the identity box project Lisa and others acquired different tools for reflection. As such, it was the work with the objects and the identity box that allowed for that insight and shift in perception.

Whilst participants saw the benefits in the work with the metaphorical representation through the objects, there was at the same time a certain level of uncertainty about it. Participants often checked back whether they were doing the right thing and whether their work would meet my requirements and expectations.

> Does it have to include regular dates? […] Or include just specific, important events?
>
> Cathy

> If I have misunderstood the assignment, please let me know.
>
> Lisa

> Well, that's the end of Dorothy's "My box" for this week. I'm hope [sic] it answers the right question(s).
>
> Dorothy

> I mean it kind of helps, if I kind of knew the answer you were seeking and then I'd know where I was pitching myself
>
> Bernie

This kind of checking back about doing or saying the right thing did not feature where data and meanings from interviews were concerned, for example. It is therefore conceivable that participants were more insecure and unsure of their work, as the creative approach was largely new to them. Most participants had not dealt with memory boxes or Joseph Cornell's shadowboxes before the identity box project for this research. They had been vaguely aware of activities involving time capsules or memories, but had not seen these at work for research purposes. Some participants truly grappled with the research approach using objects and representations as part of the data generation.

> Ok. I will try my best. My brain doesn't really work in an abstract way and reading all that [instructions for question 1], being completely honest, I do feel a bit concerned/stumped.
>
> Jill

Overall, some participants questioned this approach and wondered whether all of this actually was research after all. Not only, does this refer to the use of the identity box project for the data collection stage, this also relates to the subsequent stages of analysis and dissemination. The process described here tends to be seen as artistic expression and art, not research. If the analysis of the raw data, thus the artistic installation or outcome based on the identity boxes is art, then we need to ask ourselves the question of whose "piece" it is. On the one hand, the researcher has clearly created the analytical piece, but on the other hand, the participant has supplied the object(s) to make that possible, as the identity box itself is not merely data but artistic expression. Indeed, some of the objects presented and represented in the boxes are so personal, that participants can even be recognisable through their objects alone. In this sense, the installation based on the identity boxes is actually one way of ensuring that the objects are made accessible and disseminated in a way that they do not expose individuals, very much like interview data is commonly anonymised and pseudonymised.

Moral and ethical consequences of using arts-based methods

As I have outlined in chapter 3, having introduced the methods that resulted in non-linear and non-uniform data led to the concern of how to deal with such data, in particular as there were no specific analytical framework available that could be applied. In relation to the use of arts-based methods, there were other concerns, too. For example, if the data transcended traditional boundaries and therefore worked on a literary level, a musical level or an artistic level, was I supposed to engage with that data in the respective form and provide a literary, musical or artistic analysis and evaluation? Or could I consider that data as a piece of art and simply let it work its evocative function like I did with the creative analytical pieces in chapter 8?

Linked to this first concern, I also feel that we have to start asking questions relating to ownership. As the researcher of this project I am exploring the construction of academic identity under the influence of fibromyalgia. I formulated the research questions, and I developed the research approach and design using the creative, artistic forms of expression in this context. I own the research process, I own the research. However, the participants created their personal forms of communication and representations of their experiences. They did so in response to my questions, but it is after all their work, so they should effectively own the pieces. However, during the course of this project participants in a way relinquished their right to the ownership of their outputs. This is not because I am not willing to share their work and give them credit, where credit is due. This is because research participants may not necessarily have chosen to disclose their conditions and so, their representations need to remain anonymous. Interestingly, debates around this kind of ownership within research most often occurs when artistic outputs or works of arts are produced. Interview transcripts or survey responses are not considered in this same way, although they, too, are forms of expression and communication. There are researchers who offer participants the opportunity to go back over statements, which are intended for use in publications in order to identify whether the participants would be comfortable with that specific section being used. In a way, therefore, there is an implicit understanding that the participant owns that transcript. These forms of participatory decision-making are, however, rare, and in most social sciences research the power differential between participants and researchers characterises the relationships between the stakeholders. For me, the question of ownership is key to the relationship I have built with the participants. I am under no illusion that I have been able to fully tear down the power differential between me, as the researcher, and my research participants. However, having assumed the role of the data traveller (Brinkman and Kvale, 2015), having collaborated on the representations and having engaged jointly in the meaning-making processes, I do feel that I am more than the objective researcher in that relationship. I consider the participants' original creations as their work, but I am taking the liberty to use their work, recreate, modify and mould it to become a representation of the bigger picture. After all, I have been entrusted with personal stories and narratives and I feel obliged to act on those. This is where the analytical process described in chapter 3 is particularly relevant.

A third concern is linked to and comes out of considerations around ownership, and it relates to anonymity and recognisability. As described above, participants own their pieces of art and artistic outputs, just as they own the transcript. With transcripts, we routinely anonymise and pseudonymise participants and ensure that they are not recognisable from their personal names and stories. Where the pieces of arts are concerned the question of ownership and crediting the creator may hinder that process. Participants' contributions may be so personal that they can be recognised from the backgrounds and surroundings in photographs, or the objects they use are so personal that others could potentially identify individuals from those objects. At the same time, however, the contributions are so personal that the participants may feel proud of them and may want to have their work publicly recognised as theirs. Negotiating creativity in this sense is a balancing act of offering details, opening up deeper information and experiences whilst at the same time protecting individuals' identities and emotions.

Finally, and probably most crucially, there is a concern around the relevance and impact of creative methods of expression. Scholars recognise limitations of existing research methods and methodologies and therefore call for more embodied and sensory approaches to research. Readily applied methods include arts-based methods (Bagnoli, 2009), artistic workshops (Tarr et al., 2018a; Tarr et al., 2018b), visual materials (Mason and Davies, 2009), photo-elicitation (Orr and Phoenix, 2015) and metaphors (Nind and Vinha, 2016) combined with interviews and narrative approaches. These methods are often not applied consciously and confidently, but have been used tentatively in the hope of fruitful outcomes in the form of different, more interesting, richer data (see reports of Guell and Ogilvie, 2015; Nind and Vinha, 2016). It is this richness of data that researchers readily comment on, when they consider creative or arts-based methods. As demonstrated with the pilot study with non-academics (see chapter 4), creative or arts-based research seeks to overcome the three challenges of language being limited, of human understanding being fundamentally embodied and, to compensate for the former challenges, of human communication relying on metaphors. As such, employing arts-based approaches does indeed allow for forms of communication that differ from the linear, textual focus that interview data represents. The creative methods in use in this research helped research participants reflect through narrowing down their experiences to an essence and then subsequently in the conversations elaborate to explore the details of these experiences (Brown, 2019b; Brown et al., 2018a; Petsilas et al., 2019, Panjwani and Brown, 2019). These embodied, material representations of experiences resulted in deeper reflections than the surface reflections commonly observed in the reflective practices of diaries and logs (Fook et al., 2006). Within the current research methodology discourse we therefore consider this kind of data as "richer" and "deeper", although we do not have any means of truly making this judgment. In reality, the data is different; it is not better, deeper, richer; it is different because it draws on the arts, which function by being evocative and provocative, thus by creating emotional responses. To illustrate this point, I would like to return to what was presented in chapter 6 in the context of what fibromyalgia feels like. Amy likened fibromyalgia to a scratchy, horrible cactus, to which we would not want to go near because of the needles and spikes sticking out:

> A cactus.
> In terms of it being really scratchy and horrible, and not wanting to go near it, all those little things sticking out. That's what made me think of it. And because of sensations, to feel like a cactus scratching you, and that's I guess what made me think of it.
>
> Amy

As readers of this excerpt, we can make sense of Amy's experience, cerebrally process what she is trying to tell us and so, we can cognitively understand. If, however, this excerpt is presented together with an image, our perception and understanding is altered drastically. The choice of representation and the kind of cactus we use is deeply relevant:

It is probably easier to identify with the negative, prickly sensation Amy describes, when we look at the first of the three images, as the other two images demonstrate an element of beauty that is not described in Amy's statement. We are physically and emotionally responding to the image. Is the data richer or deeper? Or are the visuals merely tapping into our own memories evoking experiences of when we once touched a cactus and felt the sharp spikes getting caught in the skin of our fingers? The visual representation involves us emotionally effecting bodily and embodied responses. This non-linearity is obviously not easy to capture in traditionally conventional forms of representation, such as this thesis or publications like journal articles and books. Cerebrally, emotionally and academically, scholars agree on the use of the creative and arts-based forms, but in practical terms, our research outputs are largely gauged and driven by publishers' demands and our need to produce internationally recognised academic artefacts that can be entered to assessment exercises like the UK's research excellent framework. This pressure from external forces leads to creative methods of expression being recognised and accepted only within the context of data collection to "deepen" the interview data, to elicit experiences, to encourage memories and thoughts and thus to promote or stimulate conversations in social science research.

Concluding thoughts

Over the last two decades qualitative research has seen a surge of interest in innovative and creative methods, which it is argued has been due to a variety of factors such as changes in the research funding systems, the necessity of proving innovation within PhD theses, as well as researchers' personal concerns relating to ethical issues and to representations of truths (Carrington et al., 2016; Taylor and Coffey, 2009; Travers, 2009; Wiles et al., 2013). Individual research articles report of experimental approaches to data collection and highlight the beneficial outcomes of creative methods, such as the use of stimulus materials, metaphors and photo-elicitation (Bagnoli, 2009; Bartlett, 2015; Mason and Davies, 2009; Nind and Vinha, 2016; Orr and Phoenix, 2015). Latest editions of research methods textbooks include or even focus entirely on how to use visual or audio-visual materials within qualitative research (Margolis and Pauwels, 2011; Rose, 2016). However, the experimentation with new data collection methods should not be driven by the need for innovation and creativity as specified in criteria, but to genuinely gather the right data needed for specific contexts.

If the task of social science research is to provide deep understanding of the link between the personal, the historical and the social and to then use this understanding to meaningfully engage the scholarly communities and the wider public in forms of activism, then we need to look to appropriate forms of dissemination. Academic, textual representations of experiences in the forms of journal articles and book publications are certainly relevant in creating a scholarly debate around research projects, their processes, their significance, their feasibility, their quality and validity. However, to encourage public debates, to raise awareness, to support lobbying and foster activism, dissemination needs to emotionally engage audiences. By drawing on the arts, it is possible to tell stories more powerfully and to naturally connect the personal to the historical and social as well as in reverse, the historical and social to the persona. Additionally, the non-linear, multimodal forms of expression that the arts offer allow us to account for our embodied and sensory experiences.

The concern within this research project was to determine whether there is a place for this kind of embodied, creative, arts-based research within the interdisciplinary, liminal space of higher education and sociology. As with all research approaches and designs there are benefits and drawbacks on methodological and ethical levels that need to be taken into consideration. The use of the identity boxes was advantageous in particular with non-academic participants who were not used to critical reflective practices in the same way that academic participants were. Both, academic and non-academic participants experienced the creative process as liberating and therapeutic, but also as worrisome and effortful. And all participants felt that the creative outputs were particularly meaningful in making others understand what life with fibromyalgia is like. Ultimately, I argue that the most influential factor for the success of the research was the openness and flexibility I offered. Participants were keen to tell their stories and have their voices heard, but were not necessarily able to communicate in specific forms. There were those who did not want to hold face-to-face conversations and there were others for whom the identity boxes project was too difficult, but all participants embraced being able to draw on their preferred forms of expression to share their experiences.

10. Conclusion

In this final chapter of my thesis I bring together the key findings and core elements of this research. I do so by providing a brief summary of core debates and key ideas from the findings chapters, which I link back to the overarching research questions. In the subsequent section I reflect on the research with its current significance and provide a brief look ahead to other related work arising from this doctoral research.

Revisiting the research questions and thesis argument

The main argument of this thesis is that disciplinary compartmentalisation and methodological approaches limit understanding of fibromyalgia; that combining sociological thought with educational research approaches strengthens existing fibromyalgia research; and that interdisciplinary approaches allow for new insights to add to our understanding of fibromyalgia. Against this backdrop, I formulated four interconnected aims for this research: (1) to provide insights into how academics make sense of being diagnosed with fibromyalgia; (2) therefore, to provide insights into academia as a workplace; (3) to explore how this particular workplace may foster or potentially cause distress that becomes physically manifested in a disabling condition; and (4) to develop more embodied and sensory approaches to generating, recording and disseminating data. To achieve these aims, I formulated the following research questions:

(a) What is the relationship between fibromyalgia and academic identity?
    What is the role of academia for an academic?
    What does fibromyalgia mean for an academic?
    How is fibromyalgia experienced in academia?
(b) Can creative methods help explore changeable phenomena?

At this point, I consider if and in how far the research questions were answered and to demonstrate that the thesis argument was addressed I revisit the analysis chapters. The first step to answering the first research question is to understand what academic identity is (see chapter 5). Identity as a concept in itself is difficult to grasp and so academic identity is also difficult to define, as it is characterised by its fluidity and lack of clear boundaries. As such, an academic can be someone who works in academia, or someone who holds specific roles, particularly in relation to research work. Due to the changes within the higher education sector roles and positions become less permanent, which leads to temporary contracts or role-specific contracts for many of those working in academia. Where once the typical academic was someone on an open-ended research or teaching and research contract, employments in academia nowadays are often teaching only or research associate contracts for limited periods of time. For the participants in this study, academic identity represents the internalisation of values and norms around scholarship, learning and knowledge. There is a fine line between being an academic and having assumed an academic identity, as the one relates to internal and personal experiences and values, whereas the other refers to the external, public and public-facing. This discrepancy causes tensions and emotional dissonance. Participants themselves recognise a link between the work they undertake in academia of today and fibromyalgia.

The context of the neoliberal university exacerbates the condition (see chapter 7, but also chapters 5 and 6). The problematic consequence of the neoliberal university is that competition for individual students fosters the focus on league tables, which in turn determines employment contracts. As universities need to be seen to succeed in both the teaching excellence and the research excellence frameworks, there is a clearer strategic focus on developing staffing structures to reflect these specialist areas of academic work. The participants' narratives provide evidence for current restructuring measures to separate teaching and research roles. Within the context of collaborations between newer and traditional universities and further education institutions, this split is most pronounced. Institutions that held further education status and that do not have awarding powers, are now taking full ownership of the teaching for the higher education institutions, which focus more heavily on research. In this competitive context of today's higher education sector, separate professional and service roles, teaching fellow routes and pure research staff are more common than ever before. Fibromyalgia in its psychosomatic and sociomatic qualities is a physical, embodied manifestation of the tensions academics experience. With the increased stresses and pressures in neoliberal academia fibromyalgia symptoms are therefore more prominent and prevalent.

However, the relationship between fibromyalgia and academic identity is more complex, still, if individuals' personality and character traits are considered (see chapter 5). Being an academic and thus identifying as having an academic identity requires a specific mindset, one that is linked to being a high-achiever and perfectionist. Research provides evidence for a link between action-prone, over-active behaviours (Van Houdenhove et al., 2001) and fibromyalgia, and perfectionist tendencies and health concerns, more generally (Flett and Hewitt, 2002; Frost and

DiBartolo, 2002; Sirois and Molnar, 2016). The connection between academic identity and fibromyalgia can therefore not be denied. In Parsons' (1991/1951) terms, the traits that identify a specific personality are in fact internalised values and norms. In this sense, academics have internalised values and norms that create tensions and emotional pain, which in turn erupts and manifests itself in the illness experience fibromyalgia.

As chapter 6 shows, academics experience fibromyalgia as a very real and disabling condition, although they do recognise that fibromyalgia cannot entirely be explained physiologically, and so they seek to make sense of the condition on a scholarly as well as personally, felt level. In truth, the academics' engagement with fibromyalgia and their attempt to make sense of their illness manifest themselves as narratives of resistance in four forms: (1) the incorporation of cultural expectations and social conventions into personal life stories, (2) the re-making the lifeworld at a cerebral level through redefining reality and creating a new, socially acceptable reality, (3) active rejection of the fibromyalgia diagnosis and (4) active and pro-active countermeasures to assuming the sick role. These narratives of resistance highlight the tensions participants experience when it comes to reconciling academic identity and fibromyalgia. In their everyday lives as academics, participants continually negotiate their roles as academics and as individuals diagnosed with fibromyalgia.

Through managing their bodies to deal with fibromyalgia symptoms (see chapter 7), academics also undertake active bodywork to create a coherent version of self (Goffman, 1990/1959) for the public. Bodywork in this context is conceptualised as (a) the management of the fibromyalgia body, the deviant body, thus the management strategies employed in order to be able to fulfil the role as an academic and embody academic identity; (b) the management of the academic body as a public and private identity; and (c) the individual's work on and with the fibromyalgia body to make sense of one's self, whereby this final aspect incorporates physical, material bodily interventions as well as emotional labour involved in this process. Ultimately, the negotiation of managing the deviant body and reconciling that with academic identity is an ongoing process.

As stated in chapter 3 I consider myself firmly anchored within the interpretivist tradition of social science research. I therefore explore and study causal relationships according to Miles and Huberman's definition of "local causality" (1984:132), or what Shadish et al. (2002) refer to as "causal description" rather than "causal explanation"

(9ff.). I appreciate that a "realist, process-oriented" (Maxwell, 2004a:8,b, 2012) model of causality that accounts for the "interpretive nature of our understanding" (8) as well as the "explanatory importance of the context" (9) studied would potentially have made the generalisations and causal relationships more explicit in many ways. However, the focus of my research had been the close study of a particular context, which did not necessarily lend itself to an experimental or quasi-experimental design for such generalized causal inferences.

Throughout my study with academics as is reflected in this thesis I sought to explore the relationship between fibromyalgia symptoms and the context of higher education. During the study participants explicitly and implicitly in the conversations and through their additional materials, like the timelines, the CVs, their identity boxes and other photographs emphasised how at particularly stressful or important times in their careers or work life, the symptoms of fibromyalgia flared up. Through rationalising and interpreting their experiences, individuals have highlighted the role the somatic and psychological play in fibromyalgia, for example, when they refer to the deterioration of symptoms at particular life-or career stages (eg. p.156ff.). Indeed, the impact of somatic and psychological issues on an individual's experience of their body and bodily symptoms is long-documented (Wahler, 1968; Pennebaker and Skelton, 1978; Mayou, 1991). In their work relating to work stress, Wainwright and Calnan (2002) identify four potential models for explaining what they term the modern epidemic of work stress: (1) the realist perspective, (2) the claims-making perspective, (3) the social constructionist perspective and (4) the embodiment perspective (122f.). The four models "are by no means mutually exclusive" (Wainwright and Calnan, 2002:123), so that the realist model of objectively observable rises in reports relating to work stress-related symptoms may function alongside an individual's tendency to incorporate and internalise social and cultural factors and discourses to such an extent that they experience work stress-related symptoms as a consequence. In Wainwright and Calnan's terms (2002) work stress and connected ill health are therefore the employees' resistance against their employers. In the study on hand, participants expressed dismay and frustration regarding working conditions and employment status and as such the causal relationship could indeed be considered a resistance narrative against the higher education sector.

However, the data in this study also highlighted that participants inextricably linked academic identity and their selves and that they continued to focus on academic work and achievements. These factors strongly reflect the characteristics of workaholics, who are prone to external referenting, unable to relax, self-centred, isolated and perfectionist (Fassel, 2000:27-38). These character traits, in turn, are also recognised in individuals diagnosed with fibromyalgia (Van Houdenhove et al., 2001). It therefore stands to reason that academics may be workaholics and fibromyalgia a coping mechanism for the internalised values.

In summary, the relationship between fibromyalgia and academic identity is complex and fraught with emotion and meaning, such as experiences of inadequacy, failure, weakness and vulnerability. The three mechanisms of mutual influence between fibromyalgia and higher education are (i) the working conditions of academia with extensive workloads, pressures to be productive under precarious contracts resulting in individuals pushing themselves to their physical breaking points, (ii) fibromyalgia as a physical manifestation of the tensions caused by the individuals' academic identity, which means individuals must reconcile internalised external values and pressures with personal values and expectations, and (iii) the individuals' strong affiliation with the academy, which results in their active resistance against the sick role, which in turn results in fibromyalgia symptoms flaring up more strongly.

Chapters 5 to 8 demonstrate how academics make sense of their experiences, and how their view of fibromyalgia is shaped by a multitude of factors: from their personal stage of having come to terms with the condition through to the impact their condition and the label of fibromyalgia have on their academic career. The direct comparison between non-academics and academics shows that academics are more likely to hold on to their academic identity, even to the detriment of social relationships. From the academics' points of view, they are more or less successful as academics in spite of fibromyalgia and manage their academic life around the condition. The non-academic participants by contrast were more likely to have been without employment, but were able to draw out some personal benefits from having been diagnosed with fibromyalgia, such as for example, higher levels of empathy and understanding. In this sense, I consider research question (a) "What is the relationship between fibromyalgia and academic identity?" answered.

As was explored in the earlier chapters of this thesis, the difficulty with researching fibromyalgia certainly was the changeability of the illness and trying to capture all variations holistically. My focus on developing appropriate research methods was therefore key to unlocking the entire doctoral research. What then is the answer to the second research question "Can creative methods help explore changeable phenomena?" During the entire research process, I experimented with embodied and sensory means to collecting information, generating and analysing data. The fictionalised narratives in chapter 8 and the critical evaluation of creative methods in chapter 9 are evidence for my deep engagement with the methods throughout the research process. Chapter 9 demonstrates that the openness towards participants' preferences and preferred communicative media was particularly conducive. The use of metaphors and materials alongside the many forms of expressions has undoubtedly provided insight into the fibromyalgia experience in ways that other research to date has missed. One example of that is the experience of the permanence of fibromyalgia (see chapter 6) despite the fact that there are times where the illness is less intrusive or individuals may consider themselves as in remission.

Significance of this doctoral research

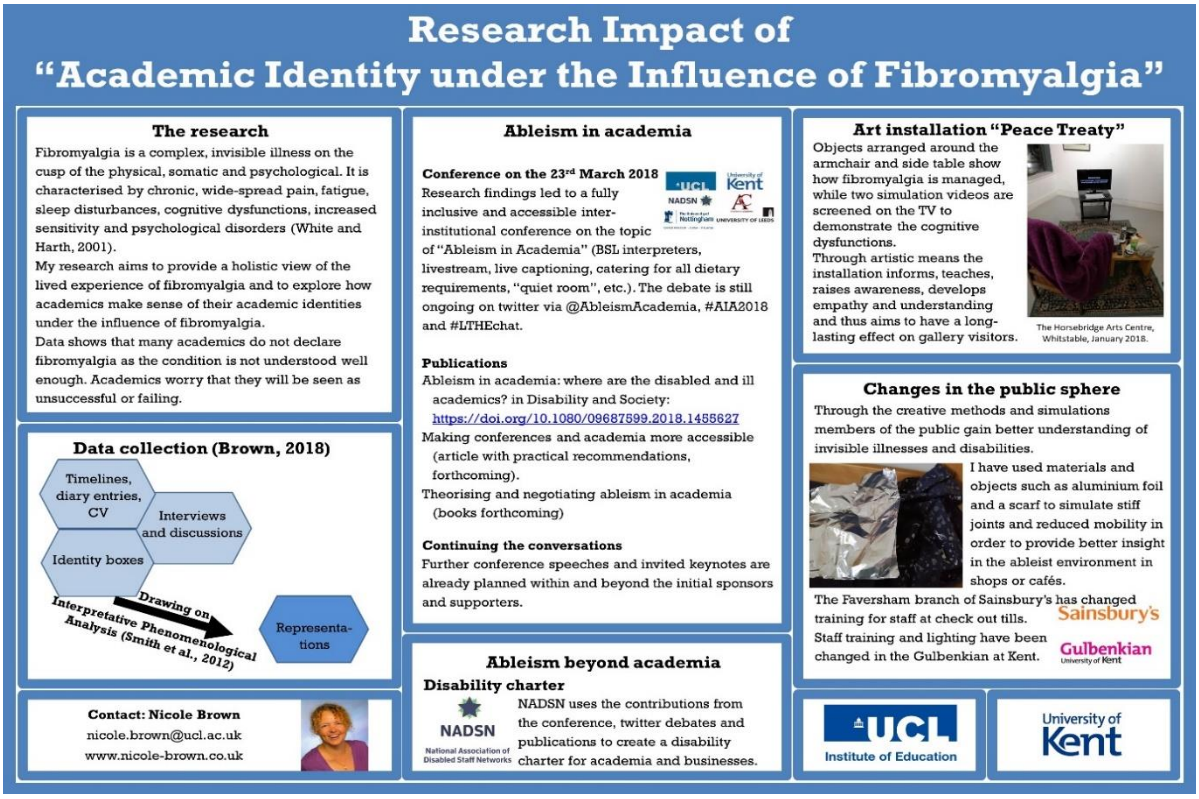
The conclusions in chapters 5 to 8 and the above brief summary show that I have shed light on the lived experience of academics with fibromyalgia and how academics may sense of and reconcile their illness experience with the demands of their work. I have also embedded their personal experiences in the wider consideration of the historical and the social, by drawing on sociological concepts of identity work, bodywork, stigma and disclosure and the presentation of self, in particular. At the same time, my participants and I have experimented with forms, functions and meanings to analyse the matters on hand more deeply. As such, I have answered the questions about the relationship between fibromyalgia and academic identity and the use of methods. But what are the practical outcomes, value and originality of this doctoral research?

In chapter 1 I describe my original contribution to knowledge as follows: this research explores fibromyalgia within the very specific context of today's changing higher education context; I introduce the identity boxes as a new data collection method; and drawing on the interdisciplinary cross-fertilisation between sociological and educational research, I apply or reconceptualise existing frameworks. The significance and originality of my research are best exemplified and evidenced in my publications and conference presentations. At the time of writing, I have published 11 articles and chapters for edited collections as first or sole author that directly relate to my doctoral research. My sole-authored article "Identity boxes: using materials and metaphors to elicit experiences" that was published in the *International Journal of Social Research Methodology* (Brown, 2019a) was awarded joint first prize in the early career researcher essay competition for 2018. In addition, due to my expertise in creative methods I was asked to contribute to further collaborative research projects exploring teaching practices. Two articles of such projects have already been published, with a further five articles either forthcoming or under resubmission.

The excerpts of the participants' reflections highlight how important it was for these academics to be heard and to be offered the opportunity to share their experiences. In terms of practical outcomes therefore the academics were largely asking for more tolerance and acceptance within a less ableist environment, thus an attitudinal shift within the sector in favour of diversity. The tangible outcomes and recommendations from this thesis are best summarised in the policy guideline (see Appendix F) I have compiled. I believe in leading by example, and so I have already shared this document in several institutions as well as across the sector in research organisations.

My engagement with participants' understanding of the traditional and typical academic led to me leading and holding a fully accessible conference on ableism in academia. This resulted in publications (Brown et al., 2018b, Brown and Ramlackhan, forthcoming) but also in two edited book collections that are currently in the process of being finalised for publication. The edited book "Ableism in academia" is under contract with UCL Press. This book aims to provide insight into the wide range of issues and concerns of those that may not fit the expected norms of the stereotypical academic. More specifically, the aim is to provide an open engagement with ableism issues that are not confined by and restricted to disciplinary conventions. Through engagement with scholarly debates and theorisations of the body, embodiment, and emotion and identity work and drawing on theories from sociology, disability studies, education studies and the like, this book foregrounds theory and conceptualisations of experiences of ableism in academia. The second edited book "Lived experiences of ableism in academia: strategies for inclusion in higher education" is under contract with Policy Press/Bristol University Press. This book explores ableism and what ableism means within the context of universities. Deeply embedded in personal experiences, this book provides practical examples for universities to develop inclusive practices and a less ableist environment for staff and students. The book aims to provide an insight into the lives and works of non-stereotypical academics, and to offer practical ideas and strategies for implementation in order to improve working conditions and learning environments for staff and students within academia. To this end, each chapter provides a personal and scholarly engagement with the topic of ableism in academia and then concludes with a series of reflective questions and practical recommendations for individuals and institutions.

My work on ableism in academia, my work on developing and using identity boxes as a data generation process and my approach to employing creative, arts-based methods as an analytical process have already gained traction within the academic community and have resulted in invitations to conferences, to be guest panellist and specialist teacher. To date, I have been an invited presenter or workshop leader on approximately 30 occasions, but I have also presented on another 50 occasions. In 2018, I took part in a research impact poster competition, in which my poster (see Figure 10.1) on the research impact of my doctoral research was awarded the runner-up prize:



Research Impact of
"Academic Identity under the Influence of Fibromyalgia"

The research

Fibromyalgia is a complex, invisible illness on the cusp of the physical, somatic and psychological. It is characterised by chronic, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, increased sensitivity and psychological disorders (White and Harth, 2001).

My research aims to provide a holistic view of the lived experience of fibromyalgia and to explore how academics make sense of their academic identities under the influence of fibromyalgia.

Data shows that many academics do not declare fibromyalgia as the condition is not understood well enough. Academics worry that they will be seen as unsuccessful or failing.

Data collection (Brown, 2018)

Contact: Nicole Brown
nicole.brown@ucl.ac.uk
www.nicole-brown.co.uk

Ableism in academia

Conference on the 23rd March 2018
Research findings led to a fully inclusive and accessible inter-institutional conference on the topic of "Ableism in Academia" (BSL interpreters, livestream, live captioning, catering for all dietary requirements, "quiet room", etc.). The debate is still ongoing on twitter via @AbleismAcademia, #AIA2018 and #LTHEchat.

Publications
Ableism in academia: where are the disabled and ill academics? in Disability and Society: https://doi.org/10.1080/09687599.2018.1455627
Making conferences and academia more accessible (article with practical recommendations, forthcoming).
Theorising and negotiating ableism in academia (books forthcoming)

Continuing the conversations
Further conference speeches and invited keynotes are already planned within and beyond the initial sponsors and supporters.

Ableism beyond academia

Disability charter
NADSN uses the contributions from the conference, twitter debates and publications to create a disability charter for academia and businesses.

Art installation "Peace Treaty"

Objects arranged around the armchair and side table show how fibromyalgia is managed, while two simulation videos are screened on the TV to demonstrate the cognitive dysfunctions.
Through artistic means the installation informs, teaches, raises awareness, develops empathy and understanding and thus aims to have a long-lasting effect on gallery visitors.

The Horsebridge Arts Centre, Whitstable, January 2018.

Changes in the public sphere

Through the creative methods and simulations members of the public gain better understanding of invisible illnesses and disabilities.
I have used materials and objects such as aluminium foil and a scarf to simulate stiff joints and reduced mobility in order to provide better insight in the ableist environment in shops or cafés.
The Faversham branch of Sainsbury's has changed training for staff at check out tills.
Staff training and lighting have been changed in the Gulbenkian at Kent.

Figure 10.1: Research poster

In the meantime, the outcomes of this research in relation to accessibility issues and modes of communication is also impacting change within teaching and assessment. Within the scope of the validation for an existing module, I have successfully introduced an assessment approach that allows students to use a variety of modes to communicate their arguments in addition to and combination with their critical essays. For the academic year 2019/20, I have been able to validate a new module that will make the course content entirely accessible via livestream and live-captions, and that will allow students to choose from different forms of assessments in order to play to their strengths in relation to forms of communication.

Finally, I am further developing the concept of the identity box for identity work and pain management most specifically in relation to medically unexplained symptoms. This study has shown that some individuals experience catharsis when they realise that, despite all their fibromyalgia symptoms, they are still the same person underneath the wall of pain. I have presented the idea to medical professionals in several hospital trusts and I am working with them to identify a way to roll out that object work.

Critical evaluation of the research

Despite the many positive developments resulting from the strengths of this doctoral thesis, I am fully aware of its limitations and weaknesses. I would like to take this opportunity to critically reflect on and evaluate my doctoral research and outline my main concerns.

The first concern I would like to raise relates to the research question in relation to the creative methods: "Can creative methods help explore changeable phenomena?". It was a key aim for me to explore methods and experiment with modes of communication, as I had considered interviews, questionnaires and pain surveys as too limiting when it comes to expressing pain, brain fog and other experiences. My focus on the methods was merely my response to observations that within fibromyalgia support groups the postings that communicated experiences best and initiated most conversations were the ones that used memes and metaphors. This thesis has shown that the use of metaphors and representations in the identity boxes was fruitful, in that a richness of data emerged that allowed for other conclusions than those drawn in existing fibromyalgia research. However, the overall effectiveness of the creative methods is difficult to evaluate. There is no way of knowing if relying solely on interviews would have brought a similar richness in data and potentially resulted in divergent insights. The mode of communication through metaphors means that participants engaged in reflections in a specific way, but there may possibly have been room for different kinds of reflections and reflective practices. I do not doubt the value the creative methods have brought to the research and our understanding of fibromyalgia. Where I am seeing a weakness in this thesis is how I set up and attempted to answer the research question "Can creative methods help explore changeable phenomena?". In the interdisciplinary spirit of this thesis my answer at this point would be "yes, but other approaches could also add value".

Secondly, I consider the strength of this thesis, its focus on marrying educational research with sociological thought, as a limitation at the same time. Drawing on practice-based enquiries in getting close to participants' experiences and the matter on hand allowed me to understand in great detail particular circumstances and contextual factors impacting experiences of fibromyalgia. Applying sociological theories to the findings and analysing the data through these specific sociological lenses has allowed me to theorise the concrete experiences. My concern in this regard is not unique to my thesis, but to all of my research work, and indeed colleagues' work, too: how do we truly justify our particular choice of concepts, frameworks and theories? As I stated in chapter 3, data analysis is a process of handling or manipulating data that requires criticality, reflexivity and transparency. In a similar vein, we need to be transparent, critical and reflexive about the theories and frameworks we apply in our analyses. For the thesis on hand, I drew on Ware's social course of chronic illness (1999), Goffman's presentation of self (1990/1959) and stigma (1990/1963), for example. I did so, because at the time of data analysis I had felt that these were the biggest and most important themes needing to be discussed. Looking back over my thesis chapters, I do wonder if an analysis from a viewpoint of suffering or of sociology of work would have been equally if not more interesting and fruitful. This is not to say that I could not still do that. This just highlights that the end of the thesis is only the beginning of further developments and understandings. In my eyes, the weakness or limitation here, is not so much a weakness or limitation of the thesis itself as it is a limitation of my own knowledge. Had I better understood and known more about sociological conceptualisations and theories at the time of analysing my data, the analysis chapters could look different now. As a practice-based educationalist working across the disciplinary divide of education and sociology meant that sociology was always a relative weakness of mine. If I was to undertake an interdisciplinary project again, I would enlist the help of knowledgeable experts in the respective fields (see agenda for future work).

Thirdly, I would like to reflect back on the content of the choice of words throughout. I realise that sometimes my interpretations may come across as too strongly worded, especially where I apparently strongly disagree with the statements of my participants; such is the power of language, after all, that connotations and associations may distort messages. For example, in chapter 6, where I discuss academics' sense-making and understanding of fibromyalgia, I highlight that their apparent scholarly engagement is in fact pseudo-scientific (p.133). and they are bound by their biomedical view of fibromyalgia (p.131). Although I did not state that explicitly in my thesis, I made these claims on the basis of the conversations around readings. Within the conversations most participants emphasised the kinds of readings they have undertaken or engage in regularly in order to get better understanding of the condition. However, upon delving deeper into the kinds of literature and publications used for these purposes, it transpired that the same participants used information related to or taken from NHS and Mayo clinic web sites, or introductory guidebooks for fibromyalgia patients on how to "overcome" the condition. Despite their academic backgrounds, the academic participants did not seek out literature that would consider character traits, socio-economic status, education-levels in conjunction with fibromyalgia. The fact that they particularly sought out literature providing information on the management and indeed overcoming of the condition, demonstrated that they were caught up in the biomedical approach.

Finally, I would like to comment on sampling and sample size. As I stated in chapter 3 sampling and sample size are often discussed in terms of small samples not allowing for generalizable results (Vasileiou et al., 2018). On the other hand, there are research approaches like practice-based enquiries in education or interpretative phenomenological analysis within psychology that specifically aim for small samples in order to gain deep insights into the particularities of cases. Working across disciplinary boundaries meant that I needed to navigate existing conventions, and in sociological publications, sample size tends to be a number between 25 and 40. I therefore sought to recruit a solid number of participants. Given that fibromyalgia is poorly understood, not diagnosed for long periods of time, and then often not disclosed, especially within academia, I was happy that individuals wishing to participate in my research found me and I accepted everyone into the study. In all honesty, to me it felt like a rather large sample size, and I was concerned that allowing for breadth and width, I would lose depth and detail. In my critical reading of this thesis, I can see that indeed a slightly different approach would have prevented that loss of depth and detail. From the entire group of academics participating in my research, I should have identified homogenous groups of 5 to 8 participants, and undertaken an IPA-like analysis to delve into more details about the specificity of the groups, like I did with the non-academic participants (see chapter 4). I did focus my analysis on differences between early-, mid- and late-career academics, for example. Where I see a problem is that there will be quite a difference between the experiences of an early-career academic aged 25 whose first position is in academia and the early-career academic aged 43 whose academic career is already a second or even third career. Life experiences in employment, family commitments and years lived would all contribute to different outlooks; and it is this particularity that my thesis does not really account for.

Probably the biggest limitation of my research is that methods accounted for emotions and personal perceptions but do not provide a second angle to validate these emotions, perceptions and feelings. When individuals talked about managing their bodies in the workplace, for example, I relied completely on their descriptions.

At one point during the research, I had contemplated drawing on ethnography and including participant observations as a data collection method. However, I did not feel I could go through with that approach for two main reasons: practicalities and ethical concerns. On the one hand, the logistics of travelling to the workplaces would have been difficult for me due to the far distances I would have needed to cover from the Southeast England through to North of England and even Scotland. In addition to the distances, many participants took time off for sickness and even had extended absences, so that the observations would logistically have been difficult to arrange. Additionally, I had ethical concerns. Firstly, as I explored chapter 3, many individuals were happy to rearrange interviews because they did not feel that they impacted my schedules too much. Had there been observations scheduled, I would have unintentionally added pressure on the individuals to push through difficult times. Secondly, most of the research participants had not disclosed their conditions at work and were happy to contribute to the research from the safety of their homes. I am not sure that they would have been equally positive about me shadowing them in their workplaces. Having said that, I do think that observing engagements and interactions would have added a particularly interesting layer to how academic individuals make sense of and negotiate their lives with fibromyalgia.

Reflection on the doctoral journey

Having considered the weaknesses and limitations of this research quite naturally leads to me reflecting on my doctoral journey, and what I have learnt throughout this process. In relation to the research process itself, it is difficult to identify one single item of learning or one single take-away point. After all, this was a process that started in 2015 and although this thesis may imply that the process was straight forward and smooth, this was certainly not the case. There were many bumps and obstacles that had to be negotiated along the way. I had had enough experience with research projects to know that changes and modifications would occur and that there would be delays for a range of reasons. My master's level research project was even doomed to fail because the participating school had pulled out and I could not find another school that would allow me access to their pupils. I was therefore quite well prepared for adjusting the identity box project or organising interviews. However, I had not been entirely prepared for the impact on me when research participants got in touch to reschedule interviews because they had experienced a flare-up. It was already difficult to balance doctoral research with work matters alongside family commitments. Being asked to reschedule interviews often had a serious impact on my weekly timetable and at times on my own personal wellbeing and health. I also experienced flare-ups throughout the research process, but felt that I needed to push through as much as I could, as I did not want to reschedule interviews "unnecessarily".

On an academic level, my learning curve has been steep. I have gained better understanding about the difficulties of interdisciplinarity, even though education and sociology do not seem to be that far apart. Throughout the doctoral research I found it difficult to connect the practitioner educational research with theories of sociology, often feeling that my knowledge as a teacher practitioner was and needed to be second to the sociological theories. Engaging with a good range of sociological theories has opened my eyes further and paradoxically, has also helped me gain confidence in my practitioner knowledge. Although I was working in academia as teacher educator, I had started out this doctoral journey as a teacher at heart. It was through the doctoral journey that I truly recognised the relevance and validity of my previous experience and classroom-based knowledge. This unlocking of understanding, in turn, has helped me establish myself firmly as an academic. As such, the doctoral journey has enabled and completed my transition from teacher to academic.

Agenda for further work

At the time of writing, I currently have four articles under review, one of which is with *Work, Employment and Society* based on chapter 7 of this thesis. I am in the process of reworking chapter 6 to submit to *Sociology in Health and Illness* and chapter 8 for *Qualitative Inquiry*. With research projects there usually are some answers and even more questions at the end. This project is no different. The statements and theorisation raise concerns that need to be the focus of further work. Also, having critically reflected on the strengths and weaknesses of this thesis, ideas for further projects develop from that.

In view of the conceptualisation of bodywork and in order to counteract the missing observations, I am interested in exploring the role of the body in academia as a location for knowledge production and transfer, as the embodiment of social conventions and understanding of academia and academic work, and finally as a mirror of the academic environment, thus how the body is inscribed with or a physical manifestation of the material academic space. I intend to pursue this avenue through another research involving a rhythmanalysis of university buildings and walking interviews with academics to explore the interrelation between buildings and bodies. I have already sought and gained full ethical approval to carry out the rhythmanalysis and walking interviews. The proposal for this particular project has also been awarded funding through the SRHE Prize for Newer Researchers (Society for Research into Higher Education). The outcomes of this project will provide new insights but will also allow me to paint a fuller picture of what it means to be disabled, chronically ill or neurodiverse in contemporary academia.

Similarly, I recognise my limitations in relation to quantitative research although I can see the benefits that quantitative research could have brought to my thesis. I am currently developing a proposal with a colleague from psychology to research perfectionism in academia. We are interested in finding out whether in comparison to members of the general public academics are more, less or equally likely to be perfectionists and whether the perfectionist tendencies observed in this study are innate or nurtured through academic work.

In relation to the development of research methods, I am currently co-authoring a book on "embodied inquiry" whilst developing a proposal for a textbook on how to keep and maintain a research journal. Many doctoral guidebooks and research methods textbooks highlight the necessity of keeping a research log and recording observations and reflections systematically. However, there is a need for more guidance on the practicalities of keeping a log, which decisions need to be taken, what needs to be recorded and how. In the shorter term, I intend to develop a publication with two colleagues that focuses on the challenges and indeed the failures of creative research methods. Within educational research there is a clear reporting bias in that successes are celebrated whilst failures are not reported at all (Dawson and Dawson, 2018). Within research methods literature, failures are either masked as challenges that need to be overcome or not reported on at all. This is particularly interesting to observe as within the practice-based enquiries and in the classroom practice, we generally acknowledge that failures provide great opportunities for learning and indeed that no learning occurs without having failed in some way first.

Finally, I feel I need to honour my participants' narratives. Throughout the process, I have been entrusted with 28 individuals' experiences and I feel compelled to act upon those. The narratives and interpretations in this thesis are only part of the story. In reality, many more established and lapsed academics, early career researchers and postgraduate students with and without fibromyalgia had reached out to me. They had felt that their stories needed to be told, but at the same time they worried about the repercussions of being publicly known to have told their stories. Some may have had personal issues around shame that they did not have what it took to be in academia or, on the contrary, to break out of the academic circle. And then there were "the untold stories", some of which I incorporated into chapter 8. These were narratives of public humiliation and embarrassment, stories of open and covert discrimination and bullying, where individuals were regularly set targets that were unfeasible for someone with a chronic illness and where no adjustments or allowances were made, and descriptions of grievance procedures and tribunal processes resulting in unfair dismissals with subsequent compensation payments, gagging orders or other forms of non-disclosure agreements. Whilst I cannot publicly tell these stories, or use them in publications, I can also not "unhear" these narratives; they – the stories and the individuals – stay with me.

In fact, I have never totally "left the field". I am still in touch with all of my participants, with some more than others. As someone who was known in the fibromyalgia support groups, I had written and weaved myself into the research, and as we are still all in those networking groups, I cannot simply write myself out of it. What I can do is honour all of those women by pushing forward with even more creative forms or expression. A fictionalised account or artistic installation anonymises these individuals' stories to such an extent that they are no longer recognisable, but still tell the spirit of what happened. Therein lies the real challenge for an embodied, sensory and evocative social science research.

Epilogue

I was first diagnosed with fibromyalgia in 2003 and with Menière's disease in 2004. In true likeness to all the academics in this study, I actively rejected the diagnoses. After years, nearly a decade of medical appointments and tests, a rheumatologist finally told me in 2012 that it was time to accept and learn to live with fibromyalgia and Menière's.

My PhD journey started out in the spring of 2015 as a simple conversation with a friend. At the time I had just started feeling comfortable with a new understanding of who I was in my body. I had thought of myself as being well-read, of knowing what it means to have fibromyalgia, and of having come to terms with my body and self. I had not realised how little I was prepared for what lay ahead.

Throughout the doctoral studies, I found myself navigating pain, brain fog, difficulties with swallowing, Menière's attacks with severe vertigo and vomiting. And although this was at times frustrating, upsetting, physically and emotionally draining, I managed and coped. What I had not been prepared for was how much scholarly publications about fibromyalgia, psychosomatic and sociomatic components to illness would affect me. But this time, it was hard to reject the link or ignore the evidence: my physical reactions to readings.

In the meantime, I have been diagnosed with Sjögren's syndrome, I have been told that my hearing loss is so profound that I will soon be eligible for cochlear implants, but on the upside, it looks like the Menière's disease may have burnt itself out.

Now, towards the end of my PhD journey, I believe – more strongly than ever – that I was meant to undertake the research at the time I did and in the circumstances I encountered. Having internalised how social and societal contexts shape health and illness experiences has offered me a new way of understanding myself.

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Appendix A

What it means to be an academic

Appendix B

As an academic you...

…are a member of something. You are part of the academy.
…look at research and assimilate research.
…look at your own personal practices and the practices of others.
…read wider and develop your own knowledge base.
…make a difference through research.
…are networking.
…communicate your research to lots of different audiences.
…present at conferences.
…are very engaged with people and very supportive.
…are very respectful of your participants.
…are incredibly ethical and self-aware.
…have a lot of insight and integrity.
…really encourage development.
…are learning all the time.
…are self-contained and have thick skin. Because it's a very hard business that you're in.
…have made sacrifices. A sacrifice is an inherent part of being in the academy.
…always have questions. Your curiosity is kind of irrepressible.

You never have an answer that you're completely satisfied with.
Regardless of topic.
It doesn't only happen in your professional life,
It's part of your everything.

You wouldn't go around saying you're an academic,
But in your heart, you feel like you are.

That's your job, that's your chosen career, and you're good at it.
You're not doing anything else.
You feel so strongly for your academic identity that it's becoming a lifestyle.
That is who you are.
There is no plan B.

Appendix C

Fibromyalgia and me

The pain you are causing me is driving me to my bed
But do you exist or are you just in my head
Should I resist you and carry on with life
Am I looking for an excuse for being a bad mother and wife

Am I just lazy
And a bit crazy
To think I need my bed
When you are just in my head

New research does suggest that you are real and not 'just in my head'
What a relief as the psychosomatic label used to fill me with dread
However does every one understand that the pain and fatigue are here to stay
Any amount of exercise, rest or medication won't take them away
At least not fully but maybe enough to take off the edge
So that I can carry on without wanting to jump off the ledge

I hope no one has to go through such pain and fatigue
As even now for some medics you are full of mystique
What hurts more is that people who don't have a clue
Give me advice on what I should or shouldn't do
Good support from family and friends over the years
Strong shoulders to rely on helped deal with you with minimal tears

You are however only a small part of me
I will acknowledge you but won't allow you to become my identity

Divya Jindal-Snape

Appendix D

Fibro symptoms as at June 2016

General

1. Activity level decreased to less than 50% of pre-illness activity level
2. Cold hands and feet (extremities)
3. Cough
4. Craving carbohydrates
5. Delayed reaction to physical activity or stressful events
6. Dryness of eyes and/or mouth
9. Fatigue, made worse by physical exertion or stress
10. Feeling cold often
11. Feeling hot often
17. Low blood pressure (below 110/70)
18. Low body temperature (below 97.6)
21. Noisy joints – with or without pain
23. Profuse sweating
25. Shortness of breath with little or no exertion
31. Symptoms worsened by stress
32. Symptoms worsened by temperature changes
33. Tender or swollen lymph nodes, especially in neck and underarms
34. Tremor or trembling
35. Unexplained weight gain

Pain

36. Abdominal wall pain
37. Bad hip pain
38. Burning Nerve Pain
39. Chest pain
42. Elbow pain
45. Headache – tension or migraine
47. Joint pain
48. Lumpy, tender breasts
49. Morning stiffness
50. Muscle pain
51. Muscle spasms
52. Muscle twitching
53. Muscle weakness
54. Pain that ranges from moderate to severe
55. Pain that moves around the body
56. Paralysis or severe weakness of an arm or leg
60. Sciatica-like pain
61. Tender points or trigger points
62. TMJ syndrome
63. "Voodoo Doll" Poking Sensation in random places

Neurological

65. Brain fog
67. Feeling spaced out
69. Inability to think clearly
70. Light-headedness
71. Noise intolerance
72. Numbness or tingling sensations
73. Photophobia (sensitivity to light)
76. Sensation that you might faint
78. Tinnitus (ringing in one or both ears)
79. Vertigo or dizziness

Equilibrium/perception

80. Bumping into things
81. Clumsy Walking
82. Difficulty balancing
83. Difficulty judging distances (when driving, etc.)
84. Directional disorientation
85. Dropping things frequently
86. Feeling spatially disoriented
87. Frequent tripping or stumbling
89. Poor balance and coordination

Sleep

92. Altered sleep/wake schedule
93. Awakening frequently
94. Difficulty falling asleep
95. Difficulty staying asleep
98. Falling asleep at random and sometimes dangerous moments
99. Fatigue
100. Light or broken sleep pattern
101. Muscle spasms/twitches at night
104. Sleep starts or falling sensations
106. Tossing and turning
107. Un-refreshing or non-restorative sleep
108. Vivid or disturbing dreams/nightmares

Eyes/vision

110. Eye pain
111. Difficulty switching focus from one thing to another
112. Frequent changes in ability to see well
113. Night driving difficulty

Cognitive

120. Difficulty expressing ideas in words

121. Difficulty following conversation (especially if background noise present)
125. Difficulty making decisions
127. Difficulty paying attention
130. Difficulty recognizing faces
131. Difficulty speaking known words
132. Difficulty remembering names of objects
133. Difficulty remembering names of people
134. Difficulty understanding what you read
135. Difficulty with long-term memory
137. Difficulty with short-term memory
138. Easily distracted during a task
142. Impaired ability to concentrate
144. Losing track in the middle of a task (remembering what to do next)
145. Losing your train of thought in the middle of a sentence
147. Poor judgment
154. Transposition (reversal) of numbers, words and/or letters when you write
155. Trouble concentrating
156. Using the wrong word
157. Word-finding difficulty

Emotional

158. Abrupt and/or unpredictable mood swings
159. Anger outbursts
160. Anxiety or fear when there is no obvious cause
161. Attacks of uncontrollable rage
163. Depressed mood
164. Feeling helpless and/or hopeless
167. Feeling worthless
168. Frequent crying
169. Heightened awareness – of symptoms
170. Inability to enjoy previously enjoyed activities
171. Irrational fears
172. Irritability
173. Overreaction
174. Panic attacks
178. Suicidal thoughts

Gastrointestinal

180. Abdominal cramps
181. Bloating
189. Intestinal gas
191. Irritable bowel syndrome
192. Nausea
194. Stomach ache
196. Weight gain

Urogenital

198. Decreased libido (sex drive)
202. Menstrual problems
204. Pelvic pain
206. Worsening of (or severe) premenstrual syndrome (PMS)

Sensitivities

208. Allodynia (hypersensitive to touch)
211. Sensitivities to foods
212. Sensitivity to light
214. Sensitivity to noise
217. Sensory overload
218. Sensitivity to pressure & humidity changes
219. Sensitivity to extreme temperature changes

Skin

222. Bruising easily
223. Bumps and lumps
224. Eczema or psoriasis
227. Itchy/Irritable skin
231. Sensitivity to the sun

Cardiovascular (heart)

234. Fluttery heartbeat
235. Heart palpitations

Hair/nails

240. Dull, listless hair
244. Pronounced nail ridges
245. Temporary hair loss

Other

247. Dental problems
249. Haemorrhoids
250. Nose bleeds

Appendix E

Ripples and waves

Calm waters

All things considered, I do think of myself as a writer.

I have always written – diaries, blog posts, letters, emails, texts, scrapbooks, poetry, fictionalised accounts, short stories. I have even been part of reading and writing groups, both opportunities to learn more about the craft of writing; and I have read about reading and writing, and reading and writing well.

But how can you sustain that writing life if you are tired?

Your body is too weak to even hold the pen, let alone move it across the page. And that is despite the pens already being of the "disability kind", pens that are meant to help old people because they are losing their fine-motor skills to grip or pens that are meant for toddlers who have yet to develop their fine-motor skills to grip.

You can perhaps overcome the challenges, perhaps with the help of a computer sprawled over your lap or a Dictaphone and other recording devices, where you can pretend to have those all-stimulating conversations with your academic self.

But even if you are somehow able to overcome the physical barriers and to bypass your body's weaknesses, what about your brain? You are simply too tired to hold and record the conversation.

Your brain is brimming with ideas, but all you can feel is the goldfish bowl that is your head, where the goldfish-ideas just wait to be caught; and you are not able to do that because as soon as you grasp at the goldfish the entire water bowl tips to one side with water lapping up at the sidewalls of the bowl. Of course, you follow that thought, reach for it, only to miss it again because the water sways the goldfish to the opposite side of the bowl. All you do is worry. You worry that your dizziness and tipsiness are visible to others. And you worry that the waves of the water will splash over on one side of the bowl washing the good, red goldfish-ideas out of your brain altogether. What do you do?

The answer is, you don't write.

You rest to try keep the waters calm and the goldfish in the bowl.

Blood is thicker than water

What a weekend this had been. Tricia was glad it was Monday and she could go back to work. The weekend was supposed to be a happy family affair, a gathering for gran's 70th birthday. But as it always goes with family get-togethers, there were tensions. And this time, Tricia had been right in the middle of it. In her 28 years she had had her fair share of debates and discussions with her brother about her career choice. Mike simply didn't understand that what she did was a proper job. In fact, he never really understood what it was she did. As far as he was concerned, she worked in an office, stared at a computer or books, and wrote about things that didn't matter. Of course, they mattered to Tricia. For Mike, they didn't matter because you couldn't become famous or rich, so what was the point of idling your time away. Tricia wondered what had happened. When she was at school, she turned out to be the academic one in the family. From an early age, Dad got Mike to mow the lawn, wash the car or help with the wood turning in the workshop. Tricia never worked. Dad always said "go and read". Even Mum wouldn't let her help. Mum and Dad had plans for her, big plans. She would be the first one of the family to go to university and study. And that was exactly, what she did. So, how come that suddenly things had gone sour?

Tricia approached the university campus. She loved this walk up the hill towards the old-fashioned building with its stately staircase. The steep steps up towards the main entrance made her feel important and relevant. It was as if she was leaving her ordinary life behind to be part of a scientific research world. Her actual workplace wasn't in this old part of the building. She was located in one of the adjacent modern open-office blocks. Tricia just enjoyed entering the main building, this felt like university. Her open-office cubicle was less impressive. But then she wasn't that important, she was only a doctoral researcher. That was what she had said to Mike at the weekend, when he had called her a "perpetual student". She was a doctoral researcher. Together with three other PhD students she was working on an interdisciplinary project to investigate the impact of digital technology on learning. The three others were focusing on the technology-side of things, whereas Tricia and Sam worked on the impact of social behaviour of those using the technology. Tricia liked Sam, they got on well with one another. They were quite similar in age. Sam was married and had finished her PhD already. It was just difficult working with Sam because she missed so many team-meetings. Tricia knew that Sam and her husband were trying for a baby and had troubles. Perhaps this was what her brother wanted for her. Perhaps he wanted her to settle down, have a family and get a job as a teacher. After all, being a teacher was quite respectable for someone who came from a working-class family.

If she was honest with herself, she did find it difficult to establish herself in her field. What field was that anyway? Even she struggled to tie it down to one area of research interest. Working in an interdisciplinary field was right at the forefront of academic work. It was what every funder was after. This was also how she was offered this PhD studentship. In reality, Tricia felt she belonged everywhere and nowhere at the same time. She didn't know enough to be part of the technology teams, but she was also not anchored in any of the social science disciplines. She was an interdisciplinary person, something that no one was really after on the job market. Over the last few months this had become a more pressing issue than ever. Her studentship would be running out at the end of this academic year. And so far, apart from that studentship, she had no salary. Yes, she was working in a café near the campus to earn a little additional income. But this would not pay the bills and debts. John had told her to attend conferences and networking events to make those connections with people that would land her a job. What John didn't realise though, was that Tricia didn't have the finances to pay for attending any of these events. How she would like to travel to some exotic place, swan around in a lab coat and engage in pompous conversations. At the moment, she didn't even have the money to pay for a train fair to a job interview, should she ever get one.

A fish out of water

From his desk John had a good view over the open-plan office on his floor. He'd been in his job for nearly five years now, but he'd only had his own office space for the last four months. And he didn't have a great big office all to himself either. He had to share, but at least he had his own desk, his own computer, and a bookshelf. He couldn't complain really.

Many of the other part-timers didn't have their own desk space; they were hotdesking. Chris, Tony and Lindsay effectively had one and half-offices between them. They couldn't ever make themselves fully at home with their books and papers. John could.

Every so often, the others jealously dug in about that. But they didn't know that John got given this space as a workplace adjustment. Working in busy, noisy environments with the air-condition blowing out cold air had made his fibromyalgia symptoms unbearable. At one point he had asked the pain management woman for coping strategies, and the response was to declare the diagnosis, see occupational health, and get help. And so, he had done that. But he had never told his co-workers. Chris, Tony and Lindsay would never understand.

John watched Tricia arrive and settle down in her cubicle. She'd done well for herself to build the basis for an academic career. She was cut out to make it in higher education. He was less sure about his own career.

He had been a lecturer in what was a different life altogether. In the college he had led the introduction to research module and had delivered the children and families module. With the lecturer contract he had had a teaching-heavy timetable, but with time written in to do research. He had enjoyed his work and life. Then the further education college got in trouble. There had been rumours of mismanaged finances and incomplete degree awards. What options had there been for anyone, other than "rebranding"?

John was one of the lucky ones. Yes, he had had to apply for a job, but in the redeployment pool he had had an advantage over many others. And now, here he was. Life was different now. Instead of doing and delivering training, he was only organising. Not quite the stimulation. He was mainly a paper-shifter. He was now working in higher education, but somehow, he was less valued and relevant than in his further education days.
How ironic – he was lucky, he was unhappy.

John got up. As he did, he needed a moment. Sitting down, he had hardly been aware of the pain. Now though, the flashes of hot were searing through his body. He didn't know which part in his body was the most painful, and which one the least. And yet, the pain wasn't what was most difficult to deal with. He really struggled when his brain stopped working mid-sentence. A few days ago, Tony had told him to cut back on his alcohol intake. As if the slowness in the brain had been a hangover. Funny enough, hung over is what he felt like most of the time – only without the buzz and excitement of a party.

John carefully checked if anyone was watching through the glass front, before he gently started stretching his neck and back. He quickly did a couple of repetitions of the exercises from the pain management classes.

As he opened the door to his office he heard voices from the kitchen. Tony and Chris were having a coffee break.
"Honestly. Who does she think she is?" Tony's anger was palpable.
"What happened?" asked Chris.

"Well, it's not like I hit her. My bag just brushed against her in the lift. That's all. Didn't do it on purpose. Just happened. That's all."
"Bloody princess on the pea, eh?" responded Chris.
"Yeah. Thing is, we're in the lift and she starts crying. Sobs and sobs. People get on on the next floor and God knows what they're thinking." Tony was just getting going. "I mean. I know she's got some health thing going. No need to overreact like that, though, is there?"

No. His colleagues really wouldn't understand if John was ever going to be honest about his diagnosis. Not only that the diagnosis was difficult to explain anyhow; it's a woman's illness! Men get it, too, but not many are ever diagnosed with it. It would be like standing on a table in the office and shouting "I have got a woman's problem." If women struggle to be recognised and taken seriously, what would it be like for a bloke?

John could imagine the sniggers and digs. He couldn't face that. After all, it had taken a long time to be semi-accepted in this office. FE is no HE.

Come hell or high water
As Sam entered the office Tony and Chris were just coming out of the kitchen. She regretted what had happened earlier in the lift. Tony's bag had hit her left arm, and the lightening of pain had shocked her whole body. The hormonal treatment for the baby project had made her more vulnerable and emotional, and so she had broken down in tears. She and Dan had tried for a baby for quite a while now, but here she was, still not a mum, not even pregnant, but the office-joke nonetheless for being weak, a wimp and a cry-baby.

Sam sat down in her cubicle next to Tricia's. Tricia seemed a little absent-minded today. Anyway, they would have to get the structure of that paper done together in the next couple of hours, because then Sam would need to pop out to the GPs. Last night Sam had been awake again. Dan thought this insomnia was to do with the baby-stress, which certainly didn't help. But, for Sam it wasn't really insomnia. Every night, she felt tired enough to sleep and fall asleep quite quickly, but then she kept waking up. As soon as she tried to turn over, her painful body would commandeer her brain to wake up, and that would then be the end of sleep.

Today, she rang to make an appointment with the GP to get some help. As it happened, even this phone call was frustrating and had led to tears this morning. When she'd phoned up, she had been told that she could only have an appointment at ten past eleven. She had wanted to shift that time to after-work hours. To no avail. Of course, she'd been emotional. Tears of anger and frustration had streamed down her face. Sam wondered who decided on these appointment times; clearly not someone who thought it possible that you could be chronically ill and still be working. Either you were ill, or you were working.

Anyway, the mid-morning appointment meant that Tricia and she needed to get going on their joint work quickly, and Tricia would need to fill her in later about that team meeting. Sam knew it wasn't the first meeting she'd be missing, and it wouldn't be the last either. She felt sorry for Tricia who needed help with her PhD work and her job applications. Really, though, Sam was not best placed to provide that kind of help. Sam didn't have a permanent job herself, and she wasn't Tricia's supervisor.

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Just in time Sam arrived at the surgery. A little later, and she would have been too late to check in for her appointment. The receptionist confirmed her name and address, and Sam sat down. Ten past eleven, surgery was running late already. At twenty to twelve Sam was called to see her GP. She liked him. He was very good at explaining details and making sure she was happy with the treatment he offered. Today was no different. She explained the sleep problems and that she wanted some medication.

"You do realise, that we don't really know what's causing your problems and therefore we are only treating symptoms?" the GP asked.

"Yes, I know."

"Well, in this case, with your previous history of things in your file, there is some form of myalgia. Myalgia just means muscle pain."

"I have been referred to rheumatology. But that appointment hasn't come through, yet."

"And you are saying that the normal painkillers don't help?" the GP enquired, doubt audible in his voice.

Sam sighed. "No." Dan didn't quite believe her either, when she said that the paracetamol and ibuprofen didn't make a difference.

"We could try you on Amitriptyline".

"What's that and would that work with me trying for a baby?"

"Yes, Amitriptyline is quite safe. It is actually an antidepressant. But you wouldn't get it for that. You would get a very low dose. It has been used in that form to treat migraines and neuralgic pains for quite a while now. It's prescribed regularly for fibromyalgia and other somatic illnesses, too. And it is even safe for children from the age of two. You couldn't have anything better to try at this stage" the GP explained.

Sam was fine with that. She didn't care about the diagnosis and about what would work, as long as it did. What if people thought she was making this all up and she was just a mental nutcase. She doubted herself in that way, too. She had been competitive and successful in the past, but now she was a failure on most fronts. Her academic career was stalling, and she was still not pregnant. Actually, this whole pregnancy bit had become hard work. She was in so much pain most of the time, she didn't even like being touched, let alone have sex – somehow a difficult predicament, when you're trying for a baby.

"You know, though" the GP interrupted her thoughts "you should really make some changes."

"What do you mean?"

"If you are trying for a baby, and also with that pain you are experiencing, you should lose some weight. If you were a little lighter, it would help you cope with the pain better, and your body would be ready to conceive."

Sam was speechless. She'd heard that before; from the pharmacist, the IVF specialist, the gynaecologist, even the woman at the checkout till in Tesco. Everyone had an opinion. She just hadn't expected it from her GP. Without saying much, she took her prescription for the Amitriptyline and left the room.

Lifting her heard up on her way out, she looked into a pair of gentle eyes. They belonged to a well-groomed and cultivated elderly lady and they looked at her with such warmth that Sam decided there and then to forget what people said. She would have that baby.

Treading water

The girl came out of the surgery with her head hung low, sad eyes, tears waiting to be unleashed. As Mary looked at her, she recognised herself in those sad eyes. She had been like that once. Young, ill. Of course, Mary didn't know that girl and whether she was truly ill or just a little under the weather. But she remembered the journey to and from doctors, from one surgery and specialist to another, meeting everyone from junior doctors to consultants, opening and closing doors; literally and metaphorically. Eventually, she had been given this diagnosis that really wasn't one, fibromyalgia. Back then, her husband had stood by her and now he still did, but now she also had the support of her two children, a son and a daughter. She was lucky. Yes, Mary struggled with the symptoms. The pain was quite well-controlled nowadays. She just found it difficult to concentrate, keep up with the pace of life and then there was this fatigue. She wondered whether all this had nothing to do with fibromyalgia after all, and was a sign of something else – dementia, heart conditions, brain tumour. It could be so many things.

"Did you enjoy this book?" Phil asked.
Mary didn't know how to answer. She didn't realise that she had finished the book, and she couldn't remember what she had just read. She could vaguely piece together the chapter before the last one.
"Never mind, Mary. It was a work book, anyway. You shouldn't be reading these on your days off."
Phil meant well. But even after all these years of being married, he still didn't understand that being an academic wasn't work; that it was a lifestyle choice.
"You are entitled to your time off." Phil finished.
"Yes".

Mary was an eminent professor. She had distinguished herself in her work around the impact of court cases on individuals. She was regularly asked to give keynotes or present on one of her four books or countless articles. She had made it in academia. At the age of sixty-four she was nearing pension age more quickly than she wanted to. Working in universities, giving lectures and supporting young researchers starting out on their careers had indeed been a lifestyle choice. More recently, she had used her status as established professor to lobby for more equality and increased support for those with disabilities or chronic illnesses. She was able to do that now. She had always wanted to stand up for these values, and felt she couldn't because she would hamper her career. Now, though, it was different. Her career would be over soon. What Phil needed to learn and understand is that her career being over would not mean her being an academic being over. He worked in an accountancy firm. Over the years, he had had his promotions and had moved up. He was no longer an accountant; he was effectively the CEO. And despite him being in such a leading position, and therefore needing to be available, he left his work at work. At the end of each day, he took his briefcase, loosened the knot to his tie and left his sumptuous office overlooking the city. As soon as the door to his office fell close, his work day finished; and no matter the seriousness of a case or the urgency of a client, he would not respond to emails or phone calls. It was as if he was underground, only to re-emerge the next day. For Mary, working life was different. She was in a rather privileged, permanent position of receiving full pay, and being able to drift in and out of the office as she wanted. But the articles and books didn't write themselves. And even if Mary didn't actively write on something or other, she was mulling over ideas, developing conceptualisations, plotting structures and theorising. To her, this was the most important and most interesting part of the job. She needed that space for reading and working through publications to finetune and finalise thoughts. It was the flexibility of her work that had allowed her to go on for that long, and indeed to continue her work well beyond retirement. She didn't see herself going for walks or tending to the garden.

"You are entitled to your time off."
But did she really want that?

Dead in the water

Full of anticipation, I approach the café after lunch on that sunny day in March. It has taken a long time to get this meeting set up. Karen and I have been in regular contact for over a year by now, but we have never met in person. She has always put off meeting me "for real". I am eager to hear her full story. From our private messages I know a lot of what has happened to her, and really want to have her contribute to my research. As I enter the café, I notice a number of tables having been taken. I become acutely aware how little I know Karen although I know so much of her. I know that she doesn't like air conditioning. The cold air blowing directly onto her makes her muscles seize up. I know she hates noisy environments. I know that the noise of the baristas handling the coffee machine will make her lose her train of thoughts and forget her words. I know that the direct sunlight will make her vision turn fuzzy. I know that the combination of the noise, the light and cold air will make her tighten her muscles, grit her teeth, clench her fists. I know that she needs to be near the toilets, in case she suddenly struggles to swallow and needs a private space to retch.

And yet, I don't know what she looks like.
I am asking myself, "Do I really know Karen? Or is it that I know about her struggles because I know what life with fibromyalgia feels like?"

I let myself fall down comfortably on the sofa in the corner off the self-service counter. From this vantage point, I will see her enter the café but we will be away from the cold air and the noise as far as possible. Karen will be here any minute.

Five minutes.

I am slowly starting to wonder if this will happen at all. Karen has often missed and rescheduled skype calls and phone conversations.
She was uncontactable for several weeks around Christmas; and she avoided longer conversations in February.

Ten minutes.

Recently, she seemed keener than ever to share her story, but her responses were largely one-liners like "I'm sorry I've been so flaky" or "I can't think about it" or "I know I should probably turn this into a paper but lack the stamina".

Fifteen minutes.

Karen is a senior academic, a professor, and renowned in her field.
Karen lost her job.
Karen was sacked.

She was appointed on the basis of her successful publications and the potential boost she would bring to the department for the next research exercise. She was under pressure to perform and conform. She did; and yet, she did not.

Twenty minutes.

She continued leading on her research and producing articles for publication. But she struggled with the pace. She was required to produce more, faster, of higher quality. Brain fog and pain interfered with that work, and she complained about the lack of reasonable adjustments. That was uncomfortable. She became uncomfortable.
Then she was let go.
That was five years ago.

Twenty-five minutes.

She has been out of employment ever since. After all, who would want to employ someone who is "uncooperative" and "incapable"? But what is going to happen to her and with her? As someone in her mid-sixties she finds it difficult to relaunch a career.

Thirty minutes.

Ping.
I look at the message that just arrived in my inbox. "Hi. I'd love to tell my story on my own terms and in my own time (if I live long enough). But I've been told I'm not allowed to make public comments that may be interpreted as critical of my university. They offered me a lot of money to leave at one point. I refused to sign any papers on the grounds that I had done nothing to lose my job."

Karen is not coming.

Commentary to the short stories

"Calm waters" presents the impact of cognitive dysfunctions, perception issues and fatigue that are associated with fibromyalgia. The goldfish in the bowl of water is a commonly used metaphor amongst people with fibromyalgia as a short-hand explanation for why individuals may find it difficult to follow conversations or streams of thoughts. The character presented in this story is meant to bring about the connection between all of the stories. There are recurrent characters in each other's lives, but the one constant is this mid-career academic who is embarking on a research project. The story will develop with and around this particular woman, without it being intended as an autobiographical narrative. From a story-telling point of view it is merely practical to have a researcher, as this person will be able to link different universities and further education colleges and will navigate the relevant context of academia to have connections with all characters in the stories.

"Blood is thicker than water" is the story of Tricia who is an early-careers academic on an hourly paid contract and who is the first in her family to become an academic (see chapter 5). The focus here lies on sense of belonging and isolation. On the one hand, Tricia does not belong into academia for the lack of her position and role; on the other hand, she no longer fits with her working-class family, who are proud of Tricia having gone to university, but at the same time do not really understand her work and its value. Ultimately, Tricia will understand that she needs to perform two identities, one for work and one for family, which in turn will make her start questioning herself who she really is.

John, the mid-career academic in "A fish out of water" is the symbolic embodiment of otherness: as a man he has been diagnosed with the predominantly female and feminine condition fibromyalgia and he has entered higher education from a further education career path (see chapter 5). John's plotline is currently the least developed of the stories. He certainly is a mentor and father-figure for Sam, but his relationship with his own work colleagues is still undecided.

"Come hell or high water" explores the difficulty of receiving a fibromyalgia diagnosis and at the same time highlights the physical and emotional impact of trying to conceive (see chapter 6). Although Sam is adamant that she will "have that baby", she will actually not. This is firmly set in the data and the reality of the experiences as they were told to me. Eventually, Sam will start realising that IVF treatment or adoption are her only options, which will create the turmoil of being weak and a failure as a mother, wife and human being.

In "Treading water" Mary is a typical academic who cannot adjust her lifestyle to the expanding health issues. Her husband means well and wants to help her, but does not fully understand that for Mary pacing herself would mean compromising and giving up on her academic identity (see chapters 6 and 7). Despite her best intentions Mary will eventually make alterations to her lifestyle, but this will be to the detriment of her family and friends, as she is firmly committed to her research.

"Dead in the water" summarises individuals' struggle between wanting to have their stories told and shared, but at the same time wanting to protect their identities for fear of repercussions. Karen is probably the most fascinating character in all of the stories, as she will remain elusive throughout. There will be connections and interactions via email and social media postings, and she will be in the vicinities of the other characters, but she will not actually ever engage directly with them. For example, in the given extract, it will emerge that she actually was outside that café at the time of sending her cancellation.

Appendix F

Equality, Diversity and Inclusivity

Background and context

As a sector Higher Education has seen drastic changes over the last decades, and more emphasis is now placed upon equality and inclusion than ever. Initiatives, such as Athena Swan and the Race Equality charter have led to more awareness of exclusionary practices. The sector has become more consciously aware of concerns around the health and wellbeing of students and staff. Individual institutions are generally responding to these changes, and yet, the responses are not necessarily well-coordinated and due to individuals' different emphases and research foci the responses are often fragmented. Additionally, HE statistics highlight serious issues in relation to disclosure rates (see Brown and Leigh, 2018), and so in many cases institutions actually do not know how to "respond" to staff needs, as they are not really aware of any needs in the first place.

The current reactive approach to EDI matters across the sector means that high-quality researchers, academics and professional services staff are unable to engage to the best of their abilities and/or do not apply for open positions.

Causes for concern in higher education institutions

Staff support

Student support is often well-developed and easily accessible, whereas staff support is often separate, or linked to cumbersome Access-to-Work assessments with a smaller budget. In some universities staff register as students to be able to access adjustments, resources and support that is otherwise unavailable. This normalises the assumption that academic staff are able-bodied. The kinds of conditions that might require support include specific learning disabilities such as dyslexia, cancer, menopause, chronic illnesses, neurodiversions such as autism, ADHD, age-related impairments such as hearing loss, mental health and physical disabilities.

Conferences

Promotions frameworks often require evidence for international impact, networking with colleagues on international level and/or conference attendances. However, many disabled/chronically ill/neurodiverse staff find conferences inaccessible (see Brown et al., 2018). Issues such as travel, fatigue, and accessibility of rooms and buildings can inhibit attendance, and remote attendance is often either not encouraged, or looked on negatively as sign of lack of commitment. In-house conferences do not always factor in accessibility considerations with a centralised check-list that each symposium or event should adhere to.

Promotions

Lack of access to support and fewer conference attendances, in addition to the extra time, effort and money required to manage a chronic condition means staff often feel that they cannot achieve promotions or maintain a career in academia. They are either not applying for promotion, or not achieving it at the same rate as their peers. This is evidenced by the higher proportion of staff nationally on zero-hours or in part-time work, and the much smaller number of those in leadership roles who disclose a disability, neurodiversity or chronic illness.

Cultural and attitudinal concerns

Staff with disabilities or chronic illnesses report being stigmatised, challenged and questioned quite overtly, with some saying that they have been told they should not be trying to pursue a career in academia as they would fail anyway. Such an environment is not conducive to work, and impacts students' experiences. If staff are discouraged to disclose, students do not have relevant role models. An institution therefore loses potentially high-quality staff and students.

Remedial work

The common approach of remedially responding to an individual's needs is not the most cost- and/or time-effective use of resources. In many cases the adjustments made would improve the experience of others. Ideally, Universal Design would be built in. A simple example is changing logos, branding and PowerPoint slides, so that writing is not in a serif font in black lettering on white backgrounds. This benefits those who are dyslexic, have sensory processing issues and/or Irlen's syndrome, and does not adversely affect the majority of the staff and student population, in fact many report they find it easier to read. Such Universal Design can be applied to many aspects of both staff and students' experiences to support learning, teaching, and conferences.

Moving forward in higher education

The changes required are not quick-fixes or developments that will be implemented overnight, as ultimately the entire change of an ingrained and embedded culture of ableism is required. However, in addition to those simple changes mentioned above, there are some more steps individuals and institutions can take to move things forward:

Strategy and policy:

A clear strategy with a five-ten-year plan and the outline of a vision for what an accessible, inclusive and diverse university looks like provides the overarching framework. This is essential for charter marks like the Athena Swan but also for other institutional and national initiatives and frameworks. Such a clear, detailed equality, diversity and inclusion strategy needs to be set in motion with a policy signed off from the highest levels. The policy should entail quantifiable commitments like "all new buildings will meet the needs of 90% of all staff and students" or "all events need to make use of the centrally available resources". The policy could be linked to separate policies for specific conditions such as menopause (as first implemented at Leicester University), or be more general given that many adjustments for specific conditions would also improve working life for others. Ideally, the implementation needs to be backed by high quality institutional research and as such seen as valuable by academics and professional services alike. Strategies and policies used in this way allow best practice to be show-cased and disseminated across the sector.

Equality, Diversity and Inclusion Ambassador or Envoy

The role of an ambassador or envoy is to enforce the strategy and policies. All departments and professional services would be accountable and report to governance structures where needed. For example, if the policy says that all events need to be accessible, then the ambassador needs to have the right to check up on that, and follow through with sanctions. No policy or vision will be followed through and/or maintained in the long-term if there is no enforcement.

Financial commitment:

The implementation of the role of the ambassador and changes required (e.g. funds to support travels to conferences; support assistants for access-to-work paperwork etc.) will require financial commitment and a budget. If the structures are changed to support staff disclosures, there has to be a budget to support them.

Leading by example

The validation of new modules, the implementation of new buildings, the employment of new staff etc. should all be checked against the comprehensive equality, diversity and inclusion policy. If all areas and aspects of academic life are governed by the policy, if staff are able to disclose their conditions, students will feel they have role models and opportunities to engage in education "despite" their needs.

Ultimately, the aim of a comprehensive equality, diversity and inclusion approach would be to make a university a truly inclusive, diverse and accessible place, where gender, race, ethnicity, disabilities and chronic illnesses, neurodiversity, sexual orientation are all treated with equal respect and commitment.