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Families' Understandings of their Experiences of  
Fibromyalgia

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## Declaration

I declare that I have composed this thesis myself and that it embodies the results of my own research. Where appropriate, I have acknowledged the nature and extent of work carried out in collaboration with others included in the thesis.

Signed,

Catriona Galbraith

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## Abstract

In this thesis I explore families' understandings of their experiences with the chronic and contested illness fibromyalgia. My research is informed by an interpretivist epistemology and draws together literature and theories from the sociology of health and illness, disability studies/studies in ableism, and UK family sociology. I thematically analysed qualitative semi-structured interviews with 17 families in the UK to explore their understandings of their experiences with fibromyalgia. I argue Experiential Illness Knowledge (EIK) is an essential concept to help families understand and navigate their experiences of fibromyalgia. Informed by the aforementioned epistemology, literature, and theories, I argue that families' understandings of their experiences of fibromyalgia cannot just be understood as disruptions to one's *self*; but rather as disruptions to multiple relational *we*. My findings support wider literature of care as an ordinary complexity within families' lives. However, I highlight that underlying families' daily understandings and experiences of fibromyalgia is a wider context of social oppression that devalues the EIK they use to navigate their daily lives over that of biomedical knowledge that can impact families' access to wider support inside and outside of the medical profession. I showed how families were impacted emotionally and relationally by their perceptions of the multiple ableist norms of family, illness, of being a worker etc. that characterised their experiences, and wider policy contexts that they live within. Additionally, I demonstrate how fibromyalgia and wider ableist structures within society impacted families' emotional and relational histories and contemporary family practices. In drawing these themes together I argue families understood their experiences and relational selves as being impacted not only by fibromyalgia's impairment effects, but also by the wider ableist norms and societal attitudes that produced the conditions for their marginalisation to occur.

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## 1 Chapter One: Introduction

Within the sociology of health and illness, two often-used terms to understand chronic illness are that of expert knowledge and experiential knowledge. Expert knowledge generally refers to knowledge held by doctors, physiotherapists, nurses etc. concerning the causes of physically manifesting disease, its prevention, and its treatment (Prior, 2003). Within this thesis expert knowledge is understood and referred to as biomedical knowledge which signifies understandings and explanations of illness as originating aetiologically within the body (Boulton, 2019). Experiential knowledge is understood as knowledge a person has of how their illness, and its symptoms, affect them physically and emotionally in everyday life (Pols, 2014). In this thesis I am interested in how these two forms of knowledge interact with the medically unexplained illness fibromyalgia, and how this subsequently affects the lives of people and families living with fibromyalgia (Harsh et al., 2016).

I chose to study fibromyalgia for several reasons. First, it is a medically unexplained and contested condition, and within current studies there is a lack of knowledge on families' experiences of fibromyalgia (particularly within the UK), with many studies highlighting how family members do not understand their loved one's fibromyalgia (Juuso et al., 2011; Armentor, 2017; Briones-Vozmediano et al., 2016). Secondly, I have a parent with fibromyalgia, and in exploring the literature on people's experiences I felt there was a lack of knowledge on the experiences of fibromyalgia for family members without fibromyalgia in a UK context (Rodham et al., 2010; Taylor et al., 2016). I felt that without this knowledge, we would only have a partial picture of the wider relational contexts within which people live (Smart, 2011). Current literature on fibromyalgia highlights that for those who have it, self-management of fibromyalgia is imperative to helping people navigate daily life (Briones-Vozmediano et al., 2016; Kengen Traska et al., 2012). However, we lack detailed knowledge from family members of those with fibromyalgia as to whether they have experiential knowledge of their family member's condition, and if so, how this might inform their daily family practices (Söderberg et al., 2003). Empirical studies on people's experiences of fibromyalgia do not provide a clear picture of whether families are a source of support (Söderberg et al., 2003; Juuso et al., 2011; Arnold et al., 2008; Wuytack and Miller, 2011). However, I argue it is important that we know whether family members understand fibromyalgia, and can be a form of informal

support to people with fibromyalgia in the UK, as within UK policy there is a tacit assumption that families will provide informal support (Dalley, 1996).

Drawing on my research with 17 families where a member experiences fibromyalgia, I argue the concept of experiential illness knowledge, here on referred to as EIK, is central for people and families to understand and navigate daily life with fibromyalgia. Furthermore, I seek to highlight that while EIK is essential to the experiences of families living with fibromyalgia, it is devalued societally based on wider norms dictating what knowledge is legitimate, which is inextricably linked to the methods we use to understand illness. Situated within families' understandings of their daily experiences with fibromyalgia, I explore how their experiences were informed by societal understandings of illness, welfare entitlement, work and family. I aim to use the findings of this thesis to build on work within the sociology of health and illness, and on studies on fibromyalgia by exploring the experiential knowledge of family members, and relational aspects of chronic illness. I do so by drawing on concepts from the sociology of health and illness concerning experiential and biomedical knowledge, Fiona Campbell's (2014) theory of ableism to highlight people's marginalised experiences with invisible chronic illness, and Carol Smart's (2011) concept of relationality to highlight the emotional and relational contexts in which people live. I seek to address gaps within the current literature on how we understand families' experiences of fibromyalgia by answering the following questions:

- 1) How do people with fibromyalgia and their family members understand fibromyalgia?
- 2) How do people and families with fibromyalgia understand their experiences of life outside of the home?
- 3) How do people with fibromyalgia and family members' navigate everyday domestic and social life?

## 1.1 Research Design

My thesis is the product of an ESRC doctoral +3 grant that I was awarded in 2016. It originated in part, as I mentioned above, because one of my parents was diagnosed with fibromyalgia and I noticed a lack of empirical studies, particularly in a UK context, from



the perspectives of family members of those with the illness concerning how they understood fibromyalgia, and how it impacts their daily experiences. My aim for this research was to hear the voices of people and families with fibromyalgia, and their everyday understandings of their experiences with the illness within the UK.

To answer the research questions stated in the previous section, I used semi-structured interviews with 29 people in total, who either had fibromyalgia (17) or were a family member of a person with fibromyalgia (12) living in the UK. The interviews explored participants' daily routines, people who were supportive and unsupportive towards fibromyalgia, whether fibromyalgia impacted aspects of their social life and household life, and whether participants found both the Scottish and UK Governments as sources of support. All of the participants who had fibromyalgia had been diagnosed at different times and had had the condition for a varying number of years. I recruited participants primarily from online advertisements or snowball sampling, and I interviewed people either in person or by phone.

## 1.2 Structure of thesis

This thesis contains eight chapters.

This is Chapter One in which I introduce the thesis, give a brief background for the research, and a summary of the chapters which follow.

Chapter Two is a literature review which provides more detail on fibromyalgia, before situating the illness within understandings of the UK medical profession, drawing on expert and experiential knowledge and wider UK policy agendas. I discuss prominent theories of illness and disability, before discussing the concept of ableism in relation to fibromyalgia. I provide a critical review of what a family is with reference to sociological work within the UK on families before going onto discuss the empirically situated concept of care and its history within understandings of families' experiences of illness. In this chapter I define key terms within this thesis, and outline in more detail the theoretical approach I took before presenting the research questions.

Chapter Three is my methodology chapter where I discuss my epistemological position in conducting this research and highlight how I conceptualise and situate the knowledge I am producing. I explain how I planned my research design, and how this worked within

practice with reference to the ethical issues I had to consider and encountered along the way. I also detail the management of participants' data. Lastly, I outline my understanding of thematic analysis, and how I used this to generate the findings of the thesis.

Chapters Four, Five and Six detail my analysis and findings of my thesis, situating it within the current literature. In Chapter Four I explore biomedical and experiential understandings of fibromyalgia in relation to the people and families interviewed. I focus particularly on the knowledge participants used to understand fibromyalgia (EIK), and how this was communicated and understood within encounters with the medical profession. In this chapter I explore how these knowledges can inform one another while also linking these understandings to wider institutionally held values around what constitutes legitimate knowledge, and how this can personally impact people.

In Chapter Five I explore how I understood the biomedical knowledge in Chapter Four to influence participants' interactions within wider society by focusing on the examples of welfare and work. I also draw together how these understandings can impact participants' daily lives.

In Chapter Six I present participants' relationships with family and friends. I explore how fibromyalgia impacted participants' normative understandings of family roles, while simultaneously impacting their emotional and historically situated relationships and daily family practices. I go on to look at how families can work around this, and how I interpreted them as drawing on the EIK outlined in Chapter Four to renegotiate their family practices and relationships within their daily lives. However, I also highlight that not everyone within the sample received the informal family support discussed, and the implications this can have for people's physical and emotional wellbeing when linked to wider policy assumptions and practice.

In Chapter Seven I discuss the findings from the previous three analysis chapters in relation to the wider literature. I structured this chapter to answer the three research questions of my thesis, and to demonstrate how my findings add to the existing work on families with chronic illness. Lastly I discuss the limitations of my study, and where I feel future research on fibromyalgia should be undertaken.

In Chapter Eight I provide a short conclusion of my thesis. I finish by detailing the theoretical and practical implications my research has in relation to families' experiences

of fibromyalgia. I also discuss what I feel are the benefits of taking a multi-disciplinary approach across the sociology of health and illness, disability studies/studies in ableism, and family sociology.



## 2 Chapter Two Literature Review

My research looks at people and their families' understandings of their experiences of fibromyalgia. In this chapter I review the bodies of literature and theories that have informed my understanding of my research project, and in doing so I highlight the gaps in the knowledge of families' experiences of fibromyalgia. I start with the Section 2.1 Fibromyalgia – What We Know which details current knowledge on fibromyalgia and people's understandings and experiences of it. In the Section 2.2 Different Types of Knowledge I review the origins of Western society's contemporary medical profession and suggest this understanding of illness may marginalise medically unexplained conditions such as fibromyalgia. In the Sections 2.3 Theorising Illness, 2.4 Theorising Disability I draw on theories we can use to conceptualise people's experiences of fibromyalgia and evaluate their usefulness in understanding people's experiences of fibromyalgia. In Section 2.5 Ableism I detail the first part of my theoretical framework and explore empirical studies on fibromyalgia. I argue that ableism can offer a better theoretical framework to explore people's experiences of fibromyalgia than other theories of illness and disability. In Section 2.6 Family in Policy and Theory I detail how UK social constructions of family, motherhood, and childhood impact policies on family life and how this may impact families with fibromyalgia. I also explore contemporary theories of family life, detail my theoretical framework for understanding families, and define how I understand families in this research. Lastly, in the Section 2.7 Families and Care I detail the literature on caring relationships within families and empirical studies of family caring in chronic illness and fibromyalgia. I then define how I understand care within this research. Lastly, Section 2.8 Conclusion reviews the gaps identified within the literature and the theoretical underpinnings of this thesis, before laying out the research questions I will answer.

In this review I explore the changes within the medical profession and theories of the sociology of health and illness, disability, and family studies in a chronological order. I do so to enable the reader to see how ideas in each of these fields around illness, the body, family and society have developed over time, and in relation to one another. At the time of writing, a chronological presentation of the development of academic thought and research appeared to me to be the most logical way to explain the history, context, arguments and debates within these different disciplines. Lastly, I included the literature

I did within this literature review based on its potential to contribute to our understanding of families' experiences of fibromyalgia in the UK. In formulating this understanding, I draw on previous studies of fibromyalgia. Where there is a gap in the literature concerning people's experiences of fibromyalgia, I draw on people's experiences of similar illnesses and family life to explore what families with fibromyalgia could experience. Before I go on to review the aforementioned literature, I will briefly define the following terms.

When I refer to Western Society, I note that it is a particular understanding of society coming from the ideals of the Enlightenment, particularly with regards to medicine and illness (Lupton, 2003). Biomedical and biomedicine refers to an epistemological position where illness is aetiological within the body (Lupton, 2003). Impairment refers to a condition or illness a person has, impairment effects refers to the physical, mental and emotional effects an impair has on a person (Thomas, 2004). Finally, within this thesis I frequently refer to norms of illness, work, family etc. and these shall be explained within the context of the sections they are in to highlight how I understand these and how I am using them. With these definitions covered, I will now discuss what is known about fibromyalgia.

## 2.1 Fibromyalgia – what we know

Fibromyalgia is an illness whose main symptoms are chronic invisible pain, fatigue, brain fog – memory issues, depression and anxiety (Sim and Madden, 2008). It is a chronic long-term invisible illness with remissible symptoms that vary from day to day (Sim and Madden, 2008). Kengen Traska et al. (2012) highlight that there is no known cure for fibromyalgia, rather medical practitioners respond to the condition by providing medication for pain and sleep disturbances, and suggest self-management practices. Fibromyalgia is diagnosed more often in woman than men, though men can also have it (Paulson et al., 2002) While fibromyalgia became a formal diagnosis in 1982 (Åsbring and Närvänen, 2003), there is controversy amongst medical professionals as to whether fibromyalgia is a real illness (Åsbring and Närvänen, 2003; Hughes, 2006; Menzies, 2016). Some medical professionals and academics argue it is a syndrome not an illness, or that it is psychological and thus not physical pain (Boulton, 2019). For example, Åsbring and Närvänen (2003) in interviewing physicians found that some felt fibromyalgia was less serious when compared to illnesses that could be aetiologically measured such as: heart problems, or osteoporosis. Jutel and Nettleton (2011) suggest a

diagnosis – the medical act of naming a condition - is supposed to ease our anxiety of unexplained symptoms as it provides a name, a prognosis and forms of treatment. However, studies on fibromyalgia suggest a diagnosis of fibromyalgia can create an uncertainty which a diagnosis is normally supposed to quell (Madden and Sim, 2016; Boulton, 2019). To diagnose fibromyalgia, a medical professional will often feel for particular tender points on the body, if the person reacts against them then fibromyalgia is generally diagnosed (Boulton, 2019). However, this diagnosis tends to come after the person has received many other medical tests to rule out illnesses which have an observable aetiological origin (Boulton, 2019). Boulton's (2019) participants associated a diagnosis of fibromyalgia with feelings of relief and dissatisfaction. Boulton's (2019) participants were relieved that they had a medical condition. However, they were dissatisfied as they found fibromyalgia has many more symptoms than the main ones I have listed above such as problems sleeping and IBS, and that these symptoms can present differently in different people. For example, one person may experience widespread pain across their body, another may experience variations in the location of their pain, and the intensity (Boulton, 2019; Åsbring and Närvänen, 2003). Due to this they found it hard to distinguish what symptoms were that of fibromyalgia and what were symptoms of other conditions such as glandular fever (Boulton, 2019).. Additionally, people's relationships with doctors can become strained after a diagnosis of fibromyalgia due to fibromyalgia's contested nature, and because doctors struggle to understand fibromyalgia through biomedical knowledge (Sim and Madden, 2008; Åsbring and Närvänen, 2003).

There is uncertainty over what can constitute treatment of fibromyalgia (Kengen Traska et al., 2012). Pharmacological treatment largely consists of painkillers, sleep and anti-depressant medications (Kengen Traska et al., 2012). However, the side-effects and the limited relief which particularly pain medication offers, means people with fibromyalgia can be reluctant to take them (Åsbring and Närvänen, 2003; Kengen Traska et al., 2012). Research has then in turn focused on how people self-manage fibromyalgia through non-pharmacological means (Kengen Traska et al., 2012). For instance, Kengen Traska et al. (2012) in California found their female participants with fibromyalgia managed their condition by constantly planning ahead, pacing themselves and trying not to do too much, to conserve energy. Other studies have also highlighted that those with fibromyalgia engage in pacing oneself and knowing one's limitations (Briones-Vozmediano et al., 2016). What these studies suggest is that doctors' biomedical understandings of illness

means they have a hard time understanding fibromyalgia, and that this can impact the lives of those who have it (Sim and Madden, 2008).

Doctors lack of understanding around what fibromyalgia is, is largely attributed to the invisibility of fibromyalgia and the uncertain remissibility of symptoms that struggle to be treated or understood meaningfully within a biomedical model of illness (Åsbring and Närvänen, 2003; Juuso et al., 2014; Boulton, 2019). By biomedical model of illness I mean illness that is has a clear aetiology. However, Rodham et al. (2010) and Armentor (2017) have highlighted that diagnosis of fibromyalgia is essential to helping people understand their experiences with the condition, and their wider relationships (Armentor, 2017; Rodham et al., 2010). This places a lot of power within the hands of the medical profession. Before exploring the wider relationships of those with fibromyalgia, I argue it is worth engaging in literature discussing why the medical profession has difficulties understanding fibromyalgia and how this can impact people's lives.

## 2.2 Different Types of Knowledge

White (2009), drawing on the work of Ludwig Fleck, suggests that how we understand illness in society is historically and culturally constructed. Lupton (2003) argues that how we understand illness, medicine and the medical profession today was not how it was understood prior to the industrial revolution. Lupton, (2003) notes that when one becomes ill, the illness acts as a threat to one's body, one's self, and causes a person to seek answers for their ailments. Within the UK we largely expect and depend on these answers to come from a medical professional (White, 2009; Lupton, 2003). However, Porter's (1985) research highlights that this role is relatively recent, and that prior to the industrial revolution and the foregrounding of medical science, the patient often played an active role in diagnosing illness and dispensing treatment. Lupton, (2003) argues this shift in how we know illness came from the ideals of the Enlightenment when societal understandings of knowledge and progress came to be conceptualised through science, technology and reason. Lacking ailments was taken as the natural state of humans, and within contemporary understandings of illness and health the body is a physical set of symptoms, a machine, for which we are responsible, and which we can put at risk by engaging in unhealthy behaviour (Lupton, 2003; White, 2009). Such an approach can now be understood in wider medical policy and practice as risk-factor epidemiology that individualises our health as something we control and downplays the significance of



broader social factors (White, 2009). Poverty, for example, is a major structural cause of health inequalities in terms of poor housing, pollution etc. with people lacking the resources to change these factors (White, 2009; Popay et al., 2003). However, when using risk factor epidemiology one can sanitise structural health inequalities from accounts of illness (White, 2009). Meanwhile Zola (2019) reminds us that health, as we understand it, is imbued with notions of morality. If we can control our bodies and exposure to risk, then ill health is one's own fault (Zola, 2019). This highlights how socially the medical profession has changed over time, and with it ideas and approaches to health and illness. Importantly, what we are left with today is that illness becomes an observable abnormality within the body, steeped in moral connotations, and it is the job of professionalised doctors to detect and diagnose illness before prescribing treatments to return one to health (Lupton, 2003; Nettleton, 2013; White, 2009).

As doctors became more professionalised, and biomedical scientific ways of understanding the body became more commonplace, the previously integral accounts of patients – experiential accounts – as a means of diagnosing illness were marginalised or silenced in medical encounters (Nettleton, 2013). Changes to technology and medicine did not only change medical practices, and how we understand our bodies and illness, they also shaped how we societally value knowledge and legitimise some knowledge over others (Castiel, 2003; Nettleton, 2013). Castiel (2003) argues that what we see as the truth are socially constructed competing knowledge claims, legitimated and based on what we reason to be the most rational explanation. I argue, in the UK we value and legitimise biomedical knowledge of bodies over people's experiential accounts as the means of knowing the real causes of illness, and that this represents an epistemology grounded in the ideals of the enlightenment (Castiel, 2003; Prior, 2003; Lupton, 2003).

When speaking about the ability to claim legitimate knowledge, Jutel and Nettleton (2011) argue that the ability to diagnose and treat illness is a central legitimating component of the biomedical model of illness. Earlier I discussed Jutel and Nettleton's (2011) argument that a diagnosis is supposed to provide relief from unexplained symptoms. They further state a diagnosis verifies what is and is not disease, it provides us with reasons as to why we experience certain symptoms, it categorises and organises our symptoms and classifies us as legitimately ill with access to treatment (Jutel and Nettleton, 2011). I mentioned that fibromyalgia subverts this, as it is generally diagnosed

in the absence of biomedical tests, has an unclear prognosis and treatment options, and does not always provide relief to the person with it due to its subversion of conventional understandings of illness (Boulton, 2019; Sim and Madden, 2008). Additionally, studies on doctors' perceptions of fibromyalgia suggest they are frustrated and at times unwilling to engage with patients with fibromyalgia as biomedical models cannot explain people's experiences, nor offer definitive treatment to eradicate their symptoms (Åsbring and Närvänen, 2003; Harsh et al., 2016).

I argue that these studies suggest we have two broad and separate knowledges of illness: biomedical knowledge on one side, and experiential knowledge on the other. Within the sociology of health and illness, broadly speaking, the two concepts employed to understand how we know illness are expert and lay knowledge (Prior, 2003). White (2009) defines expert knowledge as that of doctors, surgeons, physiotherapists etc. who hold specialised knowledge of the body, symptoms of illness, and illness. Medical professionals then possess expert knowledge, this includes knowledge of how the body works, markers of illness, illness prognosis and treatment (Prior, 2003). Additionally, although there are multiple medical roles, for example a surgeon's job will differ from a GP, they still generally operate under a biomedical rationale that there are physical, detectable markers of disease within the body (White, 2009; Åsbring and Närvänen, 2003). Williams (2004: 119) defines lay knowledge as the "*ideas and perspectives employed by social actors to interpret their experiences of health and illness in everyday life.*" Within studies on the sociology of health and illness, this knowledge is a person's personal subjective experience of illness (Williams, 2004). Thus far when I have been referring to experiential knowledge, I have understood it as reflecting Williams (2004) lay knowledge. For clarity I will refer to it as experiential knowledge from now on, and demarcate when I am not using lay and experiential interchangeably. Though lay knowledge is never explicitly used within studies on fibromyalgia, in the absence of biomedical knowledge of fibromyalgia, lay knowledge and experience is implied to be extremely important.

Kengen Traska et al. (2012) highlight that a key strategy people use to manage their fibromyalgia is experiential knowledge of their bodily limits which helps them plan their day. Briones-Vozmediano et al. (2016) based in Valencia found their female participants with fibromyalgia organised their day around their symptoms of fibromyalgia.

Meanwhile, the participants with fibromyalgia in Armentor's (2017) study in California implied some of their family members could tell they were ill based on their behaviour and actions. Madden and Sim (2016) highlight, in their study of people with fibromyalgia, that over time people became experts at knowing their own bodies and could refute doctors' suggestions for sources of pain. These studies suggest experiential knowledge is important for medical professionals and people with fibromyalgia to manage their life with fibromyalgia and indicates that the relationship between biomedical knowledge and experiential knowledge may be more mutually informing than oppositional.

However, Michael Bury's (2012) work suggests we do not share the same understandings of experiential knowledge. Bury (2012) documents the rise in use of self-management practices to treat chronic illness in English and Welsh medical practice and policy in the 2000s. Bury (2012) demonstrates how policy makers drew on and misinterpreted research on people's lived experiences of chronic illness to devise healthcare modules teaching people how to self-manage their illness symptoms in order to reduce demand on the NHS. Bury (2012: 170) documents how designers of patient self-management programmes have taken research exploring what some people in contextually specific experiences of chronic illness do on a daily basis, and created it as an implied moral "*ought*". Bury's (2012) work suggests this means one has to manage one's illness in a certain way, and that how one undertakes this management becomes a moral issue. However, Bury (2012) questions why patients are required to attend self-management programmes for their illnesses if they themselves are supposedly experts in their own condition by virtue of their experiences. Blume (2017) argues that patients' experiential knowledge is promoted when it adheres to a biomedical model – e.g. a patient's experiential knowledge that prizes herbal remedies over pharmacological medicine tends to be marginalised. Returning to Castiel's (2003) earlier point that what we perceive as the truth consists of competing knowledge claims, then the marginalisation of some experiential knowledge over others suggests that experiential knowledge exists within a hierarchy. I argue that Williams' (2004) definition of lay knowledge is different from the self-management informing experiential knowledge spoken about by Bury (2012) as the latter requires attendance at specific classes so one can learn it. Therefore, I suggest experiential knowledge is subjective and has multiple meanings; we are not necessarily talking about the same types of knowledge when we use the terms experiential knowledge, lay knowledge etc. I argue we need to be mindful of how experiential knowledge can exist within a hierarchy and be

used by powerful groups for ideological ends. To make it clear, when I use the term experiential knowledge I am talking about people's ideas of health and illness which they use to understand their own experiences of health and illness (Williams, 2004).

Research also suggests that experiential knowledge is not the only form of knowledge that can be contested and be understood by people in multiple ways (Rees, 2011). Rees' (2011) study explored how forensic medical examiners (FMEs) created evidence and facts from interpretations of injuries on people's bodies. Rees (2011) found that FMEs diagnoses of the causes of wounds could change when shifted from a medical setting to a court of law where the credibility of their profession and the making of a correct diagnosis was under scrutiny. With regards to fibromyalgia, Åsbring and Närvänen (2003: 714) found that doctors were reluctant to "*sick list*" their patients with fibromyalgia as they were uncertain whether patients were sick or fabricating their symptoms. This tension arose from doctors being unable to biomedically see visible proof of their illness (Åsbring and Närvänen, 2003). I argue that Åsbring and Närvänen (2003), Rees (2011) and Bury (2012) all suggest both biomedical knowledge and experiential knowledge are not concrete single forms of knowledge, rather they are multiple knowledges which are understood and used by people in particular social, ideological and political climates. Through using the example of the UK welfare system, I will demonstrate how the competed and contested nature and tacit disparities in the valuation of biomedical and experiential knowledge claims surrounding illness may impact people with fibromyalgia.

### 2.2.1 Biomedical Knowledge Outside of the Medical Profession

In Section 2.2 I suggested that societally we understand illness through a biomedical model, and that illness can be contested if we cannot use a biomedical model to understand it (Boulton, 2019). However, I also suggested that this biomedical model can be understood differently by different people in different contexts e.g. from the medical profession to a court of law (Rees, 2011). In this section I use the example of the UK welfare system to highlight how people with biomedically contested conditions can also face challenges outside of the medical profession in gaining State support for their illness. Similar to arguments made by Zola (2019) around the morality of health and illness, the UK welfare system has been subject to morality debates of who does and does not deserve welfare since its conception (Englander, 1998). In the same vein of worry that people with biomedically contested conditions may be faking their illness, welfare debates are

informed by ideas that people will fraudulently claim welfare to avoid working (Åsbring and Närvänen, 2003; Englander, 1998). Government fears concerning fraudulent welfare claims have increased in the last 11 years, and there has been an increasing number of cuts to welfare – notably disability welfare – and a narrowing of the eligibility criteria, which has had significant impact on the lives of its recipients (Briant et al., 2013; Roulstone, 2015). This has resulted in the UK government increasingly assessing those with impairments to see whether they are eligible for benefits with an eligibility criteria that is increasingly shrinking (Roulstone, 2015).

Expanding on the themes of knowledge I discussed earlier in this chapter, I suggest there is an implied reliance on the legitimacy and power of biomedical knowledge to support welfare assessments (De Wolfe, 2012; Disability Benefits Consortium, 2019). Eligibility for disability benefits in the UK is determined based on an assessment of what one can and cannot do (Barber et al., 2019). A significant component of the assessment rests on a medical examination, and medical documentation – GP supporting letters, medical tests etc. – to prove one has an illness (Disability Benefits Consortium, 2019). De Wolfe (2012) researched the impact of these changes on people in the UK with Myalgic Encephalomyelitis (ME), an invisible illness similar to fibromyalgia with symptoms of chronic fatigue, muscle pain, muscle weakness, disorder sleep etc. (Åsbring and Närvänen, 2002). De Wolfe (2012), and a report by the Disability Benefits Consortium (2019) on the UK disability benefit assessment process, found that people with conditions which are invisible, or with medically unexplained illnesses – such as fibromyalgia and ME – find it difficult to receive disability welfare because these conditions are invisible in biomedical tests and daily interactions. These findings suggest that what is understood as biomedical knowledge is valued more highly than that of experiential knowledge outside of the medical profession (De Wolfe, 2012; Disability Benefits Consortium, 2019). However, I suggest it indicates how understandings of biomedical knowledge can be contested, as for the participants in De Wolfe's (2012) study and the Disability Benefits Consortium (2019) report a medical diagnosis was not enough to prove impairment in a welfare application. Their participants also had to undergo a new set of tests and provide various documents which the actors (welfare assessors) within this new process interpret as evidence of illness (De Wolfe, 2012; Disability Benefits Consortium, 2019). Therefore similarly to Rees' (2011) point above, I argue this demonstrates how hierarchies in knowledge extend beyond the medical profession, and that what constitutes legitimate

knowledge depends on who has the most power. I argue unpicking these hierarchies in knowledge is important as it can help us understand the experiences of people with fibromyalgia who may be marginalised by people's understandings of biomedical knowledge and fibromyalgia (Boulton, 2019)

Currently, we do not know what people with fibromyalgia in the UK's experiences of the welfare system are like, or whether they face any challenges in obtaining welfare. Crooks (2007) in Canada and Wuytack and Miller (2011) in Belgium stated that several of their participants' received State support. Ashe et al. (2017) in England mentions that some of their participants received disability benefits for fibromyalgia. They also highlighted their participants were impacted by UK welfare narratives of disability benefits which framed them as "*unwilling*" rather than "*unable*" to work (Ashe et al., 2017: 7). This study suggests people with fibromyalgia may be required to go through a disability assessment process within the UK. However, Ashe et al. (2017) do not tell us how people may experience the UK welfare system, and whether hierarchies of knowledge may impact their experiences. I argue that this is important as we can explore how people with fibromyalgia may be marginalised within society. In order to explore how people with fibromyalgia may be marginalised, I will look at theories of illness and how they account for people's experiences.

### 2.3 Theorising Illness

In this section I discuss theories of illness from Talcott Parsons, Erving Goffman, and Michael Bury, and how they have been used in research to explain people's experiences of invisible contested conditions and fibromyalgia. Generally speaking these theories belong to a body of work known as the sociology of health and illness, and many subsequent studies on people's experiences of illness have used the following theories. By drawing on the aforementioned hierarchies of knowledge, I will critically evaluate these theories to demonstrate how these hierarchies influence the theories discussed and how this impacts how we research fibromyalgia.

When discussing theories which can help us understand illness, American social theorist Talcott Parsons's (1951) sick role theory is one of the more well-known (White, 2009; Glenton, 2003). Parsons (1951) argued that everyone has a role within society. For example, according to Parsons, a mother's role is to raise and socialise their children into society, a father's role is to be the breadwinner working to bring money into the household

(Steele et al., 2012). Parsons (1951) argued that when a person becomes ill they must be diagnosed by a doctor to legitimately enter into the sick role, show others they are trying to get better – such as complying with doctors’ orders and taking medication (Parsons, 1951). It is their family’s responsibility to care for them in the sick role (Parsons, 1951). The sick role is a temporary state, and once a person is better they must return to work (Parsons, 1951).

Fibromyalgia subverts multiple parts of Parsons' (1951) theory as it is a chronic and invisible condition with no cure that doctors cannot explain biomedically (Harsh et al., 2016; Boulton, 2019). Nonetheless, Glenton's (2003) research on people experiencing chronic lower back pain demonstrates that although sick role theory does not explain the experiences of those with chronic illnesses, it can account for wider normative understandings of those around the person. Glenton (2003) found her participants lost legitimacy and support from those around them when they did not get better and return to work. Additionally, Thompson and Parsloe's (2019) explored the rationales used by people to help them determine how they knew a family member was faking having a chronic illness. They found that participants determined the veracity of family member's illness claims by using indicators such as their use of medication, proof of medical tests, consistent illness performances over time, the experiences of others diagnosed with the same condition, and participants own normative understandings of what they thought a condition ought to “*look like*” (Thompson and Parsloe, 2019: 1442). I argue Glenton's (2003) and Thompson and Parsloe's (2019) studies indicate we have wider normative ideals, and biomedical perceptions of illness which we use to understand illness within our lives. I suggest Parsons (1951) sick role theory could give us insight into wider normative ideals which can marginalise those with chronic unexplained illnesses such as fibromyalgia.

Erving Goffman's (1990) concept of stigma can build on Parsons' (1951) demonstration of normative understandings of illness and work by accounting for the experiences of those marginalised. Stigma occurs when a person is perceived to be deviant by a non-deviant majority, and based on this perception the person is then excluded, marginalised, or mistreated by the non-deviant majority (Goffman, 1990). Goffman (1990), unlike Parsons (1951), acknowledges what is deviant is socially constructed rather than embedded within a person. For example, Goffman (1990) argues a visibly impaired

person may receive stigma from others for looking different, but there is nothing inherently deviant about the stigmatised person, the deviance is created socially by the non-deviant majority group. Those without visible stigma can engage in passing – not disclosing their impairment to appear non-deviant to the majority, however this creates a constant threat of being discredited if their illness is discovered (Goffman, 1990).

In relation to fibromyalgia, Åsbring and Närvänen (2002) in Sweden documented the strategies their female participants used to avoid being stigmatised for their fibromyalgia in social situations. Participants would disengage with those they felt would stigmatise them, control the information they gave about their illness and engage in passing to conceal the impacts of their fibromyalgia (Åsbring and Närvänen, 2002). Some of Taylor et al.'s (2016) participants in England felt stigmatised by medical professionals and their employers due to fibromyalgia's invisibility. Armentor (2017) in her study in California highlights that her participants with fibromyalgia faced reputational stigma amongst family, friends and colleagues prior to a diagnosis as their behaviour and symptoms were unexplained. The same participants felt a diagnosis lifted the stigma they received from family and friends as it explained their condition, however others still felt stigmatised by doctors who would not acknowledge fibromyalgia as an illness (Armentor, 2017). These studies explore the emotional impact that being stigmatised can have, and suggest that there are wider norms of illness as a deviant state, and as something which has a particular aetiology and cure which impacts those with fibromyalgia as it transgresses these understandings. However, stigma and sick role theory do not help us in exploring how people make sense of their illness within their lives. For this I will discuss briefly Michael Bury's (1982) biographical disruption, and subsequent developments to his work.

Biographical disruption explores how people respond to a diagnosis, and the onset of serious chronic illnesses which disrupt their assumed life trajectories, identities and their taken for granted notions of the body as asymptomatic. In his study of people with arthritis in England, Bury (1982) highlights the importance his participants placed on finding a reason for their arthritis, and how they reshaped their biographies in relation to the illness to accommodate and manage their lives with the onset of symptoms (Bury, 1982). Carricaburu and Pierret (1995) in France added to biographical disruption by arguing that while their participants saw an HIV diagnosis as a biographical disruption, it also enabled them to engage in biographical reinforcement of their previous identities – either as gay



men, or as haemophiliacs. Asbring (2001) used biographical disruption to explore fibromyalgia, and found that the illness disrupted participants' imagined biographies and life trajectories. However Asbring (2001: 315) argues these disruptions were "*partial*" as many formed a new identity and changed their hobbies and interests to accommodate their physical capabilities. Asbring (2001: 316) mentions, but does not expand, on the idea that families themselves had to engage in "*biographical work*" in accepting their ill family member and themselves. Additionally Asbring (2001) highlights that the change of identity for the person with fibromyalgia could also impact relationships with partners and lead to separations. Asbring's (2001) work is important as it suggests that illness does not only disrupt people's lives and identities in a negative way, that it can be a means for people to develop new identities.

Wilson (2007) in Scotland has shown how identities could be disrupted and reinforced. She found that although her female participants experienced biographical disruption with an HIV diagnosis, their pre-existing identities as mothers who wanted to raise and care for their children were reinforced (Wilson, 2007). Bell et al. (2016) in exploring the progressive Meniere's Disease highlight how biographical disruptions can also be studied in the context of changes to family life over time: such as parenthood, and how changes in illness progression also cause disruptions to people's lives. Bell et al. (2016) conceptualised participants' experiences as biographical oscillations, where their normative expected life trajectories were challenged by the remissible and progressive stages of their illness. Wilson (2007) and Bell et al. (2016) indicate that our perceptions of norms of parenthood, age and time can also impact and interact with norms of illness to shape our lives.

I suggest biographical oscillation could capture people's experiences of the remissibility of fibromyalgia along with the series of disruptions felt by Asbring's (2001) participants. It can also enable us to explore these experiences in relation to various points during the life course, not just at one juncture as biographical disruption suggests. However, although Bell et al. (2016) argue they are responding to calls to extend biographical disruption into people's experiences of families, I argue they do not adequately interrogate the norms surrounding illness, family, and roles of motherhood, childhood etc. (Chambers, 2012). The daughter of one of Bell et al.'s (2016: 181) participants highlights that they feel "*grateful for each day of normality*" whereby remission days allow

participants to develop their relationships and family despite being ill. Bell et al. (2016) understand this respite from illness and the building of relationships as cherished time. I argue this does not challenge a wider assumption that cherished time implies time is only valued when the person is not ill, suggesting experiences of illness and loving family relationships are at odds with one another. Carol Thomas (2012), writing from a disability studies perspective, highlights the theories of illness discussed thus far all leave unchallenged the notion that illness is a socially deviant state. Illness within these theories is a definitive step away from the able body we once had, to a body that cannot work Parsons (1951), a body which experiences stigma or is under constant threat of being stigmatised (Bury, 1982; Carricaburu and Pierret, 1995; Goffman, 1990), or of a body that is unpredictably disruptive to family life (Bell et al., 2016). The studies above predominantly discuss people's experiences of chronic illness, and as such these studies do not explicitly fit Parsons' (1951) sick role theory of acute illness. This is despite the findings from Glenton (2003) and Thompson and Parsloe's (2019) studies which suggest that the experiences of chronically ill people may be evaluated through Parsons' (1951) understanding that illness as acute, visible and predictable. However, in some of these studies participants speak of their illnesses as flaring up: e.g. a brief intense spike of symptoms impacting a person in their daily life, followed by a remission (Wilson, 2007; Bell et al. 2016). From this, I suggest that illness is still conceptualised as acute periods where one's impairment effects fluctuate. Therefore, for the purpose of this thesis I define norms of illness as something which is visible, acute, with a clear aetiology, and that can be treated through pharmacological medication. Subsequently, fibromyalgia falls outside of the 'norm' of illness.

Shakespeare and Watson (2012) acknowledge that more contemporary sociology of health and illness theorists have started to discuss the inequalities and power disparities that people with impairments have – see Bury (2012) in Section 2.2. However, Shakespeare and Watson (2012) are critical that these analyses do not take a centre stage within studies. I agree with Shakespeare and Watson (2012) and argue these theories of illness cannot interrogate what Boulton's (2019) research has identified as wider biomedical epistemological rationales which can result in fibromyalgia's marginalisation. I argue that in order to explore Boulton's (2019) findings of a biomedical epistemological rationale that can marginalised fibromyalgia, and to critically evaluate the assumptions

made by illness theorists concerning illness, work and family life, we need to explore theories of disability.

## 2.4 Theorising Disability

In Section 2.3 I demonstrated that theories of illness have largely focused on people's individual experiences of illness, and the emotional and physical pains it can cause. Conversely, disability studies within the UK started from the opposite perspective (Barnes et al., 1999; Bury, 1982; Bell et al., 2016). In the UK, up until the 1980s, disability was primarily viewed as a personal tragedy experienced by an individual (Barnes et al., 1999). UK policy relating to the support of disabled people focused on either the institutionalisation, or normalisation of disabled people (Barnes et al., 1999). People who were institutionalised were placed in care homes, hospitals etc. (Barnes et al., 1999). People who experienced normalisation faced invasive medical procedures by doctors to eradicate their impairments (Barnes et al., 1999). The underlying ideology of normalisation states that to be disabled means one is socially deviant, and that the purpose of medicine is to normalise disabled people and give them a socially valued role in society (Barnes et al., 1999). In reviewing the history of disability in the UK, Barnes et al. (1999) highlight the damaging impact a socially deviant approach to impairment can have on the lives of those with impairments. I argue we need to be mindful of this history when theorising and researching chronic illness.

In the 1970s and 80s grassroots disability activists argued that disability was a form of societal oppression, rather than the possession of a deviant body (Barnes et al., 1999). Michael Oliver's (2009) social model of disability encapsulates this argument as he argues people are disabled by society, not their impairments. Oliver (2009) argued that disability occurred through the physical design and capitalist economy of UK society that tacitly assumes that one is not blind, deaf, in a wheelchair etc. (Oliver, 2009). Morris (1991) and Swain et al. (2003) argue that this model was transformative to the lives of disabled people as rather than being told by professionals and society that they are the problem, it argued society was the problem. Oliver's (2009) model suggested that to be disabled is to be part of an oppressed category one could identify with, and be able to fight for rights and equal participation within society (Morris, 1991). Morris (1991) and French (1999) acknowledge the contribution Oliver's (2009) model played in supporting

and empowering disabled people, however they criticised his understandings of disability as underplaying one's experience of one's own body and impairment.

In the 1990s feminist disability theorists Morris (1991) and French (1999) argued that Oliver's social model overlooked the emotional and physical pains and impacts that impairments have on a person, that cannot be eradicated through changing the physical and economic structures in society. I argue this is important when considering fibromyalgia as previous studies have documented in detail the impact its impairment effects can have on a person (Åsbring and Närvänen, 2002; Paulson et al., 2002; Armentor, 2017). Carol Thomas (2004) expands on Oliver's social model of disability to amalgamate the social oppression a person with impairments can face alongside the emotional and physical pains impairment can cause. Thomas (2004) argues disablism and impairment effects bridges this gap as disablism refers to acts of discrimination, physical and/or emotional violence against people with impairments similar to racism and sexism, while impairment effects concerns the physical and emotional pains of having an impairment. Donna Reeve (2002; 2012; 2014) built on Thomas' (2004) work by coining psycho-emotional disablism (PED) which focuses on the internalised oppression disabled people have (what they feel they can and cannot do) which stems from society's disabling physical structures and social attitudes which devalue a disabled person. However, Thomas (2004) and Reeve (2002; 2012; 2014) do not reconcile a wider debate on whether chronic illness such as ME or fibromyalgia can be considered a disability where one has a disabled identity (Crooks, 2007; Wendell, 1996; 2001).

Wendell (1996; 2001) asserted her ME was a disability as at times she is disabled by society, and at other times by the impairment effects of her ME. However, Owens (2015) criticises the disability movement for relying on one to identify as being disabled in order to campaign for disability rights, as it may marginalise those who are chronically ill, but do not identify as disabled. In turning to people's experiences of fibromyalgia in Crooks et al.'s (2008) study on women with fibromyalgia only 28 out of their sample of 55 identified as disabled. I argue this suggests there may not be a coherent disabled identity amongst those with fibromyalgia. Additionally, as Keith and Morris (1995) and Olsen and Clarke (2012) highlight, a disabled identity is only one aspect of identity - similarly to Wilson (2007) and Bell et al.'s (2016) studies on illness - and that people with impairments also have identities as parents.

In Sections 2.3 and 2.4 I have discussed how social theorists and researchers have conceptualised issues of disability and illness, and the impact it has on a person's life. I have highlighted that sociology of health and illness approaches often perceive illness as a socially deviant state, while disability studies often highlight it is society which disables people with impairments in addition to impairment effects. I argue theories from the sociology of health and illness may not be able to conceptualise people's experiences of fibromyalgia as they do not detail issues of social oppression or normative roles of families which people may experience (Thomas, 2007; Keith and Morris, 1995). However, I propose that disability theories may also not be able to conceptualise people's experiences of fibromyalgia as Crooks et al.'s (2008) study highlights it is not clear whether people with fibromyalgia identify as disabled. I argue we need to use the theory of ableism to critically grapple with the normative understandings of illness and to maintain a theoretical approach which can account for social oppression while avoiding the presupposing of a disabled identity on those with fibromyalgia (Campbell, 2009). The following section will now explore ableism in more detail.

## 2.5 Ableism

Fiona Campbell's (2009) theory of ableism explores the processes and practices within society which determine who is, and is not, able rather than disabled. Campbell (2014) is critical of the biomedical and social models of disability which only attribute one factor to people's oppression (in this case an impaired body or capitalism). Campbell (2014) argues that we experience multiple sources of oppression through various daily processes and practices. These processes and practices are born from the processes and practices which came before them – in other words they are interdependent and exist for as long as the conditions which contribute to their production and reproduction exist (Campbell, 2014). To relate this to the current study, I am arguing that rather than conceptualising changes within the medical profession to a biomedical model of illness as a structural change, I argue the processes of understanding and diagnosing illness and the practice of this understanding of diagnosis and illness changed how we perceive the medical profession (Lupton, 2003; Campbell, 2014). Campbell (2014) asserts the endurance of practices over time gives the impression that something has a concrete structure. However, by using processes and practices what we conventionally understand as societal structures become more fluid and malleable to change (Campbell, 2014). This fluidity

allows us to see how the medical profession changes over time – such as the expansion of diagnostic criteria (Campbell, 2014).

Campbell (2009; 2019; 2014) uses her conceptualisation of processes and practices to then explore what processes and practices exist within society to create and maintain the ideal of an able body. Campbell (2014) argues all societies have a culturally and socially relative understandings of a “*species-typical*” being who we all compare ourselves to, and are compared to by others (Campbell, 2009: 5). Like processes and practices, Campbell (2014) argues this ideal is constantly changing due to changes in technology and the medical profession. However, Campbell (2019) argues this able ideal endures due to the divide between able and disabled which rejects the bodies that fit in-between. The processes that maintain this divide are purification – the mechanisms that diagnose our bodies as able or unable, and translation - which categorises our bodies to fit within these diagnoses. Campbell (2009; 2014) acknowledges that most of our bodies do not fit neatly into a diagnosis (i.e. processes of purification). However, through translation she highlights how the able/disabled dichotomy can be maintained, and how those with contested illnesses – such as fibromyalgia – can have their experiences marginalised (Boulton, 2019; Armentor, 2017). Campbell (2014) asserts we cannot escape ableism, however, she acknowledges that we can challenge it.

Campbell (2014) draws on microaggressions from critical race studies to highlight how words, looks etc. can be used to marginalise people in daily interactions. She argues that we can challenge ableism through these micro-interactions by subverting the codes (norms) of who and what are assumed to belong to certain spaces (Campbell, 2014; 2019). An example of this could be in a doctor’s understanding of fibromyalgia and their perception of it being a legitimate illness. Over time this could lead to changes in perception across the medical community and thus fibromyalgia then becomes an accepted illness. Additionally, Campbell (2019; 2014) suggests that by studying how we compare ourselves to others, and through reflecting on why we are doing so, we can learn about the wider norms which influence aspects of our lives and experiences. I suggest ableism can help us explore the processes that create illness as deviant, while also accounting for the societal oppression people may face. To illustrate this I will now demonstrate in the following section how ableism can help us understand norms of what it is to be a worker and how this might impact people with fibromyalgia.

### 2.5.1 Fibromyalgia, Ableism and Employment

In a keynote address Campbell (2014) discusses the ideal of an ableist unencumbered worker, one who does not have people to care for such as children, or ill and older relatives, who can be available whenever their employer needs them, who does not have to do housework, and is not themselves impaired. Drawing again on Glenton's (2003) study of people with chronic back pain, her participants were expected to fill the role of an unencumbered worker until they were deemed legitimately ill and placed into the temporary sick role. I argue this not only illustrates my definition of norms of illness above, but that it also is indicative of an ableist ideal of a worker who does not experience impairments. Juuso et al. (2016) in Sweden explored women's experiences with work and fibromyalgia and argued part-time hours, adjustments to their work environment and employer and colleague support could help people with fibromyalgia stay in employment, and quell financial worries of losing work. However, several studies indicate barriers in how this support could be implemented. Juuso et al.'s (2014) participants in Sweden highlighted that their work was not supportive of them when they experienced painful fibromyalgia symptoms. Taylor et al.'s (2016) female participants in England who were unemployed felt their bosses were unsympathetic to fibromyalgia due to a lack of understanding of the condition and the stigma surrounding it. Ashe et al. (2017) in England suggests that UK welfare narratives may reduce employers' willingness to employ people with impairments. The participants of Ashe et al.'s (2017) study experienced fibromyalgia, and the authors argue participants' impairment effects and the understandings of fibromyalgia held by participants' employers and colleagues impacted their participants' ability to retain employment. Crooks (2007: 586) study on women with fibromyalgia in Canada highlighted that her participants struggled to retain employment, that losing employment impacted their finances, which resulted in a loss of socialisation with colleagues, and that many participants were impacted by no longer feeling like a "*productive worker*" which the author implies was important to them. Lastly, Palstam and Mannerkorpi (2017) in reviewing studies on people's experiences of work and fibromyalgia highlight that some studies suggest having a colleague with fibromyalgia can be a cost to the productivity of the workplace. I argue these studies suggest people with fibromyalgia can face adverse experiences at work based on an amalgamation of ableist understandings of what it is to be a worker, a lack of knowledge and understanding of fibromyalgia, fibromyalgia's impairment effects and that this can cause people

financial difficulties. Additionally, Söderberg et al. (2003) highlight that loss of work also impacts families, as families could face economic difficulties as their family member with fibromyalgia was no longer able to work.

With the exception of Ashe et al. (2017) and Crooks (2007), the studies above often attribute people's difficulties in retaining employment to the impairment effects of fibromyalgia. However, I argue that when we consider people's experiences through ableism, we can critically interrogate why some studies indicated that having colleagues with fibromyalgia was viewed as a cost, and why other employers were unwilling to understand or accommodate employees with fibromyalgia. I argue that we do not know enough about people with fibromyalgia and their families' experiences of employment, particularly through a theoretical framework such as ableism. I argue that ableism can help us explore both the norms that I highlighted as underpinning theories of illness, worker etc. that impact people's experiences, and explore how these norms can marginalise people with fibromyalgia who may not have a unified identity – such as that of disability (Crooks et al., 2008; Campbell, 2009; 2014; 2019). I suggest in using ableism we can critically interrogate the norms that lead people to stigmatise those with fibromyalgia (Åsbring and Närvänen, 2002; Armentor, 2017). Additionally, I propose ableism provides us with a framework that can also expand on Boulton's (2019) research highlighting the existence of a biomedical rationale which defines illness and that marginalises and excludes fibromyalgia. I argue this means we can interrogate the processes of purification and translation, the epistemologies and processes and practices that facilitate them, and maintain the previously identified hierarchies in knowing illness which operate to marginalise fibromyalgia. Ableism could help us address two gaps within the literature. First, what people and families' understandings of fibromyalgia are, considering that fibromyalgia is an illness that subverts norms of illness and biomedical understandings of illness. Secondly, what are people and families' experiences of public institutions – such as work and welfare - when we consider that we have societal ideas of an able body and worker, and processes and practices that work to maintain this ideal.

However, although Campbell (2009; 2019; 2014) provides insights into understanding oppression and norms, she does not look at the emotional relationships between people within daily life, which Bell et al. (2016) have highlighted also impacts experiences of illness. Notably, within disability studies there have been numerous debates on normative



ideas of family and childhood, and presumptive connotations of care (Keith and Morris, 1995; Aldridge and Becker, 1993a). Therefore, while ableism could contribute to conceptualising our understandings of how families understand fibromyalgia, and public bodies, I suggest to explore families' daily experiences of fibromyalgia we need to understand the wider theoretical and policy contexts of family and care within the UK. I detail this in the following section.

## 2.6 Families in Policy and Theory

In this section I highlight how policies on care within the UK are formed based on a tacit assumption that families will provide informal support for those with illnesses. I draw out normative and ideological assumptions of family within UK policy, before exploring sociological theories of family life. Within the context of wider policy, and of contemporary family theories, I then define how I understand family within this research.

The social model of disability, grassroots activism by disability activists, and changes to neo-liberal market economies contributed to the de-institutionalisation of many disabled people who would then receive care within the community (Morris, 1991; Evans, 2003). This was met with criticism from non-disabled feminist academics who argued it would be women who would primarily undertake this care work, as normative gender roles suggested women would do the bulk of the physical and emotional care work out of altruism, selflessness and self-sacrifice (Dalley, 1996; Ungerson, 1983). Meanwhile, disability feminist academics criticised these arguments for assuming that they did not have families, nor provide care for their loved ones (Morris, 1991; Keith and Morris, 1995). During this time, Aldridge and Becker (1993a; 1994; 1996) promoted research into young carers by researching instances in which children under the age of 18 provided care for an adult family member – usually a parent. These early studies suggested the children of disabled parents were effectively parents of their parents due to the amount of care work they had to perform (Aldridge and Becker, 1993a; 1993b; 1994; 1996). These studies were met with significant backlash from disabled parents, however they were also picked up by academics and third sector charities concerned for children's welfare (Olsen and Clarke, 2012; Keith and Morris, 1995; The Children's Society, 2013).

These debates, though diverse, are connected by wider normative assumptions of the family, and the role of the family within UK society (Edwards et al., 2012). Dalley (1996) argues that there is an assumption within policy on care that people have families, and

that these families will provide an element of informal care for their loved ones. However, the debates and controversy around young carers highlight that who provides this care is as important as the actual provision of care (Aldridge and Becker, 1993a; Keith and Morris, 1995; Aldridge, 2018). I believe it is important to acknowledge these debates as families' experiencing fibromyalgia may be living within the context of these discourses around care and childhood. Additionally, these debates indicate that care is a very politically and emotionally loaded concept that is empirically situated and, within a UK context, is embedded within ideological understandings of family (Morris, 1991; Dalley, 1996; Aldridge, 2018). In this section I will unpick ideological assumptions of family and family roles, before exploring in detail where families, care and illness interplay.

As I suggested with the young carers debates above, family within the UK can be associated with very entrenched values and exclusionary ideologies. Gillis (1996; 1997), in exploring the history of the idea of family, has highlighted how this family is a social construction; up until the mid-19<sup>th</sup> Century motherhood, fatherhood and childhood were viewed as states that could be learned. By the 1950s a functionalist view of the family was dominant, and again Talcott Parsons' understanding of the nuclear family is one of the more popular normative ideas of family (Chambers, 2012; Steele et al., 2012; Smart, 2005). The nuclear family was the optimal modern family of two parents and two children who could meet the demands of a capitalist society (Chambers, 2012; Smart, 2007). According to Parsons, just we have a sick role, we also have family roles (Parsons, 1951; Chambers, 2012). In this context I understand roles as something we feel we ought to do if we are a mother, father etc. Parsons' argued that the family's function was to support the development of children, who the family would socialise to be good members of society (Steele, et al. 2012). According to Parsons' role of fathers was to be breadwinners, while mothers' roles were to stay at home, perform domestic labour and raise the children (Steele, et al. 2012).

This is understood as the traditional nuclear family (Chambers, 2012; Smart, 2005), which Chambers (2012) notes was viewed as morally superior to other family forms. Jenks (1996), writing from the perspective of the sociology of childhood, highlights how ideas of childhood as an idyllic state of innocence underpin the nuclear family as understood by Parsons. He argues that families who are unable to live up to this ideal, e.g. if parents have an impairment, can then face intervention from the government to

maintain children's experiences of childhood as an idyllic state of innocence (Jenks, 1996). Jenks (1996) asserts that constructions of parenthood are a product of particular constructions of childhood. Gillis (1997) highlights childhood and motherhood have changed over time to become biologised, rather than learned states, and these changes have shape law and social expectations which place the onus of children's care on women. Gillis (1997) argues fatherhood and motherhood have swapped places, as historically fathers would raise children, however he argues fathers are now located within the periphery of family life. Therefore, in debates on care policy within the UK we can better understand the panic inspired when it was thought that children provided care, rather than women, as this appears to transgress both family norms, and socially constructed biological categories (Dalley, 1996; Aldridge and Becker, 1993a; Aldridge and Becker, 1996).

However, this is not all there is to the family. David Morgan (1996; 2011) and Carol Smart (2007) have worked to allow a reconceptualization of the family from the nuclear image. Morgan (1996; 2011) argued to conceptualise the family as a verb, rather than families and their members having roles. Family then becomes constructed based on the actions people do, and reinforced and defined by a continuation of these actions (Morgan, 1996; 2011). Smart (2011) argued that research needs to pay more attention to the multidimensionality of family life, and to aid this she proposed various concepts which could help us explore this. Smart (2011) states these concepts do not have to be discussed together as a definitive key to exploring families lives, but she does argue it is hard to write about one concept without drawing on the others. In this thesis I primarily draw on Smart's (2011) concept of relationality to explore families' lives and practices. However, I acknowledge that in doing so I will at times draw on her interlinked concepts of memory, embeddedness, biography and imaginary. I am also using Smart's (2007; 2005) Personal Life perspectives on love and commitment to characterise the emotional relationships and practices between family members. I will briefly discuss these concepts and then define how I plan to use them.

Relationality is how we live and make decisions in our daily lives in relation to others; embeddedness highlights how lives are linked as it is impossible to remember ourselves without it being in relation to another person or the people who have gone before us; memory is informed by those around us and how we shape past events to contribute to

ideas of family; biography explores how we create stories of ourselves, our families and who we are over time through family photos etc.; imaginary concerns how we imagine our relationships could be (Smart, 2011). Smart (2011) draws on Gillis' (1996) idea of “*the families we live ‘with’*” e.g. the families we have in our daily lives, and “*Families we live ‘by’*” which are our ideals of family that we try to enact in our daily lives (Smart, 2011: 27). Gillis (1996; 1997) suggests that by doing culturally relative, and historically specific practices of family life such as birthdays, Christmases etc. we are reassuring ourselves, and reproducing, the family values we live by, even if the families we live with are not reflected in our practices (Gillis, 1996; 1997; Smart, 2011).

Smart (2011) demonstrates that her concepts of relationality, embeddedness, biography, memory and imaginary can be used to explore emotionally fulfilling family practices, and shared histories. However, she argues that these concepts can be used to explore emotionally suffocating and physically harmful relationships in cases of abuse, and through the power of having a shared relational history they can be something that ties people down (Smart, 2011). Despite this acknowledgement, Smart (2011; 2007) has been criticised by Gilding (2010) and Edwards et al. (2012) for taking a micro-interactional performative view of family life, as it can undermine how ideals of family can be used to exclude and marginalise people. For this reason they also critique Smart's (2007) appeal to move from a sociology of family to a sociology of personal life (Gilding, 2010; Edwards et al., 2012).

Gilding (2010) and Edwards et al. (2012) argue that by only studying the micro everyday interactions of families, researchers could miss the wider institutional and ideological systems within society that express and enforce their practices through a normative lens of the family. Gilding (2010) acknowledges that fluid forms of family offer more to the sociological study of family life than that of previous theories such as functionalism. Nonetheless, Gilding (2010) argues that a focus on family practices and their diversity could also mask the endurance of certain family practices which are valued over others. Family practices can be dynamic and fluid, however they can also be engrained normative practices that endure over time (Morgan, 2011; Gilding, 2010). Edwards et al. (2012: 740) attribute increased policy intervention to a renewed focus on narratives where “*good*” parenting and the family are needed to protect children and secure a harmonious future society. Edwards et al. (2012) and Murray and Barnes (2010) highlight that within

professional services and government reports there is an emphasis on parenting as the main stabilising force within a child's life. This emphasis does not consider the underlying structural issues facing families such as poverty, illness, and discrimination that can cause challenges within people's and families' lives. Edwards et al. (2012) remind us that the family ideals we live by are as every bit as important as exploring the personal lives of the families we live with. If families do not make the "*correct*" choices when engaging in family practices with those they live with, they can face government intervention and marginalisation on behalf of the imaginary of the families we live by (Edwards et al., 2012: 739).

I previously mentioned that parents with fibromyalgia may be affected by normative understandings of the family within the UK due to debates on the appropriateness of children providing care which were influenced by ideological notions of childhood (Jenks, 1996). When we turn to studies exploring families' experiences of fibromyalgia, many are silent on whether norms of family impact people's experiences. I argue that in exploring normative understandings of family we can get a more nuanced comprehension of families' experiences of fibromyalgia (Paulson et al., 2003; Arnold et al., 2008; Rodham et al., 2010; Wuytack and Miller, 2011). Paulson et al. (2002) found in Sweden that fathers with fibromyalgia felt sadness at playing less with their children due to their illness. Paulson et al. (2003) also found that female partners of men with fibromyalgia were supportive of their husbands and felt frustrated that their husbands would not communicate their symptoms. Paulson et al. (2003) participants felt their children could suffer because of the illness and felt the need to protect them from it. Söderberg et al. (2003) qualitatively interviewed the male partners of women with fibromyalgia in Sweden. They found that partners had a sense of loss around previously shared activities that they could no longer do together such as hill walking (Söderberg et al., 2003). However, the men also acted as advocates for their partners in settings where their illness was challenged such as meetings with doctors or welfare assessments and felt they had stronger relationship with their children due to their wife's fibromyalgia as they were more involved in their children's lives (Söderberg et al., 2003). Arnold et al. (2008), in their focus groups with women with fibromyalgia in the US, highlight that participants felt they missed out helping their children with homework. They state that their female participants felt burdensome to their families, and that their relationships with their partners suffered as their partners had to take on a larger share of domestic labour and

had a reduced sex life (Arnold et al., 2008). Wuytack and Miller (2011), in Belgium, found fibromyalgia impacts experiences of family as mothers with fibromyalgia felt guilt at spending less time with their children, and social outings decreased. Within these studies the authors do not reflect on why the mothers in their sample feel guilt, or like burdens to their family, and the fathers in their sample feel sad (Arnold et al., 2008; Wuytack and Miller, 2011; Paulson et al., 2002). I suggest that the emotions expressed by these participants indicate the normative power of family practices which Gilding (2010) and Morgan (2011) use to explain why some family practices and ideals of what it is to be a family, a mother, a father and so on endure over others.

A reason for omitting norms could be that most of the debates around families have occurred within the UK, and most of the studies that I am drawing on are not from the UK (Smart, 2011). However, even studies from the UK have relied on normative assumptions. For example, Rodham et al. (2010) in their study on women with fibromyalgia and their partners state that fibromyalgia made the women in their sample more dependent on their husbands. They state their husbands' had taken on the role of "wife", as caregiver to their partners, while the women take on the dependent role as "child" (Rodham et al., 2010: 70). The authors see no problem in making these conclusions, they rely on normative understanding that a wife is a caregiver, a husband is an autonomous agent, and a child is dependent in order to invoke the loss fibromyalgia creates for these families due to the changing of these roles (Rodham et al., 2010; Somerville, 2000; Jamieson, 1998). Therefore, they take family norms for granted to emphasise the loss that fibromyalgia invokes within participants' lives. Given the emotional impact that previous studies have reported around motherhood, being a partner, and childhood, I suggest people's perceptions of norms of family may impact their family practices more than previous studies have suggested and that it is important to keep this in mind when researching families with fibromyalgia (Smart, 2011; Gilding, 2010).

I understand families in this research to be the people that my participants live and experience their daily lives with, but also the wider ideals and norms of the families they may live by, and how this might inform their experiences (Gillis, 1996; 1997; Smart, 2011). I argue that this definition can aid in exploring the practices families do in relation to one another with regards to chronic illness (Smart, 2011; 2007). I also argue that this conceptualisation of family can acknowledge wider policy agendas and normative

enduring ideals of family, childhood, motherhood etc. potentially held by people and others, and how these might inform peoples' lives (Edwards et al., 2012; Gilding, 2010). However, norms and daily practices of families are only one aspect that impacts their lives. Having defined family and discussed ideals and norms, we now need to explore how these constructed aspects of family could impact how we think, write, speak and do care in the context of the families we live with. In the next section I briefly summarise care as understood within policy, before exploring experiences of care as discussed within studies on chronic illness. I then explore what we know about care in relation to fibromyalgia, before outlining the research questions.

## 2.7 Families and Care

The discussions in Section 2.6, concerning UK policy on family, highlighted that tacit assumptions of family roles meant that women would provide care for young, older and impaired relatives (Dalley, 1996). I discussed the controversial debates around young carers and the fear that children might be providing care. I also mentioned that feminist disability scholars such as Morris (1991) and Olsen and Clarke (2012) were critical of non-disabled feminists for assuming that disabled women did not have families and provide care for them. In this section I discuss families and care in more detail. I start by reviewing studies of caregiving within families without chronic illness, and the norms that inform this. I then explore how care has been conceptualised in studies where a family member has a chronic illness. I end this section by detailing how I define care within this study, I highlight the gaps in our knowledge and how this relates to fibromyalgia.

Finch and Mason (1993), in a study on the caring relationships within families in Manchester, found that families engaged in temporal processes of negotiating family responsibilities of who provides physical, emotional, and financial care. While age and gender impacted who would provide care, employment commitments or childcare could exempt people from caring (Finch and Mason, 1993). Finch and Mason (1993) found that the shared relational and care histories of families were just as important in deciding who would provide care within families. Their participants saw care as a reciprocal and normal part of family life where care would be provided in the knowledge that this act would be repaid in the future (Finch and Mason, 1993). Charles et al.'s (2012) study of families caring relationships in the UK found that gender impacted the type of care provided e.g. participants felt women were better at providing child and older relative care, while men

were better at giving practical support like driving or decorating. However, Charles et al. (2012) emphasises the reciprocity of care within families, and the expectation of participants that actions will be repaid. The authors acknowledge that care is gendered, yet in detailing care as negotiations amongst family members, care becomes something more complex than the debates on child carers and informal community caregiving imply (Finch and Mason, 1993; Charles et al., 2012). Yet, these studies do not tell us about caring relationships in which a family member has a serious chronic illness, or whether this changes relationships of care between family members.

In exploring chronic illness, Cheung and Hocking (2004) and Öhman and Söderberg (2004) interviewed families using a phenomenological hermeneutic approach. Cheung and Hocking (2004) conceptualised care as worrying, amongst the spousal caregivers whose partners had multiple sclerosis (MS), as they argued that worrying could be an act of care through thinking through acts of potential or actual perceived problems, which causes the person to care more. Öhman and Söderberg (2004) juxtapose the emotionally and physically taxing and stressful aspects of care and feelings of guilt if their family members were to receive residential care, with family members feelings that providing care was rewarding. Their participants stated they felt like a “*mother*” or “*nurse*” to their ill family member in attending to their family member’s basic needs (Öhman and Söderberg, 2004: 401). Yet, Öhman and Söderberg (2004) leave the normatively ideological implications of this – which is reminiscent of Parsons (1951) idea of family norms - undiscussed when reviewing their findings.

Cheung and Hocking (2004) and Öhman and Söderberg (2004) demonstrate that care is a complex multifaceted concept, however they overlook family relationships and norms of family by focusing on family members as caregivers and care receivers. This could be because these studies explored terminal illnesses (Öhman and Söderberg, 2004; Cheung and Hocking, 2004). I will now explore studies looking at understandings of family and care in non-terminal chronic illness to look into how these three aspects may interact, and what this could tell us of families’ experiences of care and fibromyalgia.

Corbin and Strauss (1985), in the US, found that families frequently negotiated household tasks in the context of chronic illness. Corbin and Strauss (1985) state non-ill family members placed a lot of importance on perceiving these negotiations to be reciprocal. Despite emphasising the flexible balancing acts families engaged in to manage chronic



illness, their account mainly highlights the diminished role that an ill family member has (Corbin and Strauss, 1985). Corbin and Strauss (1985) treat illness as a socially deviant trait of the ill family member, whom the authors emphasise should be made to feel loved despite being ill. Corbin and Strauss (1985) do not question wider ableist norms of illness, or norms and family and whether these impact peoples' experiences (Gillis, 1996; 1997; Edwards et al., 2012).

Richardson et al. (2007) in England explored families' experiences of chronic pain. They used Goffman's ideas of norms and identity management and Hochschild's theory of emotion work to argue that care within families can be a reciprocal daily negotiation of needs and identities, rather than a relationship of carer and caregiver (Richardson et al., 2007). They argue emotion work is a form of care as non-ill family members considered the emotions and preferred identity of their ill family member to decide what support to provide in a situation to maintain this identity (Richardson et al., 2007). Although Richardson et al. (2007) speak of reciprocity, they still view illness in a socially deviant paradigm, and at the centre of families' experiences. For example, they question a participant's account that her loss of identity as a mother stems from her daughter's aging and changing needs rather than because of her own illness (Richardson et al., 2007). Additionally, they underplay the role of emotions in family caring relationships i.e. people manage emotions, implying emotions are something that are controlled not felt. However, we know from Cheung and Hocking (2004) and Öhman and Söderberg (2004) that non-ill family members feel emotions when caring. I suggest care for Richardson et al. (2007) is in part about protecting the emotions and identities of the person with the illness from their socially deviant body (Richardson et al., 2007). Although, Richardson et al. (2007) do imply that those with illness have more agency in caring relationships in providing care, and that family relationships are more interdependent. I argue that we need an understanding of care that can highlight the agency of the ill family member, explore how family norms may impact participants' experiences, and explore emotional aspects of relationships and providing care for ill and non-ill family members (Richardson et al., 2007; Öhman and Söderberg, 2004; Cheung and Hocking, 2004).

When we look at wider studies of illness, care, families and childhood, they suggest a sense of interdependency within relationships. Wilson (2007) found, in her study on mothers' with HIV, that her participants provided care and raised their children, and

implied that their children could provide care by helping their mothers when they were ill. However, Wilson's (2007) participants stated a desire for their children to have a normal childhood that does not involve their child seeing the impacts of their illness. Evans and de Souza's (2008) study on mothers with chronic pain and their children in New Zealand contradicts Wilson's (2007) study by suggesting the mothers in their sample were more dependent on their children, rather than the two being interdependent. Årestedt et al. (2014) interviewed families with an array of chronic illnesses in Sweden and found that families adapted what they did around illness. Årestedt et al. (2014) do not offer an explanation as to why families did this. However, they do suggest adapting to chronic illness required families to be flexible, and change their activities to suit the person with the illness, while enabling them to spend time together (Årestedt et al., 2014). Årestedt et al. (2014) conclude that families are interdependent, and together they found ways to live together in the context of chronic illness.

In reviewing these studies I argue family members have complex and multiple relationships to one another, rather than that of carer and caregiver, and that care may depend on the severity of one's illness. Additionally, while Årestedt et al. (2014) suggests families may change what they do to accommodate for illness, Wilson's (2007) study suggests there is a complex interplay between perceived family norms we live by, and the realities we live in.

When exploring fibromyalgia we have limited knowledge of caring in families. Briones-Vozmediano et al. (2016) interviewed women with fibromyalgia in Valencia and argued that fibromyalgia impacted their participants feminine identity as it meant they could no longer engage in the gendered expectations they felt they ought to engage in, such as caring for their family, housework etc. Briones-Vozmediano et al. (2016) highlight that as the women in their sample hid their emotions from their children, they were engaged in cultural understandings of feminine identities where other's needs go before their own. Their participants felt they were transgressing their roles as wives due to the loss of physical intimacy caused by fibromyalgia symptoms (Briones-Vozmediano et al., 2016). By exploring the impacts of fibromyalgia on gender identity and family relationships, Briones-Vozmediano et al. (2016) remind us of Bell et al. (2016) and Keith and Morris's (1995) point that there is more to those with fibromyalgia/disability/chronic illness than the lived experience of these illnesses. These studies highlight people are also mothers,

grandparents, friends, and fathers etc. who live alongside others, and that these relationships can inform how they view care within their lives (Briones-Vozmediano et al., 2016; Bell et al., 2016; Keith and Morris, 1995).

I argue the above studies suggest care in families can be reciprocal, flexible, stressful, emotional, performed by various family members and embedded within wider norms of family that can inform aspects of people's identities. For this reason, I understand care as an ordinary complexity (Elden, 2016). Elden (2016) found that care could be emotional, physical, and that it differed socio-economically. For example, childcare enabled some parents to work and maintain a middle class socio-economic status, but for other parents childcare was a necessity so they could work and pay bills. Elden (2016) argues that this care is an ordinary complexity in her participants' lives as her participants saw the care as ordinary, though the reasons for it, and its practice, were complex. I am taking Elden (2016) approach to care as it encompasses the ordinariness of care suggested in previous studies (Finch and Mason, 1993), while also acknowledging how societal inequalities can inform caring relationships. By taking an approach to care that does not come with presumptions of reciprocity, burden, caring and gender identities etc. while also accounting for structural inequalities, I aim for participants' understandings of care to inform this research. I argue this is particularly important within the context of fibromyalgia as little is known about how families care, and whether norms of family impact them. Previous studies suggest they do (see (Briones-Vozmediano et al., 2016), however we do not know how this translates to a UK context, nor do we know the experiences of multiple family members.

## 2.8 Conclusion

Most of the studies on fibromyalgia discussed within this review have focused on people's experiences of fibromyalgia (Åsbring and Närvänen, 2002; Paulson et al., 2002; Undeland and Malterud, 2007; Rodham et al., 2010; Armentor, 2017). Within some of these studies there has been a lack of critical engagement with experience and how it can be informed by wider tacit assumptions of illness, knowledge, and other social norms (Åsbring and Närvänen, 2003; Boulton, 2019). For example, by focusing on stigma there is a lack of acknowledgement of wider societal ideals and disparities in how we value knowledge (Åsbring and Närvänen, 2002; Armentor, 2017). Fibromyalgia studies that only focus on experiences of illness can overlook people's relational experiences with

family (Asbring, 2001). However, fibromyalgia studies exploring family can take family norms for granted rather than engage with them and how they may shape people's experiences (Rodham et al., 2010; Arnold et al., 2008; Wuytack and Miller, 2011).

In reviewing the literature on fibromyalgia and surrounding disciplines of the sociology of health and illness, disability studies/studies in ableism, and the sociology of family, I have aimed to highlight the gaps within current knowledge around people's experiences of fibromyalgia. Firstly, we lack information on how people within families understand fibromyalgia. This is important in the context of how illness and illness knowledges are normatively viewed and legitimated, and when we consider that previous studies on fibromyalgia have associated families as sources of support and stigma (Söderberg et al., 2003; Armentor, 2017). We lack information on how knowledges of illness are legitimated and valued in institutions like work and welfare, and how this might impact the experiences of people and families with fibromyalgia. However, knowing this is important as it could highlight wider societal attitudes towards fibromyalgia, and what support people feel may, or may not, be available to them. Lastly, we do not know what families with fibromyalgia understandings' of their daily experiences are, and whether wider norms of family life impact their understandings. This is important as research suggests norms of family life have tacit assumptions around the ability of family members that may impact families' experiences. In drawing together Campbell's (2009) ableism and Smart's (2011) understandings of relationality, embeddedness, memory, biography, and imaginary, I will address these gaps through answering the following questions:

- 1) How do people with fibromyalgia and their family members understand fibromyalgia?
- 2) How do people with fibromyalgia and their family members understand their experiences of life outside of the home?
- 3) How do people with fibromyalgia and family members navigate everyday domestic and social life?





### 3 Chapter Three: Methods

#### 3.1 Research Aims

In the previous chapter I highlighted gaps within the existing literature and research on fibromyalgia. To address these gaps, I am conducting an exploratory study on people's understandings of their experiences of fibromyalgia within the UK. In this chapter I will discuss my epistemological position in conducting this research, the research design of this project - and how it worked in practice. I will then discuss the ethical issues that I had to consider when conducting this research. Lastly, I will explain and detail how I conducted my analysis with reference to my epistemological position.

#### 3.2 Epistemology

I started this thesis by critically appraising epistemological positivism as understood and situated at the heart of biomedical paradigms of illness whereby illness is aetiological and measurable within the body. In rejecting positivisms' rationality, objectivity and insistence of universal truth, I epistemologically locate myself and my thesis within interpretivism. Crotty (2015: 67) argues that interpretivism "*looks for culturally derived and historically situated interpretations of the social life world.*" Interpretivism posits that there are multiple lived realities that people experience within their lives, rather than one objective reality with concrete social phenomenon which we can impartially measure (Bryman, 2016). My thesis explores participants' and my own interpretations and perceptions of their lives and experiences with reference to the wider historical and cultural factors that could influence us. I understand wider cultural and historical factors to mean, for example, the dominance within Western knowledge and conceptions of ontology for, as Campbell (2009: 6) terms "*the 'species-typical body' (in science), the 'normative citizen' (in political theory), the 'reasonable man' (in law).*"

Blaikie (2000: 115) defines interpretivists as being:

*Concerned with understanding the social world people have produced and which they reproduce through their continuing activities. This everyday reality consists of the meanings and interpretations given by the social actors to their actions, other people's actions, social situations, and natural and humanly created objects. In short, in order to negotiate their way around their world and make sense of it, social actors have to*

*interpret their activities together, and it is these meanings, embedded in language, that constitute their social reality.*

I am using Blaikie's (2000) understanding of interpretivism as I argue this understanding helps us get a sense of how participants interpret their daily practices, but also how these practices may be interpreted by participants in relation to wider norms of illness, ability, and family. Though I approached my research project from an interpretivist epistemology, by exploring participants' interpretations of their lives, and through my own critical reflection of the relationships within their lives, my epistemological positioning began to change. I began to understand their experiences as characteristic of aspects of postmodern liminality and as defying the able/disabled dichotomies, the knowledge and ontologically ableist understandings of the body typical of Western biomedical science (Lupton, 2003). By postmodern liminality I am referring to postmodernism's propensity to eschew dichotomous binaries characteristic of modernism such as nature/culture, emotion/reason etc. (Crotty, 2015). By 'ontologically ableist' I mean peoples' understandings of their bodies where a lack of impairment is the natural state of being, and where illness is visible, and measureable as discussed in Section 2.2, where I argued the rise of the modern medical profession created ideas of healthy and ill bodies. Although I conducted and analysed this research with an epistemology of interpretivism, in the context of my findings my epistemological position has shifted slightly to that of a postmodern understanding as I understand my participants' experiences as being situated between socially constructed ontological binaries (Crotty, 2015).

Mason (2002: 149) highlights that reading data interpretively will involve the researcher "*constructing or documenting a version of what you think the data mean or represent, or what you think you can infer from them.*" She also notes that "*A reflexive reading will locate you as part of the data you have generated, and will seek to explore your role and perspective in the process of generation and interpretation of data.*" While participants interpret their own lives and lived realities, I too interpret my own lived reality and that of others and am intrinsically not detached from this research. I come to this research with my own personal biases that I had to be reflexive of when designing the research and interacting with participants (Mason, 2002). This is why I elected to using 'I' within the research, as opposed to 'the researcher', to be mindful of my own assumptions and



presence within reviewing the literature, constructing the research questions, conducting the research, the analysis and the writing up. Specifically, having a parent with fibromyalgia, and as such relating to a lot of the research that explores the experiences families have with the illness on a personal level, meant that I had to be particularly careful and reflexive on my stance towards the research. However, this does not mean that I did not use my personal background to inform aspects of my research design such as the interview schedule. My personal background at times helped me in asking participants questions whose answers I felt were missing in others' accounts of people's experiences of fibromyalgia. For example, when asking whether fibromyalgia would impact time spent with family. Before I move onto the research design in question, I have one last point to discuss about reflexivity and my personal background with the research.

Adamson (2014) in discussing the role of insider and outsider in her research with psychologists in Russia, promotes the argument that insider/outsider are not dichotomous positions, rather they operate on a flexible continuum. For example, at times Adamson's (2014) participants treated her as an insider in interviews, as like her participants she had been educated in psychology in Russia and was Russian herself. However, Adamson (2014) discusses instances in interviews where her insider status was questioned, for example when she asked questions about practicing psychology that her participants felt she should know the answers to (i.e. have insider knowledge on). Within this research I identified strongly with Adamson's (2014) position that insider/outsider positions are on a flexible continuum. This is what I mean when I use insider/outsider within my research.

My participants did not make me feel like an outsider in the way that Adamson (2014) describes. However, I feel it is useful to conceptualise insider/outsider as a fluid continuum rather than a static position when I reflect on my research. Furthermore, I think my experiences of insider and outsider exemplify the sentiment expressed by Mason (2002) who challenges the assumption that by sharing the form of oppression that her participants face, she as a researcher then has insider knowledge of the oppression which her participants experience. On one hand I felt like an insider as understood by Adamson (2014) because I have experiential knowledge of fibromyalgia having grown up with a family member who has it. It was this experiential knowledge which prompted my interest in the experiences of families and family members, rather than only focusing on the experiences of individuals with fibromyalgia. However, I felt in part like an outsider as I

do not have fibromyalgia and thus do not have an intimate understanding of the embodied experience of fibromyalgia. Additionally, my family member did not have a diagnosis of fibromyalgia while I lived with them, meaning at times I did not relate to the struggle families expressed in getting fibromyalgia recognised as it was unknown to my family until I was an adult living outside of my parents' house. From this, at times I felt I had insider knowledge with my participants, and at other times I did not. I do think my personal experience of having a family member with the illness gave me an insider status when conducting interviews that I felt helped within the data collection process. This is because I was viewed as someone understanding, sympathetic, and acknowledging of fibromyalgia as an illness. I feel this was important given how misunderstood fibromyalgia is, and particularly because I was asking participants to tell me, and trust me, with aspects of their personal lives.

By discussing this my aim is to acknowledge how feeling like an insider and an outsider was something of a fluctuating experience for me within this research, and that I am not situating my experiences of fibromyalgia as experiences in which my participants may share (Mason, 2002). I acknowledge that the way I have conducted my research within my thesis will be informed by my own cultural, social and personal history, in other words an amalgamation of the literature I have read, my own personal experiences and the social research training I have received (Bryman, 2016). By having personal experience of a family member with fibromyalgia it gave me some ideas on areas in which to ask questions. However, these were also guided by my professional background as a researcher and the wider literature I had read on the area, so as not to impose my experiences and topics I found interesting, on that of my participants (Mason, 2002).

### 3.3 Research Design

Within Section 2.2 I criticised attempts to measure and generalise what I understood as the personal illness experiences of others (Blume, 2017; Bury, 2012). Mason (2002) argues that qualitative research has the following characteristics: a basis in an interpretivist epistemology, is conducted with adaptable research methods rather than structured, standardised methods, and whose analysis, explanation and argument forming focus on the intricacies of the data. For this reason, I chose qualitative over quantitative methods as I wanted to use methods that would allow me to explore the nuances of people's understandings of their everyday lives.

Prior to data collection, I explored a wider range of methods which could help me understand people's experiences. I could have conducted individual focus groups with people with fibromyalgia and their family members. However, I was interested in people's perceptions of the relationships within their own lives, rather than how they interpreted these within groups (Bryman, 2012). I considered using participant observation where I would observe families' daily practices to understand their experiences (Bryman, 2012). However, I felt this would be incredibly intrusive on families as the literature highlights how fibromyalgia taxes one's physical and mental resources (Briones-Vozmediano et al., 2016), and I felt having a researcher within the family home for an extended time could aggravate this. Additionally, as fibromyalgia is an invisible, subjectively experienced illness (Boulton, 2019), I did not think I could then observe how their lives could have been impacted by fibromyalgia in as much detail as I could have if I asked them within interviews. I also considered using online methods. Davis et al. (2004) conducted online and face to face interviews with men with HIV in London. In a paper comparing the two methods (Davis et al., 2004), argued that online methods enabled them to access hard to reach populations. However, they felt the data they obtained in interviewing people in online chat rooms was not as rich as data from the face to face interviews, and they lost a lot of nuances such as tone and body language (Davis et al., 2004). They also argued it was hard to interpret meaning within the transcripts as the responses were more ambiguous. Davis et al. (2004) argue that online synchronous interviews (e.g. interviews conducted in chat rooms) could supplement face to face interviews, and that asynchronous interviews (e.g. through email) may be useful to give participants more time to reflect on responses. Online interviews (synchronous or asynchronous) may have enabled me to access participants who I could not travel to (as I am unable to drive) or who would not be able to make a face to face interview. However, I was particularly interested in how participants understood their experiences and the meanings they attributed to them. Therefore, I chose not to do online interviews as I shared Davis et al.'s (2004) concerns that it would not provide me with rich, contextual data which I could then analyse to interpret participants' understandings of their experiences.

For these reasons I chose the methods detailed below, which themselves came with their own complexities in conducting.

Initially, I had proposed a three-stage research methodology to understand the experiences of families with fibromyalgia. These stages involved:

- 1) An initial exploratory semi-structured interview with individual consenting family members.
- 2) A written (or audio recorded) account of a time someone was supportive to a person's fibromyalgia, and a time when someone was not.
- 3) An interview based on the written accounts.

My intention was to sample 10 families with these methods. I aimed to recruit a person with fibromyalgia, and members of their family as defined by them: such as but not limited to children, partners, siblings, parents, or their friends. I planned to include anyone who was 10 years old or older, with the capacity to give informed consent. I chose 10 as the cut off age as Wuytack and Miller's (2011) adult participants suggested their (non-participating) children under the age of 10 were not old enough to understand fibromyalgia. Personally, I feel this perspective goes against what I have written and believe about the sociology of childhood in Section 2.6 where I argue children are competent social actors. Interestingly, in interviews many of my participants highlighted that the age of their children appeared to matter when understanding fibromyalgia, with younger children – subjectively defined, and non-unanimously held by my participants as ages that ranged from 6 to 13 – being viewed as less understanding of fibromyalgia. I also felt at 10 years old people may be going from primary to high school, thus changing their social relationships and possibly the people they could go to for support. I found it hard to recruit young people for this study, most of the participants who put themselves forward either had adult children, or did not have children. Those who did have children stated they wanted them to take part, however the young people themselves did not want to. I am not sure why this is the case, and while I feel future research should explore in more detail children's understandings of fibromyalgia, including those under 10 where possible, it might also be difficult to recruit young people. For a breakdown of the sample for this research, see Section 3.4.3.

The methods I used were informed by my reading on methodology, and came from an understanding that different methods are means to capture different aspects of people's lived realities (Mason, 2011). Stage 1 interviews were an exploratory look into people

and families interpretations of their lived experiences with fibromyalgia. Stage 2 written or audio accounts were to capture their interpretation of their lived realities in another way, as theoretically participants could reflect on events they may not have felt comfortable talking about, or may not have mentioned in the interview (Bell, 1998). Bell (1998) highlights that diary methods can be used to explore participants' emotions towards certain topics that they may not feel comfortable expressing within an interview. I had hoped that diary methods would provide me with emotional data if participants were unwilling to discuss emotional issues within interviews. The diary-based interviews in stage 3 were a means for me to ask participants about various aspects of what they had written and were comfortable to discuss, and how their presentation of themselves and others within the diaries could be reflected (Spowart and Nairn, 2014). See the Appendices in Sections 10.1 and 10.2 for the diary based interview guides.

In practice, I only managed to conduct this approach with one of my 17 families. I started data collection in October 2017, and found it hard to recruit participants using this method. I liaised with fibromyalgia support group organisers and asked them for feedback on my research design. They advised me that three stages was a lot for people with fibromyalgia, given the fatigue and pain associated with the condition and all the other responsibilities and events within their lives. After receiving this feedback I modified my methods. I could have kept the diaries and interviews within the research design and eschewed the third stage. However, similar to Davis et al.'s (2004) concerns on the abstractedness of online data, the written diaries that were conducted required follow up interviews as my reading of the diaries alone was not sufficient for me to understand the significance of the entry to the participants.

As someone who does not experience fibromyalgia, chronic pain or fatigue, upon reflection, my initial research design was ableist in that I did not acknowledge how fibromyalgia may or may not have impacted people's willingness and energy to take part (Campbell, 2009). However, at the same time, this runs the risk of appearing disablist in assuming those with fibromyalgia could not take part only due to fibromyalgia, rather than an amalgamation of the multitude of social responsibilities they had which would limit the time they had to participate (Thomas, 2012; Smart, 2011). The diaries which were conducted did expand on some relationships discussed in the initial interviews, and the follow up interviews of these were a good chance for me to clarify things within them

and ask other questions I wanted to ask. However, I found that once I started to practically gather my data the method which suited both my participants and my wider research aims was that of semi-structured interviews. Despite this, I would recommend future studies to consider these methods alongside interviews to provide the diaries with context. However, I argue researchers must consider how much they are asking participants to do and the energy and resources involved in doing it.

### 3.3.1 Semi Structured Interviews

To answer the research questions, I used semi-structured interviews. I discuss in this section why I chose semi-structured interviews, for how these worked in practice please see Section 3.4.5. Bryman (2016) argues that there are broadly three types of interview. Structured interviews where one asks all participants the same set of pre-selected questions. Unstructured interviews where the researcher is guided by one question, and through listening to the participant's response, they may follow up unwritten questions on events that seem of interest to the research (Bryman, 2016). Lastly, there are semi-structured interviews, where the researcher follows a general interview guide, questions may not be asked in a uniform manner like structured interviews, participants have a lot of scope to respond, and participants can ask questions. I chose semi-structured interviews for this project so that it would enable me to ask questions surrounding the gaps I had identified within the literature, while also allowing participants to ask questions and discuss topics I may have missed within the research design (Bryman, 2016). I am in no way claiming this research was participant led, as I am aware that by doing this method and writing the interview schedule, I very literally set the agenda for the interviews (Mason, 2002). However, I felt semi-structured interviews would enable me to follow up and modify my interview schedule to ask questions and raise issues that initially I did not think would be important, but that participants found important (Bryman, 2016). This was important to me when designing the research as another means to prevent imposing my lived experience of fibromyalgia on that of my participants (Mason, 2002). Earlier I mentioned that my personal experiences with fibromyalgia gave me ideas on where to ask questions for families' experiences, these largely related to usage of things like public transport, physical and logistical access to it and affordability, and were backed up by wider literature (Crooks, 2007). I devised two separate interview schedules, one for over 16s and one for those under 16s. For details on the interview schedules, see the Appendices in Sections 10.3 and 10.4.

Stroh (2000) argues that interviews should be similar to conversations, by this he means as researchers we need to ask open-ended questions. Harding (2006) warns us of creating subjects through interview designs, and Thomas (2008) in her interviews with end of life cancer patients highlights that had she only asked about people's experiences of cancer, she would not have obtained as rich a level of data about people's understandings of support and care. Inspired by this approach I started by asking participants what their daily routine was, and participants at times interpreted this in relation to how fibromyalgia impacted them, at other times they did not and I would then follow by asking whether fibromyalgia impacted it. This enabled me to see how they positioned themselves, those around them, and fibromyalgia within their lives. I argue that by not making an assumption that fibromyalgia would impact their lives, participants then gave me rich details of all the other relationships, and daily responsibilities within their lives, to which my follow up questions could ask whether fibromyalgia impacted them. I used Richardson et al.'s (2009) life grid approach which they argued was beneficial for participants with chronic illness to map their lives, and their perceptions of support over time after the onset of illness. However, I adapted this by getting participants to map their relationships to people within their lives which I felt could offer a more detailed discussion of their relationships. I also felt this could jog people's memories about who they can ask for support in a similar way that life grids can cause people to remember events (Richardson et al., 2009).

Phone interviews were not in my initial research design, I obtained an ethical amendment to conduct them. I did this because as I recruited participants across the UK, it became more practical to give participants the option to being interviewed over the phone, or face to face. In this sense, it was up to them whether they would prefer to meet in person or talk via phone. Bryman (2016) argues that phone interviews might make it easier to discuss sensitive topics with participants, as the interviewer is not physically in a room with them. On reflection, I felt participants were possibly more open with me when being interviewed over the phone. However, I cannot be sure as to whether this was because: they felt more comfortable talking about potentially private issues; or, whether it was solely related to being interviewed over the phone.

I felt phone interviews came with a series of advantages and disadvantages which I am going to discuss. I felt the advantages to phone interviews were that they enabled me to

access participants who lived too far away for me to travel, or who would not be well enough to interview in person. I felt this was extremely important in helping highlight the voices of people who otherwise would have been marginalised had I only conducted face to face interviews. Another advantage is that I found it easier to write notes during phone interviews. This was because as the participant was not in front of me, I did not feel I had to maintain eye contact and take part in other visual cues which are often required in face to face interactions (Bryman, 2016; Irvine et al. 2013). Notes were useful for me to keep track of what we discussed in the interview. However, during face to face interviews, I often felt self-conscious taking notes despite explaining to the participant that they were things I wished to follow up on, as I did not want the participant to think I was writing things about them. I found it easier to take notes during phone interviews as it made me feel less self-conscious about doing so. Lastly, phone interviews meant: I was less exhausted from travelling to research locations; I felt well rested as I had not travelled for hours to meet a participant; I was in a university environment which I felt comfortable in; and I did not have to face the logistical challenges of public transport, nor my own anxieties of meeting strangers in their homes.

However, phone interviews came with their own set of disadvantages. For instance, I agree strongly with Bryman (2016) that a disadvantage of phone interviews is the lack of visual cues from participants on whether they are uncomfortable or confused by a question. At times I found phone interviews frustrating due to the lack of visual cues. It was harder to get a sense of how the participant responded to my questions because I was not able to see their facial expressions or reactions to my questions, nor when they were recounting their experience. In hindsight, visual cues were a great help to me in face to face interviews for determining the mood of the participant and their feelings towards people and events. These cues would prompt me to ask additional questions. It was harder to do this in phone interviews as I could not see the participant, and I could misinterpret their reactions. For instance, in a phone interview a participant was yawning but I thought they were crying. Long pauses within the phone interview made me feel the line had been disconnected, when the participant was just thinking of a response. This made me worried in case the participant felt I was trying to hurry them up.

I used various strategies to overcome these challenges. For example, I remained silent when a participant paused in a phone interview to see if they would continue talking. This



was also a strategy I employed in my face to face interviews to enable a participant to fill the silence and keep talking. However, I argue remaining silent in phone interviews was more important because sometimes participants would stop talking at my interjection and we would lose the thread of the conversation and what they were discussing. Therefore, silence became a means to help me obtain valuable data during phone interviews. Note-taking was another strategy which helped me overcome the lack of visual cues. Note-taking provided me with a physical record of what we had discussed, and topics I wanted to follow up on. Despite being similar to the function of notes in face to face interviews, I felt notes were imperative for me to keep track of the conversation in phone interviews in a way that they were not in face to face interviews. By this I mean in face to face interviews I could remember a participants' word choice, their tone, their facial expressions and make a mental note to return to this. In phone interviews I had to listen closely to what the participant was saying, and by putting most of my concentration into understanding what the participant was telling me, it was harder to recall tone and word choice without using notes to remind me.

In addition to the challenges posed by a lack of visual cues, Timbrook et al., (2012) identify background noise and connectivity issues as challenges to conducting phone interviews because it can be harder for people to hear one another, and requires repeated clarification of questions and answers. I found this to be the case in some interviews, as phone signal would fade in and out and make it harder for me to understand the participant. Asking for clarification was challenging because I did not want to frustrate the participant by having them continuously repeat themselves. However, I felt asking for clarification in phone interviews was comparable to asking for clarification when interviewing face to face in a noisy café and the challenges this poses with background noise. Lastly, similar to face to face interviews, I gave participants the option to draw relational maps over the phone – this process will be discussed later in this chapter.

Overall, phone interviews came with their own advantages and disadvantages. Nevertheless, despite missing the visual nuances that I could have obtained from face to face interviews, I do not regret using phone interviews as they enabled more participants to take part, and I feel their benefits outweighed the negatives.

### 3.4 Researching in Practice

#### 3.4.1 Recruitment and Data Collection

After I obtained ethical approval from the University of Stirling's General University Ethics Panel (GUEP), I started recruitment. In the research design, my main idea was to recruit participants' through putting posters in public spaces and pharmacies, and contacting fibromyalgia and carer support groups. Within the first few months of data collection, I contacted various pharmacies across central Scotland asking to advertise my research with a poster, my reasoning being people might see the advert when collecting medication (see Appendix 5 in Section 10.5). Public spaces involved having posters in community centres and sometimes shops. I liaised with fibromyalgia and carers organisations as mentioned above and asked if I could advertise my research on any notice boards and at monthly meetings and if the staff could make people aware of the research project. It was around this time (End December 2017) that I changed my data collection from the three stage process to semi-structured interviews, and at this point (7<sup>th</sup> December 2017) I also obtained a GUEP amendment to conduct interviews by phone.

Physical posters in public spaces, and attending support group meetings had limited success in obtaining participants, and ultimately I only recruited three families from fibromyalgia support groups, and none from carers associations or public posters. I was given the opportunity to post an advert on an online forum in Mid-January 2018 and received an overwhelming number of responses.

The change of research design coincided with the online advertisement, and as such I am unsure as to whether it was the reduction of methods, or this different recruitment space which promoted more people to want to take part. It could have been a combination of the two. With the advent of the online advert, I was rapidly overwhelmed with responses of people wishing to participant (mid-January 2018). This resulted in rapid data collection. Conventional research practice highlights one should conduct an interview, transcribe and reflect, then conduct more interviews (Stroh, 2000). I found that the longer I took to respond and set up interviews the harder it was to engage people in the research, and I had found this population extremely hard to access prior to the online advert. Therefore, the majority of my data collection was between January and March 2017 (12 people and families). As recruitment took place online, some participants lived too far for me to travel to them via public transport. Due to this, interviews were a mixture of phone

(n=7) and face-to-face (n=24). I took a break from research after March 2018 to transcribe my data. In June 2018 I recruited and interviewed three more families before ceasing data collection and focusing solely on transcription. The break gave me a better sense of my data, and of things which I felt were becoming important to the research and this then helped my direction in interviewing the final three families, for example in asking whether participants felt the weather impacted their fibromyalgia. Rather than change the interview schedule directly, I kept notes on a separate sheet of paper to ask about things such as medication during the interview.

Prior to conducting the research, I had designed information sheets for participants based on age: one for those over 16, and two for those under 16 (see Appendices 6, 7, and 8 in Sections 10.6, 10.7 and 10.8). These sheets were for potential participants to look at to provide more information/to allow them to decide whether they would like to take part. Once participants had read them and agreed to be interviewed, on the day of the interview I provided them with additional copies of the information sheets and answered any further questions they may have had about the research. In all cases, the person with fibromyalgia had to be interviewed for the interviews to take place. This was not to deny the voices of other family members. However, I felt, and it was decided between my supervisors and I, that it would be unethical for families to speak about a person's illness if the person with it did not want to discuss it. Where all family members agreed to take part we would sign consent forms. I had two separate consent forms, one for participants over 16 (see Appendix 9 in Section 10.9) and one for participants under 16 (see Appendix 10 in Section 10.10).

#### 3.4.2 Location and Sampling

This research took place across the UK via face to face and phone interviews. I recruited most participants from physical and virtual fibromyalgia support groups, and online advertisements on social media. A few participants were recruited through my own social networks; however, I had never met or interacted with any of the participants prior to setting up interviews. I purposely sampled participants, they had to have a diagnosis of fibromyalgia, or have a family member/friend with fibromyalgia (Bryman, 2016). I also recruited some participants through snowball sampling where participants introduced me to others who wanted to take part in the research (Matthews and Ross, 2010). It must be noted that in contacting participants I used what I called my research phone, I did not use

my personal phone mobile. I also made the choice to interview people with fibromyalgia where none of their family members wished to take part to see how they spoke of support and if it was spoken about differently than by families where multiple members took part.

### 3.4.3 Participant Demographics

17 families were recruited in total which resulted in 31 interviews (two participants were interviewed twice). This broke down to 17 individuals with fibromyalgia, 15 families where the person with fibromyalgia and their partner (all married) were interviewed, and 3 families where the person with fibromyalgia and their child were interviewed. In one instance the child was under 16. All participants lived within the UK, some in England (n=3) and others in Scotland (n=26). A minority of participants (n=4) were not originally born in the UK. All participants who were in relationships were primarily in heterosexual relationships at the time of interview. The ages of participants ranged from 12 to their 70s. In addition, four participants were medically retired (three with fibromyalgia and one without). Five participants were unemployed at the time of interview (four with fibromyalgia and one without). Six participants worked full-time (one person with fibromyalgia and five partners), five participants worked part-time (all with fibromyalgia), one participant had a flexible working arrangement (with fibromyalgia), two participants volunteered (one with fibromyalgia and one without), two participants were university students (both with fibromyalgia), two participants were school students (neither had fibromyalgia). For a more detailed breakdown of participants' relationships see Table 1 below.

**Table 1: Participant names and relationships**

<b>Family</b>	<b>Person with Fibromyalgia</b>	<b>Family Member</b>
Family 1	Louise	Michael (husband to Louise)
Family 2	Paul	
Family 3	Ana	
Family 4	Heather	Duncan (husband to Heather)
Family 5	Andrea	
Family 6	Greg	Samantha (wife to Greg)
Family 7	Lily	
Family 8	April	
Family 9	Paige	Gordon (husband to Paige)
Family 10	Cheryl	Ewan (husband to Cheryl)
Family 11	Abby	
Family 12	Claire	Benjamin (husband to Claire)
Family 13	Vicki	Daniel (husband to Vicki)
Family 14	Olivia	Emily (daughter to Olivia)
Family 15	Hannah	Eve (daughter to Hannah)
Family 16	Natasha	Jacob (husband to Natasha)
Family 17	Jessica	Jack (husband to Jessica) Lucy (daughter to Jessica)

**To return to Section 4, click the [hyperlink here](#) and scroll to the second paragraph.**

My sample is supportive of wider literature on fibromyalgia which highlights that more women than men have fibromyalgia as 14 of those interviewed with fibromyalgia were women, and two were men (Boulton, 2019; Armentor, 2017). However, this could also be attributed to more women offering to take part than men.

I have deliberately chosen not to display participants' employment status alongside their pseudonyms to protect their confidentiality and chances of being identified. Despite doing this I cannot guarantee that participants will not be identified. However, their confidentiality is important to me and I wanted to protect this as best as I could.

Interviews lasted between just over an hour to 2 ½ hours, with an average time of an hour and a half. Where interviews took place in participants' houses, all bar one family was interviewed in the same day, as it was more convenient for them. This was easier for me in that I only had to make one journey to participants' houses, but it was harder when gathering data as it could result in interviewing multiple people for a duration of five hours. In the case of phone interviews, these could occur at different times that suited my participants. I transcribed my data throughout the data collection, and I frequently discussed my initial interpretation of themes within the interviews and transcriptions with my supervisors. When I had collected 50 hours of data they encouraged me to stop data collection and start transcribing and coding my data.

#### 3.4.4 Arranging Interviews

Stroh (2000) highlights that interviews generally involve power disparities in which the researcher has more power than the interviewee from having initiated and organised the interviews. I let participants decide where they would like to be interviewed: in their home or in a café. I did this so to make it as easy and unobtrusive for them as possible. When interviewing participants face to face I tried to set up the interviews so that we were not sitting opposite one another as this might appear intimidating, rather beside or perpendicular to one another. This was not always possible when I interviewed in a public space such as a café, or if I entered a participant's house and they told me where to sit, and chose a seat for themselves which was opposite to me. However, by interviewing participants within their houses it readdressed (though never mitigated) some of the power

imbalances as they could dictate where I sat, and where I was allowed to go (Elwood and Martin, 2000).

Prior to obtaining consent I also made sure that I had an information session in which I explained the research to the participants, went through the information sheets with them and answered any questions they may have had. I did the same in phone interviews, asking participants if they had read the information sheet, and again explaining the research to them and answering any questions they had.

Face to face interviews were conducted either in participants' houses or in a café. (Elwood and Martin, 2000) point out that while the home can be a source of oppression, it can also be a source of comfort where people can conduct interviews. Wilson (2007) highlights that when interviewing mothers with HIV that conducting the interview without being overheard by other family members was very important to some of her participants. With this in mind when interviewing in participants' houses, the other family members often left the room to give the interviewee and myself privacy to do the interview, as I felt participants may not feel able to speak in front of other family members and it could have caused some uncomfortable family power dynamics. Therefore, family members were not present in the interview in all but one instance, which I discuss in Section 3.6.4. In cases where family members were not present, they were in other rooms within the house, occasionally in the next room, and often further away in the house or upstairs. I could not guarantee the interview would not be overheard in other rooms of the house, and this was detailed within the information sheets. After informing participants of these issues, I left it up to their discretion as to what they felt comfortable to discuss.

During the interviews I gave participants the option to map out people who were supportive and unsupportive to them. We were then able to discuss the relationships in relation to fibromyalgia, and what they meant to the participants in more detail than was covered in asking participants about their daily lives. Participants could return to their maps throughout the interview and add relationships that they may have forgotten as they went on. This allowed us to continually explore their relationships throughout the interviews. Some participants were eager to draw maps and colour coded them based on whether the person was viewed by the participant as supportive or unsupportive, seen as family, friend, a health professional, and at times the distance of the lines participants drew indicated emotional or physical closeness. I found this method useful, and would

recommend it for future research on relationships. However, not all participants wished to engage with it. I do not think that non-engagement with the maps impacted the data collected, rather using them was a means to facilitate data collection, rather than as a primary method.

When conducting phone interviews, I booked a room in the university to prevent being disturbed and had my participant on loudspeaker while I recorded the interview. In this instance participants gave verbal consent which was audio recorded. Before starting the interview, I asked participants if they were in a comfortable and private space to do the interview so they would not be interrupted, and if they would not mind being on loudspeaker while I recorded. The research phone I used to contact participants was also used to conduct phone interviews. Participants were still given the option to do relational maps. However, in this instance the participant and I were not able to interact with the maps as we were in face to face interviews as we could not see each other and I could only inquire about relationships participants informed me of. Although maps could still serve to jog participant's memories of people they had relationships with, it was not as easy to use them to demarcate physical closeness or distance as some participants had in face to face interviews. I do not think this impacted the data collection dramatically as not all participants interviewed face to face were enthusiastic about mapping their relationships. However, this example does highlight the challenges of attempting visual methods through non-visual mediums such as phone calls.

#### 3.4.5 Reflections on Practice

I viewed this study as an exploratory study given the lack of data on family perspectives on fibromyalgia, particularly within the UK, and my participants' as the people with knowledge of this (Paulson et al., 2002; Wuytack and Miller, 2011; Rodham et al., 2010). Because of this, flexibility in the interview schedules was extremely important to me. By exercising flexibility within my research practice and adapting my interview schedule to be mindful of issues participants were identifying as important, this enabled me to explore topics I did not initially think would come up. For example, I mentioned earlier that I was able to adapt my interview schedules to ask about issues that participants felt were important to them such as medication. At the end of the interviews, I asked participants if they felt there was anything left uncovered in the interviews, and at times this also led to interesting insights and discussions I may not have gotten with either unstructured or



structured interviews. Additionally, I felt that my gender identity as being female meant that my predominantly female sample of those with fibromyalgia may have been more open to me in discussing personal issues of motherhood, pregnancy, sex etc. However, this is my impression and reflection on the interviews and participants with fibromyalgia did not remark on whether my gender identity made it easier for them to speak to me. This also does not mean that the men in my sample were less open with me for being female rather than male, which emphasises that this is my reflection rather than something which I feel certain of.

If participants had not asked me already, I informed them during or prior to the interviews that I have a parent with fibromyalgia. I feel this may have helped me build a rapport with participants as someone who understands the condition, as at times participants would suggest we had a shared understanding of our experiences. I argue this may have been important considering how misunderstood fibromyalgia can be by medical professionals (Armentor, 2017). However, this is my own reflection, not something that I am sure participants felt.

### 3.5 Ethical Considerations

I faced a multitude of potential ethical issues I had to consider when preparing to do research with families. This section will cover ethical issues in conducting research in the context of informed consent, data storage, participant harm and harm to the researcher.

#### 3.5.1 Informed Consent

Kent (2000) highlights that informed consent involves: giving participants information about the research and anything that might influence their willingness to participate; making sure potential participants understand what the research is about and what is involved; making sure their participation is voluntary and that they are not coerced by others; making sure participants have the capacity to consent, for example if they have dementia; lastly, having the verbal or written consent of participants. The following section details how I actively obtained consent and the ethical issues involved.

Prior to conducting the research, I devised one information sheet for potential participants over 16, and two for those under 16 that explained the research (See Appendices 6, 7, and 8 in Sections 10.6, 10.7 and 10.8). I made two different sheets for those who were under 16 as I was not sure about potential participants' reading ability and comprehension.

Therefore one under 16s information sheet resembled that of the over 16s interview sheet, with occasional changes to the language used and parental/guardian consent requirements. The other under 16s information sheet had a simpler breakdown of the research with larger text and pictures.

For under 16s I left it to family members' discretion over which information sheet they read. I sent these in advance to conducting the interviews to the family member I was in contact with – in all cases this was the family member with fibromyalgia. As I was only communicating through one family member, on the day of the interviews I carried copies of all the information sheets with me so that participants could also read them there. I also made sure to explain the research and answer any questions participants had to ensure to the best of my ability that consent was informed (Kent, 2000). Regardless of whether the participants had read the information sheets, prior to conducting interviews I went through the information sheet again explaining the research and answering any questions participants had. As some interviews were conducted by phone I gave participants the option of written or vocal consent. For vocal consent I read out the consent for to the participant and answered any queries they had about the form and what it meant. Participants would state *yes* or *no* at the end of each statement within the consent form to signal their understanding of it before giving their consent to take part (See Appendices 9 and 10 in Sections 10.9 and 10.10 for the consent forms).

Farrimond (2013) highlights that when conducting research there is not enough information given to participants at the start of data collection – e.g. prior to an interview neither the researcher nor participant can be fully prepared for what will come up when asking for, and obtaining consent. Edwards et al. (2012) highlight that while families can be a source of comfort, they can also be a source of violence and coercion. To try and mitigate against coercion I told participants, and stated it within the consent forms, that they did not have to take part because a family member was taking part. Therefore, while it was important for me to get written consent from the participant prior to participation, I also wanted to make sure this consent was continual throughout the interview (Farrimond, 2013). To do this I would ask the participant if they still consented to take part when we were alone to mitigate the risk that participants agreed to conduct the research because they were in the presence of family members. Asking this gave people a means to opt out. At the end of the interviews, I asked participants if they would be

happy for me to include what we discussed within the research. By using continual consent it gave participants a means to leave the study, or a chance for them to erase something from the interview if they had said something they did not want to be used in the research. Where participants were interviewed twice (n=2) I obtained verbal continual consent.

### 3.5.2 Obtaining Consent for Under 16s

Farrimond (2013) argues that children under 12 normally give assent whereby agreement to take part is either through saying yes or through active participation, while children over 12 are thought to be able to give consent e.g. read information sheets and sign consent forms. Within this research all the participants were 12 years old or older, therefore consent rather than assent was obtained. The procedures leading up to obtaining informed consent for participants under 16 were the same as that for participants over 16; I provided the appropriate information sheets, and discussed the research with them and answered any questions they had. The process differed, in that in addition to the young person signing the consent form or providing vocal consent, a parent or guardian also had to sign the consent form or provide vocal consent due to their legal status as minors.

I was aware of the power disparities within the relationships between children and adults, and I asked the young people before and after the interview, when we were alone, whether they wanted to take part. This was to try to minimise the risk that they may have felt pressured by other family members to take part (Nixon et al., 2012; Finch and Mason, 1993; Phelan and Kinsella, 2013). I also obtained a PVG in case young people under 16 who wanted to take part and with their parents' consent – wanted to be interviewed outside the house. Within this research at no point did I interview a young person outside of their house.

### 3.5.3 Vulnerability and Consent

Farrimond (2013) highlights that young people and those with chronic illnesses can be defined as vulnerable people. The definition of vulnerable I felt was most appropriate to use within this research was that stipulated by my funders. The ESRC states that:

*Vulnerability may be defined in different ways and may arise as a result of being in an abusive relationship, vulnerability due to age, potential marginalisation, disability, and due to disadvantageous power*

*relationships within personal and professional roles. Participants may not be conventionally 'vulnerable', but may be in a dependent relationship that means they can feel coerced or pressured into taking part, so extra care is needed to ensure their participation is truly voluntary. (ESRC, 2019).*

Using this definition, my participants were considered vulnerable, and therefore prior to interviews I assessed their vulnerability to see whether ethically they could take part by considering the impact the research could have on them, and of what I was asking them to do. I did not use this assessment of vulnerability to refuse a participant a chance to take part in an interview if they wanted their voice to be heard. Rather I used it along with my training on mental health first aid, and my participant harm protocol (See Appendix 11 in Section 10.11 for more details) to guide me in conducting the interviews - for example when deciding to ask participants to draw relational maps if they had documented consistent lack of support in their personal life, or in deciding whether an interview should continue. In one instance an interview had to be stopped as a participant became upset – to which I had the relevant protocols in place and was able to ensure they were alright. I informed participants how the recorder worked so they could switch it off if they were uncomfortable.

### 3.6 Anonymity, Confidentiality and Privacy

Anonymity is when identifying information about a person: name, location, job etc. are omitted and often obfuscated through pseudonyms (Farrimond, 2013). Confidentiality is the right one has to manage information about oneself (Kent, 2000). Privacy is the right people have to refuse bodily, mental or emotional access to themselves (Farrimond, 2013). Throughout my research, I undertook various strategies to maintain these three principles.

#### 3.6.1 Anonymity

Within my information and consent forms, I stated to participants that I would supply them with pseudonyms and uphold their anonymity to the best of my ability. However, I highlighted to my participants within the information sheets, consent forms, and when we were discussing the research prior to starting interviews that there were aspects of anonymity that I could not uphold. For example, while I would supply them with

pseudonyms and omit where they lived and worked, I informed participants that I could not be sure that even through these measures they would still be anonymous within the final thesis to someone who knows them well. By informing participants of this I left it to their discretion as to what they disclosed to me.

### 3.6.2 Confidentiality

Within the information sheets, consent forms and the information session prior to the interviews, I informed participants that I would not share what they had disclosed in interviews with another family member – unless issues of potential harm arose (Kent, 2000). By not disclosing information of events, this resulted in participants saying things such as, “*I’m sure X mentioned*” to which I did not indicate whether they had or had not. I felt this approach was best to safeguard confidentiality for participants, while also allowing me to explore how different family members may have viewed/spoken about events, or whether it occurred to them to mention it at all.

### 3.6.3 Breaking Anonymity, Confidentiality and Privacy

Within the information sheets, consent forms and information sessions prior to the interviews I informed participants that I would break anonymity and confidentiality (and subsequently privacy) if they disclosed involvement in criminal activity, abuse or serious immediate harm to themselves, or others, which would make me concerned for their safety. I informed participants that if they disclosed any of the aforementioned issues, I would stop the interview, ask them if they had a preferred person to tell, and refer them to the relevant organisations who would have a duty to help the party at risk of harm (see Appendix 11 in Section 10.11) (Kent, 2000). I did not have to do this in practice; however having a plan in case this occurred helped me feel more prepared and safe when conducting research.

#### 3.6.3.1 *Anonymity, Privacy and Confidentiality for Under 16s*

As I was interested in interviewing children under 16 years old, I was aware I would need to consider the ethical issues of interviewing children and upholding their confidentiality and right to speak freely with their parents right to protect their interests (Phelan and Kinsella, 2013; Helseth and Slettebø, 2004).

Helseth and Slettebø (2004) discuss the ethical issues involved in interviewing children under 16 whose parents have cancer in Norway. Helseth and Slettebø (2004) discussed the ethical issues of interviewing children alone, while addressing parents' concerns regarding their wanting to know what their child had said in an interview. They resolved this by telling the parents and children they would only break confidentiality if the child mentioned something they felt had to be disclosed to their parents or healthcare professionals (Helseth and Slettebø, 2004). However, they would inform the child participant that they would not disclose information without speaking to them first (Helseth and Slettebø, 2004). Phelan and Kinsella (2013) balanced the ethical issues of interviewing children alone by having a parent in an adjacent room outside of ear shot but still able to observe the interview. I followed the advice of Helseth and Slettebø (2004) and Phelan and Kinsella (2013) when devising my study, by informing children that I would only break confidentiality if they disclosed abuse, criminal activity or serious harm to themselves or others. In this case I would ask the participant if they had a preferred person to tell. Following Phelan and Kinsella's (2013) advice I was ready for a situation where a parent may want to observe an interview by proposing their solution. This issue did not arise during my fieldwork, but I found it reassuring to have an array of options if it had.

#### 3.6.4 Reflections on Privacy and Family Interviewing

When obtaining ethics for this project and throughout the majority of my data collection I was adamant about interviewing family members separately to uphold confidentiality and privacy. I was a stranger to my participants and I would not know their family dynamics and histories, nor what they would be comfortable disclosing, and I did not want to put people in a situation which could jeopardise this. Farrimond (2013) highlights that when writing about privacy that how she understood privacy when interviewing couples, and how her participants understood it was different as couples at times wanted to do joint interviews concerning medical interventions. In one instance, I interviewed a family member while another was in the room, and although the interview was focused on one person, the other family member would chip in occasionally similar to Farrimond's (2013) experience. Prior to the interview, I expressed my desire to interview them separately. However, the participant stated they felt comfortable being interviewed in the presence of their partner. This left me with an ethical dilemma as I was a guest in this participant's house, I did not know their relationship in great detail beyond their marital

status, and both participants had their own illnesses of which I had no embodied experience of their personal pains and intricacies. I was not sure whether it would be more unethical to make one to wait uncomfortably in another room while I interviewed their partner for the sake of upholding ethics on paper. Whether to engage with ethics in practice, uphold participants' autonomy to decide their own limits of privacy and confidentiality, and conduct the interview. Alternatively, whether I should to refuse an interview altogether as they did not meet *my* ethical parameters. Additionally, as I stated I was a guest within their house and did not feel I had the power to ask them for any other arrangement to conduct the interviews than that of what they offered me. Kent (2000) argues within the Western philosophical tradition the ethical principle of autonomy (understood here as one's right to self-determination) is usually the first one to maintain within an ethical dilemma, and that participants have a right to engage or disengage with the research. In the end, I conducted the interview, trusting the judgement of my participants to know and assess their own limits of confidentiality, and privacy.

Later I was asked by a colleague why I had not asked for five minutes at the end to speak to them in private. Upon reflection of this I felt it would not address the practical issue of the lack of space. Secondly, I did not want to imply that I did not trust my participants accounts, and that by asking one to go into another room I was seeking the 'truth' of what their relationships were 'really' like. Such a stance would go against my epistemological beliefs that we have multiple constructed realities (this one being a co-created reality by my participants). I also did not know how this would impact their relationships, and I felt it would again transgress their autonomy to decide the conditions of the interview on their own terms.

### 3.6.5 Data Storage

In order to maintain participants' anonymity, confidentiality, and privacy with the data obtained during data collection, typed interview transcripts, audio recordings, and typed reflexive diaries were stored in a password protected folder on a University of Stirling server. All names and places that may be identifiable were given pseudonyms by participants or by myself. Physical data, such as hand written field notes, diaries, and photos of participant's maps, were stored in a secure, locked drawer at the University of Stirling, to which I have the key. Data is stored under the Data Protection Act (1998) (Crown, 1998).

### 3.6.6 Participant Harm

Most of what has been discussed in relation to informed consent, confidentiality, anonymity and privacy are in their own ways a means to mitigate harm coming to participants. Within those sections I have detailed the steps I took to prevent harm coming to participants, such as stopping interviews in cases of distress, and having information sessions to discuss the research etc. To avoid repeating myself this section refers to information sheets, training and practices I did to try and mitigate harm coming to participants.

Before conducting the interviews I devised lists of geographically specific support services and counselling services participants could potentially access if they become distressed or were in need of support (see Appendix 12 in Section 10.12 for an example of this). I took these with me to interviews, and I used these a few times in interviews to signpost participants to where they might obtain support. I found them incredibly useful and reassuring to have.

I undertook an NHS mental health first aid course to try and minimise participant harm in interviews. I found the course helpful in training me to discuss difficult and distressing topics calmly, and I recommend future researchers who research challenging areas such as chronic illness should undertake this training.

When conducting the research I was also prepared to halt research with a family if I felt my presence, or the topic was causing too much disturbance. However, I did not have to utilise this in practice. To try to mitigate my presence causing tension amongst family members, I informed participants in the information sheets, consent forms and information sessions that the research may emotionally affect them, and how they view their relationships with those around them. As mentioned previously continual consent was used to check that they still gave their consent and that they were not distressed by the research.

### 3.6.7 Harm to the Researcher

Prior to conducting this research I took several steps to ensure my mental and physical wellbeing during the research process. Before engaging in any fieldwork I informed a fellow PhD student – also a friend – of my location. I also kept my GPS enabled phone on me at all times, and planned routes to and from research locations prior to meeting



participants. I would tell my friend when and where the interview was taking place, and at what time I would phone to tell her I was safe. If I did not phone at this time she would contact me, and if I did not respond she would follow the Researcher Safety Procedure in Appendix 13 in Section 10.13. I was also prepared to engage with University of Stirling counselling services during this time, and during the data analysis process to avoid burnout, or if I found the topics discussed within the research distressing.

Having done the research and reflected on it I am surprised at how little it impacted me emotionally. While one or two interviews were distressing to myself, I was able to talk about this with my aforementioned friend while respecting the participants' confidentiality and anonymity.

### 3.7 Data Analysis

#### 3.7.1 Transcription

Bailey (2008) argues that transcription is the first step in data analysis as it lets the reader become more familiar with their data. For this reason I transcribed the interviews myself as I felt it was important to help familiarise myself with my data. I started transcription in November 2017 alongside data collection. However, the speed of which the bulk of the data collection for this project occurred meant I was not always able to transcribe interviews before conducting more. I tried to mitigate this through being reflexive of my interviews by considering what was coming up as important themes for the participants and myself. I would then discuss these themes with my supervisors.

Interviews were audio recorded, with handwritten notes used to facilitate follow-up areas of inquiry in the interview. Bailey (2008) also points out that researchers can never capture the full nuances of interviews in an audio transcript alone. She highlights that the act of transcription is an interpretive process in which the researcher decides what to include and what to exclude. On reflection, it was impossible for me to transcribe interviews verbatim with reference to accent, actions of participants etc. though I tried to do them as faithfully as I could (Bailey, 2008). Spyrou (2016) reminds us that silence often goes overlooked in qualitative research, yet it can also have its own meaning. I tried to keep this in mind when transcribing my data, writing when there were pauses and silences so that when I came to the analysis I would have more contextual information and understanding of the moment (Spyrou, 2016). I inserted laughs, sighs, accents and –

where I interpreted it to be inflected – certain parts of the text in italics. I did this to give a sense of context and familiarity to the text, rather than present it in well-polished Standard English. It was also valuable to me in trying to discern the emotional contexts and expressions within the interviews.

I also chose to keep in repeated words of participants as I argue it highlights how difficult it can be to find words to explain personal experiences and chronic illness.

### 3.7.2 Thematic Analysis

I used thematic analysis (TA) to analyse the data within my thesis. Braun and Clarke (2016) highlight that the origins of TA are not clear as some sources state it originated from Glaser and Strauss' grounded theory. Meanwhile, Clarke had believed it to originate from content analysis predating grounded theory, but she had also seen resemblances of it in psychotherapy research from the 1930s to 1950s (Braun and Clarke, 2016). Their point in highlighting TA's complex and hard to trace history is to demonstrate their belief that there is not a set way to go about doing qualitative TA. Approaches range from what Braun and Clarke (2016: 740) term a "*coding reliability*" approach popularised by writers such as Boyatzis, where one searches for themes hidden in the data, and tests their reliability against multiple people's interpretations; to their own approach where one acknowledges their active construction and interpretation of themes (Braun and Clarke, 2016).

I use Braun and Clarke's (2006) definition of TA in this thesis, where TA is a process whereby researchers look for repeated patterns of meaning across their data. Braun and Clarke (2006) argue that a benefit to TA is its flexibility, as while certain methods such as interpretive phenomenological analysis, or conversation analysis denote a particular theoretical or epistemological positioning, TA can be compatible with various epistemologies and theoretical perspectives. This flexibility appealed to me, as I understood it as signifying my theoretical framework could change as my analysis progressed. Many existing studies on fibromyalgia have largely taken a micro-interpretivist lived experience perspective, using phenomenological analytical approaches, hermeneutics, ethnomethodology, or inspired by symbolic interactionism (Åsbring and Närvänen, 2002; Söderberg et al., 1999; Juuso et al., 2016; Armentor, 2017; Paulson et al., 2002; Paulson et al., 2003). However, Thomas (2012) reminds us that when we are studying chronic illness and disability that it is important to not only consider

personal lived experience but also the wider social oppression that people may experience. While being reflexive not to presume my participants would interpret their lives from a social oppressive lens, I still wanted to take an analytical approach which would allow me the option to consider wider structural factors, which I felt TA was more equipped to do (Braun and Clarke, 2006; Clarke, 2017). This section will discuss how I understand a theme, and how I conducted my analysis in practice including coding. Lastly, I will discuss how I interpreted my themes and wrote up the data before concluding the chapter.

### 3.7.3 Theme Definition

Clarke (2017) argues that one can understand themes as bucket themes or storybook themes. A bucket theme – also known as a domain summary- is often a surface level summary of what a participant has said and filed under a research or interview question which gets reported as a theme (Clarke, 2017). An example Clarke (2017) gives in her lecture is a theme discussing the risks and benefits of drug use in a study on adolescents' perceptions of risks and benefits of drug use. Clarke (2017) argues that this theme is very descriptive of the data, and that there are no concealed unified meanings, ideas or concepts within its content. In other words bucket themes are literal descriptions of what participants said. Storybook themes on the other hand are more conceptual understandings of the data which share unified meanings, ideas and concepts (Clarke, 2017). This understanding of a theme views it as abstract, it can denote wider political ideological perspectives, and has been drawn from an aggregation of small codes from various parts of one's data set (Clarke, 2017). Storybook themes explain large parts of the data not just the responses to interview questions as in bucket themes (Clarke, 2017). When starting my analysis I was keen to look for what Clarke (2017) terms storybook themes, and the underlying meaning within the interviews.

Before explaining how I did my analysis I need to stress that while I am discussing these themes and my desire to look for the underlying meaning within them, I am not suggesting these themes are intrinsic properties within the data waiting to be discovered. I acknowledge that I constructed and interpreted these themes through my own social, political and cultural background (Clarke, 2017). Clarke (2017) argues that the researcher takes an active role in the knowledge production of these themes. Bryman (2016) highlights that in an interpretivist analysis a triple interpretation occurs as participants

interpret their social world, the researcher then interprets their participants' understandings, then the researcher interprets their own interpretations of their participants' interpretations through the already existing literature and theory in this area. Mason (2002) highlights the researcher then must be reflexive of these interpretations. I am arguing, in line with Clarke's (2017) position and my own epistemological position, that while my themes are reflective of my continual immersion, reflection and interpretation of the data, and an attempt to write it as faithfully as I can in a way that will reflect participants' experiences, they were created through my active interpretation.

#### 3.7.4 Analysis in Practice

Braun and Clarke (2006; 87) detail six basic steps as a means to conduct thematic analysis:

- 1) Acquainting oneself with the data: this involves transcription, repeating readings, and note takings of one's thoughts.
- 2) Initiating coding: the researcher codes data across the data set.
- 3) Looking for themes: codes are grouped into possible themes.
- 4) Evaluating themes: creating "*thematic maps*" of the research and seeing if codes fit with the proposed themes.
- 5) Designating themes: demarcating each theme and the overall "*story*" they tell.
- 6) Writing the report: writing your themes with reference to the literature, the research questions and exploring what they mean for the area you have studied.

By exploring each of these steps briefly, I will describe how I conducted my analysis. I finished transcription in January 2019. Prior to this, I had undertaken a three-month internship between October and December of 2018, and upon my return I had two interviews left to transcribe as a means to reacquaint myself with my data. Epistemologically I do not believe I could ever approach my data atheoretically and impartially, nor do I believe this is a useful position to analyse qualitative data. However, this break from the transcription and analysis of my PhD was invaluable as I was able to put some conceptual distance between myself and the theories and ideas that throughout transcribing the data I had begun to suspect were helpful in making sense of it. I wanted

to approach coding as inductively as possible while acknowledging my own biases. Prior to leaving for my internship, I wrote up my main ideas of the data, and theoretical possibilities so that future me would know what past me was thinking.

### 3.7.5 Coding

I started coding in early/mid-January 2019 using NVivo. I understood codes as Miles et al.'s (2014: 71) definition which is “*labels that assign meaning to the descriptive or inferential information compiled during a study.*”

Braun and Clarke's (2006) stage two states codes should be generated from the data, and can denote either semantic or hidden content. By semantic they mean codes are descriptive of an activity e.g. housework (Braun and Clarke, 2006). Latent (or hidden) content refers to “*the underlying ideas, assumptions, and conceptualizations – ideologies – that are theorised as shaping or informing the semantic content of the data*” (Braun and Clarke, 2006: 84, emphasis original). Clarke (2017) argues that there are three broad approaches to coding. Coding Reliability, where qualitative methods are used to gather and analyse data, but quantitative epistemologies and measures are used to verify the accuracy of the interpretation. Codebook approaches, where a codebook is developed in advance, and themes tend to be domain summaries (Clarke, 2017). This approach is informed by qualitative epistemology and methods and there is more flexibility for codes to change. Lastly, Clarke (2017) identifies Reflexive/Organic coding, which is qualitative in epistemology and methods, and advocates multiple social realities and that coding will be informed by the researcher’s subjective social and cultural understandings and their reflexivity and understandings of their data. Here coding is flexible, codes can change, merge with one another as the researcher becomes immersed in the data, and requires that the coding keep pace with changing understandings of the data (Clarke, 2017). Clarke (2017) argues that in Reflexive/Organic coding that the reliability and accuracy that Coding Reliability strives for is impossible, and themes generally reflect storybook themes. Clarke (2017) highlights that Reflexive/Organic coding often has a disposition towards social justice whether it be by giving a voice to silenced groups, or of promoting social change or critique.

My approach to coding reflects that of Clarke’s (2017) Reflexive/Organic approach. I started coding with broad descriptive areas in mind that I felt captured the various aspects of my data: Daily Life/Navigation, Illness, Medicine, Places, and Transport. Initially I

coded data descriptively based on the topics participants spoke about such as housework, going out with friends, diagnosis (Miles et al., 2014; Braun and Clarke, 2006). However, I soon started using more conceptual codes such as experiential illness knowledge, which was not something participants referred to explicitly, but which I interpreted within their responses (Braun and Clarke, 2006). I started off with the above 5 codes and created sub-codes from there which might appear structured and closed off at first (Miles et al., 2014; Clarke, 2017). However, I added more codes to this framework and was open to how codes would change name, and take on new meanings as coding progressed. I acknowledge that by naming the codes I was inferring my own meaning onto my data (Clarke, 2017). Throughout this process, I kept a coding diary to highlight what codes initially meant when I first identified them, then how they had changed meaning over time so I could map out the changes in my thought process. I coded across my data set similar to Braun and Clarke's (2006) stage two.

I coded my data using NVivo 12 software and with pen and paper. I started my coding using NVivo, and once I had coded the data into sub codes I printed these and coded them by hand by making annotations around relevant areas of text, and mind mapping potential themes and codes, and their relationships to one another. I felt this helped me to get a better sense of the conceptual themes that I was interpreting. I acknowledge that there are debates around the benefits and disadvantages in using computers within qualitative data analysis (Nagy Hesse-Bieber, 2004; Kelle, 2004; Bryman, 2016). I primarily used NVivo to organise my transcripts in a way that was manageable, before using pen and paper to code by hand. When I was trying to interpret conceptual codes I found hand coding easier than coding with NVivo. However, coding with NVivo did not stop me from coding for conceptual meaning in the data.

### 3.7.6 Themes

Once I had coded the data I started to group my codes into possible themes. I started by reading and writing up the conceptual codes which I had sub-coded from my descriptive codes. I then placed these under loose themes within NVivo seeing how they fitted under different codes. Similar to Braun and Clarke's (2006) stage four, I then took these themes and drew physical thematic mind maps to look at how they were connected to each other to see which themes might subsume others, and which were more distinct. To test the validity of themes, Braun and Clarke (2006) suggest two steps. First, exploring each

theme and the codes that build them up to look for shared meaning across the codes which is consistent with the overall theme. Second, to look at one's thematic map and the story that this tells, and whether it is consistent with the meanings and tensions one identifies in the data set as a whole. Around this time I followed Braun and Clarke's (2006) advice of going back to my data and coding data I may have missed when first coding my transcripts to see how these codes fit within my interpreted themes, modifying them as appropriate to better reflect the data. Clarke (2017) states that central to a Reflexive/Organic approach to TA is in the researcher being reflexive of their interpretation and analysis of their data. During this time – between March to October 2019 - my supervisors would challenge my interpretation of my themes using alternative theories such as biographical disruption or stigma. This process enabled me to think critically about my analysis and to defend my interpretation of my themes, data set and the theories I used to explain my interpretations. This process was key in aiding my reflexivity in my interpretation of the data and in helping me address my own biases, while also helping in demonstrating the strength of my interpretation of the data set against other possible interpretations. In Mid-March 2019 I engaged in stage 6 of writing up my data, themes and contextualising them with theory and literature.

Most of this process appears incredibly neat and orderly and I have only presented as such for the sake of reporting in a textual linear manner the way in which I conducted my analysis. While Braun and Clarke (2006) argue stage six is the writing up of the report once you have your finalised themes, I found that it was only in writing up and re-drafting my first analysis chapters that I managed to name and conceptualise my themes I described in stage five. Clarke (2017) argues that when doing qualitative analysis it is the researcher who can ensure analysis is good, as opposed to good analysis being understood as having followed certain criteria. Braun and Clarke (2016) argue that the strength of reflexive/organic TA comes from a finely detailed coding, enabling the researcher to construct themes that have specific distinct meanings from one another and a knowledge of why they are important within their data. My supervisors continually challenged my interpretation of my themes and the theories I used throughout writing up my findings and thesis drafts, and this involved on my part a frequent going back and forth between my data and the literature to demonstrate the strength in my interpretations. In doing this I was able to be closely involved in my data and interpret patterns of meaning which I felt were significant, and which contextualised participants' experiences. In my thesis I do

not speak of reliability. I find it epistemologically problematic as it implies some kind of external verification of a meaning that is ‘out there’, rather than one that is constructed. I feel maintaining this idea of reliability can devalue approaches that do not follow this approach and contribute to hierarchies of knowledge that are ‘more true’ than others (Castiel, 2003). However, I argue that the strength of my interpretations comes from my intuitive, conscious construction of my themes, my immersion in my data, and the reflexivity I have exercised in debating alternative explanations of my data throughout my analysis and writing up process.

Finally, although I present Braun and Clarke's (2006) six stages to thematic analysis as a means to give an order to the process of analysis which I undertook, I acknowledge that in practice this was a far messier and fluid process of moving back and forth between the stages, particularly when interpreting and coding my themes as I discussed in the paragraph above. Despite this, I found Braun and Clarke's (2006) approach and Clarke's (2017) approach invaluable in the analysis and write up of my thesis.

### 3.8 Conclusion

I started this chapter by reiterating the research questions from the literature review. I then outlined my epistemological perspective and demonstrated throughout this chapter how it has informed the design and conduct of my research, and my data analysis. I discussed how I recruited my participants and the methods used, where the research took place, and how I sampled the participants. I then explored how interviewing was conducted in practice both face to face and by phone, discussing the pros and cons of each. I highlighted the ethical challenges I had to navigate when conducting this research. Lastly, I outlined how I went about my analysis, my approach to it, and what it means for how I understand the findings that the subsequent chapters will present. Before moving onto the analysis, I would like to mention that I have avoided having a particular section dedicated to reflexivity. Instead, I have tried to weave my reflexivity throughout this chapter, and the thesis, as a whole. I have done this as a means to make reflexivity more of an active dynamic process within my writing up, rather than a single section within one chapter.

Having outlined the epistemological, methodological and analytical approach to conducting my research, I will now present the main themes and findings in the following chapters.



#### 4 Chapter Four: Introduction:

In this chapter I take the concepts of biomedical knowledge and experiential knowledge from Chapter Two and discuss them in relation to participants' understandings of their experiences (Lupton, 2003; Williams, 2004). I explore participants' understanding of their experiences with the medical profession, and how these experiences were informed by two types of knowledge: biomedical knowledge and experiential illness knowledge (EIK). I detail people and families' experiences in obtaining a diagnosis of fibromyalgia, how they perceived the medical profession to respond to fibromyalgia, and how they and their family members understood fibromyalgia. I argue in this chapter that my participants understood diagnosis as not only something which happens to an individual, but as a relational concept understood and experienced by those around them. I reason that this relational understanding of a diagnosis helped some of my participants develop what I term EIK. In this chapter I also explore how biomedical knowledge of fibromyalgia and participants' EIK interacted with one another, and, in drawing on the literature from Chapter Two I detail how these two forms of knowledge impacted participants' ability to obtain support outside of the medical profession.

Prior to my introducing the findings, please refer to Table 1 in Section 3.4.3. for a reminder of the participants' names and relationships with each other.

In this chapter I discuss the following themes: firstly, body talk which refers to the inability of medical tests to detect fibromyalgia in the body, meaning fibromyalgia is biomedically silent. At the same time this theme explores how fibromyalgia speaks experientially, as the person who has it, and at times those around them, are aware something is wrong with the onset of symptoms. Creating dialogue is a subtheme of body talk which refers to post-diagnosis of fibromyalgia where families can – though not always – develop what I term Experiential Illness Knowledge (EIK) of fibromyalgia. EIK is experiential knowledge obtained specifically about fibromyalgia. Secondly, lost in translation explores participants' implied post-diagnosis expectations with their interpreted experiences. I suggest that as fibromyalgia is biomedically silent, participants' expectations around receiving a diagnosis and treatment did not align with doctors' understandings. I demonstrate this pharmacological medication, and highlight how the biomedical knowledge and participants' EIK mentioned previously could clash with one another. The subtheme of bilingualism is used to highlight instances where doctors were

supportive of participants' fibromyalgia. Lastly, the theme of lingua franca highlights that even though biomedical and EIK could work together, biomedical language and understandings of illness were implied by participants, and interpreted by myself to have more value in wider society than that of participants' EIK.

After each participant's excerpt there is a pseudonym, for those with fibromyalgia there is the initials FM, and then the family number from the sample. Family members have designations like 'Partner' or 'Child'. For example Abby, FM, Family 11 means the participant is Abby, who has fibromyalgia and is from Family 11. Jacob, Partner, Family 16 means the participant is Jacob, he is a partner to someone with fibromyalgia, and is from Family 16.

#### 4.1 Body Talk

Participants' with fibromyalgia generally framed their experiences prior to a diagnosis in uncertainty as neither they, nor their GPs knew what was wrong. Pre-diagnosis often involved their experiencing symptoms of fibromyalgia, while the medical tests from their doctor failed to indicate that these symptoms stemmed from fibromyalgia, or whether they existed at all. As Abby and Cheryl recall:

*I'd spoke to ma GP and I'd been having all these dreadful symptoms and I'd gone away and like, I don't think my GP really knew what was going on. I'd had lots of tests [...] I'd tried all sorts myself. I'd like done like a deep, sort of changed my diet, I'd been trying to cut out certain things in case it was like a gluten thing or a diary thing or, so I'd like tried all things and none of them seemed to work. And I'd, I think I just in the end [...] I'd seen all these people, the GP had said to me I'm, you know she she was a bit at a loss what was going on. (Abby, Family 11, FM)*

*Int: were you diagnosed [here] or when you were in [omitted]?*

*Cheryl: [omitted] after aw, hundred I say hundreds of tests. Loads and loads of tests, vitamin D tests, oh pin prick tests, blood tests and loads and loads of different tests just to rule everything else out, which I totally understand they have to do. (Cheryl, Family 10, FM).*

Medically the body communicates illness through displaying visual symptoms or processes within the body that indicate something is causing the uncomfortable symptoms (Lupton, 2003). Abby and Cheryl's negative results from multiple biomedical tests is similar to findings from other studies on fibromyalgia highlighting that pre-diagnosis is a time of uncertainty and that there are no aetiological tests for fibromyalgia (Rodham et al., 2010; Boulton, 2019). I interpreted Cheryl's account as highlighting the dominance of medical perspectives as once biomedical tests have been conducted and ruled out, her account of discomfort can be categorised as fibromyalgia (Boulton, 2019).

I understand this as demonstrating two types of knowing. Firstly, there are the participants' experiences of their bodies informing them that they are in pain and suggesting to them that something is wrong. Secondly, there is biomedical knowledge in the form of tests, which were telling Cheryl, Abby and their respective doctors that there cannot be anything wrong because the tests do not indicate there is a process occurring within their bodies that matches how doctors' biomedical science understands disease. This supports Boulton's (2019) argument that fibromyalgia is not something easily understood by doctors' biomedical ways of knowing illness which require visual evidence of disease such as a tumour. Therefore I interpreted Cheryl and Abby's bodies 'talking' to them experientially through unexplained symptoms, while also being biomedically silent as doctors' biomedical understandings of the body cannot explain fibromyalgia's symptoms (Boulton, 2019).

However, the body as biomedically silent has consequences for how families understood fibromyalgia as Natasha tells us with her pre-diagnosis experience:

*I booked us a prize em weekend away [...] and ma husband and the boys were down in the pool and I couldn't be bothered. And they came back and I was lying on the bed crying. And they were like "What's wrong? What's wrong?" and I was like that "I just don't want to do anything, I can't move" and they just couldn't understand it, and they went off [...] and I was in the bed crying and crying and crying because I couldn't understand why I couldn't move, didn't want to move, felt so bad (Natasha, Family 16, FM).*

I understood this as meaning while our experiential knowledge can tell us something is wrong, without having a diagnosis we have no external framework to understand illness symptoms, as Natasha and Paige suggest:

*Int: em I suppose... what was it... how did it feel to get a diagnosis?*

*Natasha: well I, do you know it, it was such a relief to have a name to what I was feeling. Em, that was the main thing for me but that it got a name and I'm not just a moaning grumpy old woman, you know it had a name to it. And the reason for all these things and the way I'm feeling there's a reason for it now. (Natasha, Family 16, FM).*

*You're feeling a little bit reassured that it's at least a thing. At this point you're thinking "I'm nuts!" (Paige, Family 9, FM).*

For Natasha and Paige, and other participants in my sample, I interpreted a diagnosis as legitimating to them that their unexplained symptoms were a real illness. Jutel and Nettleton (2011) point out that we learn about illness when it is diagnosed by a medical professional. To use Campbell's (2014) understanding, we are translated and coded into a category of ill. My findings support Armentor's (2017) argument that a diagnosis of fibromyalgia is important as it gives a name to previously unknown experiences.

However, my participants did not just consider how a diagnosis impacted them. Cheryl and Jessica stated that they experienced their diagnoses relationally:

*A couple of ma pals actually were, they eh, went in so much research about it cos I'd niver heard ay it, they'd niver heard ay it and we all sorta researched it together tae try and get a better understanding of it because when I first got diagnosed I was like "Ugh this is going to have to change, that is going to have to change. There might be times Ah huv tae cancel hooking up wi you," you know these sort of things. And they just took it all on board, which was great, so I think I was really really lucky (Cheryl, Family 10, FM)*

*Int: [...] did a diagnosis like em... change anything in your relationships with em your family or?*

*[omitted disruption: something fell off of a shelf]*

*Jessica: It's em... it suddenly changed in a sense of I had to think about everything a lot more and my predominant thought was the impact on Lucy [daughter] and the impact on Jack [husband]. And also, as my parents got older how does that impact on my ability to help them and em... so... I definitely became withdrawn and distant. But, Jack worked really hard to be reassuring and supportive and he's fab (Jessica, Family 17, FM)*

Cheryl and Jessica's experiences of diagnosis support previous understandings by highlighting how diagnosis acts as a framework of meaning for an individual person (Jutel and Nettleton, 2011). However, Cheryl and Jessica imply their diagnosis experiences were understood, experienced, and responded to in relation and in the context of a history of relations with others. In this case their relationships with their friends and families. Diagnosis also had importance for family members as Gordon and Michael informed me:

*Int: so did a diagnosis, so did a diagnosis change anything? Or?*

*Gordon: ... it... did and it didn't. It gave ye something thit ye could actually look up and read about, rather than different things know what a mean? Em, it could be this it could be that, but it actually kinda pulled it all together and ye can actually read up and realise that it's no just her, there's millions of people suffer from it and... so it wis easier getting a diagnosis.*

*Int: so, it helped in making everything more... I don't know did it make things more?*

*Gordon: easier tae understand mm hmm. (Gordon, Family 9, Partner)*

*Int: em how did the diagnosis make you feel?*

*Michael: em, well I guess by that time I I I knew [...] Louise [...] as of such the diagnosis wasn't so much a new thing it was more a em confirmation of something we already knew. With the added bonus that now the beast had finally had a recognised name em some avenues of dealing with it could be explored (Michael, Partner, Family 1)*

I interpreted Gordon and Michael's accounts as highlighting three things. Firstly, Gordon and Michael imply the power that comes of having a name to categorise the many and variable symptoms of fibromyalgia for those with fibromyalgia and their family members. A diagnosis provided a framework of meaning for families to understand the condition, its range of symptoms, and the idea that there is a way forward through the uncertainty of pre-diagnosis. The power of naming fibromyalgia as something which provides context to people's experiences has been commented on by Armentor (2017). I understand Experiential Illness Knowledge (EIK) as a type of knowledge that participants obtain over time about fibromyalgia and how its symptoms present. I explore participants' experiences of this knowledge below, however I will first discuss how EIK is related to obtaining a diagnosis.

For the person with fibromyalgia, this knowledge is obtained through experiences with their body and how it changes over time as fibromyalgia sets in. For those close to the person with fibromyalgia, I argue it is obtained through observing changes within their colleague/friend/family member of what they can/can't do after the onset of the illness. While family members can notice that something is wrong with the person prior to diagnosis by noticing how their actions may change, I argue that a diagnosis is essential to EIK because it gives a legitimated medical name to people's experiences and a shared recognised language with which to discuss it. In other words, a diagnosis is more than a starting point for participants to obtain experiential knowledge of their/their family member's bodies. Rather they have experiential *illness* knowledge whereby their experiential knowledge can be categorised and understood as belonging to the symptoms associated with fibromyalgia.

Secondly, the requirement of a formal diagnosis to obtain this knowledge highlights the need of a biomedical understanding of illness for participants to then have their experiences legitimated, known, and understood through their EIK. Until then, the person and those around them are implied to be in a state of uncertainty. Thirdly, I argue that this suggests a complex relationship between experiential and biomedical knowledge of fibromyalgia which emerges where experiential knowledge of fibromyalgia depends on a medical diagnosis to be legitimated as illness knowledge, yet a diagnosis of fibromyalgia requires experiential reporting (Boulton, 2019). I will illustrate fibromyalgia's relationship to the medical community throughout this chapter. However,

before we unpick it further, it is important that I expand further on the idea of EIK and the body talking in a post-diagnosis context.

#### 4.1.1 Creating Dialogue

During pre-diagnosis a person's bodily experience acted as a way of knowing something was wrong within their body. When participants spoke about their experiences post-diagnosis I noted a shift in participants' accounts of their daily life, and their experiential knowledge was suggested to take on a new purpose in which people would learn what they could and could not do with fibromyalgia, as Louise informed me:

*Int: so is it like em, if you have a big event on you need to like rest beforehand so you don't, so you kinda save your energy so you can use it later?*

*[...]*

*Louise: Yep. Em... like a big party or a bigger event that's like one or two days, then I would need to make sure I take it easy the week before and make sure I'm not too busy the week after so I've got the energy to do it and I don't need to cancel and stuff because I hate to cancel.*

*Int: is that like fatigue or?*

*Louise: Mostly, yeah when I get tired everything else spirals. So, I get more pain, I get grumpier, I forget things, everything just stacks on top of each other if I'm tired. If I'm rested I just have more energy to keep going and manage better. (Louise, FM, Family 1)*

Louise repeatedly states the need to conserve energy to perform tasks, something which I noticed other participants discussing:

*I will sit down to clean my teeth rather than stand up to clean my teeth. So I know in that way I'm conserving some energy to maybe do other things. (Abby, Family 11, FM)*

And:

*Ye've got tae know yer limitations [...]. Ah used to be able to do the whole house, no worries. Whereas now I'll maybe be one room one day one room the next day. (Cheryl, Family 10, FM).*

*Em, I try to do as much as I can in the morning cos that's when I have more energy. (Claire, Family 12, FM)*

Louise, Abby, Cheryl and Claire all detail the complex negotiations which occur when trying to plan their days and listen to their bodies. Through their emphasis on knowing they need to conserve energy, I suggest that energy in this context is a finite resource that needs to be managed, and that life with fibromyalgia is a balancing act in managing what one wants to do, and what one needs to do. This is similar to the experiences of the women interviewed in Briones-Vozmediano et al.'s (2016) study of how women with fibromyalgia negotiate housework and daily tasks.

To expand on the metaphor of the body talking, participants were creating dialogue and talking back to their body, as Vicki suggests:

*Tomorrow, when I'm going to the hospital I decided not to go out tonight to the Church cos I knew I would be tired [...] If I just carried on with, you know, what I was going to do and stuff like that I would have been really really knackered you know. So, it's it's almost like an accounting system of what, what you can and can't do and recognising it. [...] It's almost as if at some point my brain tells my brain not to do too much [...] and I think that took a lot of time. I didn't you know, I didn't fully twig that, that it had to be taken into account to that extent. Em, but now [...] I prioritise what it is I want to do. And if by necessity what I have to do. (Vicki, Family 13, FM)*

Vicki, and the participants above, imply that when one has fibromyalgia, a system is developed of what you can and cannot do based on what your body is telling you. This is similar to Kengen Traska et al.'s (2012) study on how women manage fibromyalgia. Vicki implies that the mind still has pre-fibromyalgic assumptions of what it can and cannot do. Vicki, and the participants above, suggest that through listening to their bodies, their minds develop ways to manage their fibromyalgia and obtain knowledge of how it impacts them. I argue that as a person listens and learns from their bodily experiences of



fibromyalgia, they develop a dialogue between the mind and body over what they can and cannot do. This is Experiential Illness Knowledge (EIK).

Participants implied that obtaining EIK is a temporal process and that it takes a certain amount of time to build EIK. For instance, Heather suggests that during this time experiences can be trial and error, and laced with pain and uncertainty:

*Eh, so my days are very different and if I just overdo a thing, cos I'm not good at saying no to people so if people ask me to join in with something or help them with something or whatever I still forget my own limits and do that and then you know end up out of action for a week or whatever. [...] I like to think it might smooth out a wee bit more this year if I just can get if I just kinda pitch it a wee bit better. (Heather, Family 4, FM)*

With Heather's account I suggest that our understandings of our bodies are ableist Campbell (2009), as we assume we can and should do things until we physically cannot. Fibromyalgia in this instance forces oneself to listen to the body by highlighting the possibilities and limits of the social action one can engage in. I understood "*my own limits*" as meaning this is a personal, experiential process separate from more standardised biomedical ways of knowing illness through, for example, lists of symptoms (Campbell, 2014).

However, despite knowing she has to pace herself, Heather implies with "*I'm not good at saying no to people*" that she is not just assessing what her body can do, but that she deliberates this based on what she feels her social relational self *should* do. I understood this as meaning that when assessing what one is bodily capable of with fibromyalgia there is a deliberation between a 'what can I physically do?' and 'what do I feel I ought to do?' I argue that Heather's attempt to balance what she knows her body can physically do and what she feels she is socially expected to do in a relational context can be difficult in practice, and underpinned by ableist understandings of the body (Smart, 2011; Campbell, 2014).

As I mentioned above, I interpreted participants as experiencing fibromyalgia in relation to those around them. Some family members suggested they could see their family member's fibromyalgia, and through their accounts of this I interpreted them as developing their own personal and subjective EIK of what their family member can and

cannot do. Research on fibromyalgia has created a mixed picture as to whether a person with fibromyalgia's family members can tell when a person with fibromyalgia is in pain or having a flare up of symptoms. I understand a flare up as when symptoms such as pain, fatigue are particularly acute (Armentor, 2017). In Section 2.1 I suggested fibromyalgia's variability means close friends and family members may doubt one's insistence of feeling ill (Sim and Madden, 2008; Armentor, 2017; Crooks, 2007; Paulson et al., 2003). However, studies on partners where one has fibromyalgia have also shown them to be supportive and accepting of the illness (Wuytack and Miller, 2011; Söderberg et al., 2003). Within my sample I had instances of both experiences occurring, which I will discuss further on. I interpreted EIK as a means for family members without fibromyalgia to assess how their family member with fibromyalgia was feeling on a particular day, as Lucy and Michael explain:

*Int: em... can you tell when your mum's in pain or?*

*Lucy: yeah, it's all over her face and she'll probably be limping, looking down or... even if when I ask her I'll ask her "Are you okay?" She'll just smile at me and say "Yes I'm fine I'm just a bit sore" and I know she's not just a bit sore she's like really sore. (Lucy, Family 17, Child)*

*Michael: people don't- tend to not see Louise when she doesn't have a good day simply because if she doesn't have a good day she's not getting out of bed [...] and that that that skews the image people have of how it is to have fibromyalgia because em, when she is having a good day and or drinking alcohol or stuff then she em can, can can can do some quite a lot of stuff and she can be active and happy and dance and stuff. And em,*

*Louise: I'll regret it in the morning but yeah I can. But they don't see that part*

*Michael: part of that is the thing, they don't see that part hardly anyone knows.*

*Louise: you do.*

*Michael: yeah well that's because I live in the same house.* (Louise and Michael, Family 1)

Lucy and Michael state they can see their family member's illnesses, which Louise and Michael attribute to their living in the same house. I understand embodiment of fibromyalgia as not just about how the person with the illness experiences it, but how others around the person also experience the impacts of fibromyalgia through living in interconnected relationships and embodied experiences with the person with fibromyalgia. Additionally, while above it was suggested that obtaining experiential knowledge of fibromyalgia was an on-going doing process for the person with fibromyalgia, Benjamin suggests obtaining EIK was a learning process for families as well:

*Knowing about it to start with is one thing, but seeing it in person and actually living with it, and knowing how it can impact and not just physically but mentally as well is a completely different thing.* (Benjamin, Family 12, Partner)

Benjamin highlights that a diagnosis was important for him to contextualise his wife's and his own experiences of fibromyalgia. However, he also states that through having this diagnosis he can obtain experiential day to day knowledge of how it can affect his partner Claire. Benjamin implies he values this knowledge over symptomatic knowledge of fibromyalgia. As Jutel and Nettleton (2011: 799) argue, it is important to look at how a diagnosis can help us conceptualise "*forms of knowledge, social structures, relationships and actions.*" I contend that within the data so far we are already viewing a complex picture of how medical knowledge and experiential knowledge not only clash with one another, but how they also inform and are contingent on one another.

However, family members' knowledge did not just come from interactions with their partner on a daily basis. Jacob notes that directly talking about the impacts of fibromyalgia was incredibly important for his relationship:

*It just took time, you know, a couple of weekends where we sat down maybe over a glass of wine, [...] she would bring the subject up and she said "Listen I'm genuinely- when I tell you to do stuff I'm genuine about it it's not you it's me". And she actually makes a point of saying "It's me,*

*I'm not up for it. So, it's not you, it's me." And then I realised right okay it's nothing to do with me [...] and she said "Look you've got to realise there's times where this fibromyalgia will kick in I'm not up for it, I can tell I'm not up for it. I've had a hard week at work, and I just need to chill out this weekend." And I'll say to myself "Okay that's fine." But I know after a few hours maybe I come back and go "How are you feeling, do you want to go for a drive?" and she'll say "Right okay I'm up for a drive" you know. (Jacob, Family 16, Partner)*

Jacob suggests that despite knowing his wife Natasha has fibromyalgia, deliberate conversations between his wife and himself were important as it helped them move illness from a phenomenon which happens to Natasha, to understanding it as something which affects their relationship and daily lives. Armentor (2017) highlights that verbally communicating how fibromyalgia impacts a person can also be important for generating understanding, though Briones-Vozmediano et al. (2016) suggest that communicating the impacts of fibromyalgia does not guarantee that family members will understand fibromyalgia. My research suggests that communication between family members is a very important aspect in helping them understand how fibromyalgia impacts their daily experiences.

While biomedical knowledge presents itself as an objective fact (Boulton, 2019), participants' implied their EIK was not a universal knowledge. Participants from the same family implied they could have different interpretations of how fibromyalgia impacted them or their family member, as Ewan informed me:

*Int: [...] how does it make you feel if you tell her to just rest and she doesn't, is that?*

*Ewan: em... again it used to be... it would cause quite a few arguments because I think from the outside looking in towards, Ah could see that she was startin tae get tired and she was pushing herself. Whereas now she will listen and she will take on board the fact that you know "Right Cheryl ah'm seeing yer startin tae flag a wee bit here, go lie down for half an hour ah'll bring ye through a cup of tea." (Ewan, Family 10, Partner)*

I propose that family members' EIK could cause them to interpret a situation differently from their family member with fibromyalgia. Additionally, I understand that family members could use their EIK to help them respond to instances where they felt their family members were unwell or pushing themselves, as Duncan demonstrates:

*You've also got to remind them of that sometimes or they'll think they can run a mile and you kinda have to remind them and say you can hardly walk 200 yards today [...]. You've got to be on their side so when [...] they're set with a situation with their friends and things are happening and they have to get out of it because they know it's not going to be right for them and they're not gonna feel- you gotta help them and maybe tell the white lies [...] "The reason I'm not going... something else has come up." (Duncan, Family 4, Partner)*

In both of these cases Ewan and Duncan interpret their partners' behaviours as meaning they are tired, even if the person themselves does not always recognise it. While this can be seen as a clashing of different types of EIK, and highlights that EIK is subjective to the person who has it, it also suggests that EIK is something family members can use and communicate to one another to navigate daily life within the context of fibromyalgia.

Before concluding this section, it is worth mentioning that not all families were implied to have EIK of their family member's fibromyalgia. Like many studies before on partners and those with fibromyalgia's perceptions of fibromyalgia, some family members were implied to have no understanding as Abby suggested:

*He'll tap me or like, you know, pinch me or something, like a playful pinch or something, and you know, and I'll be in agony and then of course he feels upset because he's hurt me but then you know but then... I then have to explain it's just because it hurts it's not, you know. And in a sense he'll say "Oh you're a bit of a wuss then aren't you? Cause I can't do that to you" kind of thing but em. So em, so... we'll talk about it in that instance but then if I suppose out of that instance you wouldn't mention it again kind of thing. (Abby, Family 11, FM)*

Although Abby states that she and her partner would speak about fibromyalgia, suggesting communication and an exchange of information was taking place, she

positions this as a one-off event as her partner never mentions it again. Abby was interviewed alone and I had the impression throughout her interview that there was a lack of continual communication about fibromyalgia within her family. Abby refers to her fibromyalgia as “*elephant in the room nobody ever speaks about*” and “*I wouldn't mind if they mentioned it because it, they- it knows- I know then they're accepting that it is something that's part of my life*”. I interpreted Abby's experiences as demonstrating, similarly to Jacob, the need for continual communication between family members' in order for them to recognise the symptoms and impairment effects of fibromyalgia. However, Abby's account also supports findings within the wider literature that family members do not always recognise or understand fibromyalgia (Armentor, 2017; Briones-Vozmediano et al., 2016).

#### 4.1.2 Conclusion

I started this section by exploring a diagnosis of fibromyalgia, highlighting how a biomedical model dominated understandings of illness which supported previous studies of fibromyalgia as a diagnosis of exclusion by biomedical tests through the metaphor of the body talking (Madden and Sim, 2016; Boulton, 2019). My findings support previous studies, as participants with fibromyalgia highlighted how a diagnosis brought them relief and confirmation that something was wrong (Madden and Sim, 2016). My data also supported Briones-Vozmediano et al. (2016) and Kengen Traska et al.'s (2012) studies which argue that a diagnosis allows those with fibromyalgia to learn how to pace themselves. This section also expanded on Armentor's (2017) findings that in some instances those around a person with fibromyalgia – such as family – can obtain knowledge of how fibromyalgia impacts their family member. This creates the idea of the body talking experientially within the relational context of families, helping them navigate aspects of daily life. I understood this as experiential illness knowledge (EIK), which interacts and informs, but is the same time discredited by biomedical understandings of illness. I will explore this discrediting in the remainder of this chapter.

#### 4.2 Lost in Translation

Dialogue between the biomedical profession and those with fibromyalgia could be strained as I understood both to use different ways of knowing to interpret fibromyalgia. I understood EIK to be subjective everyday knowledge held by people with and without fibromyalgia, obtained through experiencing bodily or relationally the symptoms of

fibromyalgia. This knowledge was communicated either through people's embodied daily experiences of fibromyalgia, or in their interactions and relationships with their family member with fibromyalgia. Meanwhile, participants implied doctors had a biomedical way of knowing illness and found it hard to understand fibromyalgia because it was not detected in biomedical tests. In this chapter through exploring participants' experiences of obtaining treatment, I detail how this misunderstanding between users of biomedical knowledge and EIK did not end at diagnosis, as Hannah and Olivia mention:

*First of all I didn't have the diagnosis so that was a big triumph. But once I did have the diagnosis there was a lot doctors that didn't believe that the condition really existed. Em and so their treatment of you was: "Oh, it's psychosomatic, it's something that you're imagining. You think you're in pain but you're not." I was referred to a psychiatrist you know at one point. Em which was quite difficult for me, but [...] when I actually met with the psychiatrist he completely understood everything I was saying to him, and em he said you know this isn't psychosomatic it's not all in your head [...] I'm going to discharge you.. (Hannah, Family 15, FM)*

*I was elated when I got the diagnosis but [...] I had to... go to my doctor for something he was off and somebody else had stepped in. They went "But fibromyalgia's just a name for something when they don't know what's wrong with you it's not really a diagnosis as such." And that again makes you feel that side it's like "Do they think it's still all in your head?" You know although I've got a name for it now because there wasn't a cure and nobody was giving you any advice as what to do or where to go. (Olivia, Family 14, FM)*

Hannah and Olivia interpreted illness and diagnosis as creating legitimacy to their experience and acknowledging it as a real condition. However, they imply that not all medical professionals they interacted with saw this diagnosis as legitimate, and gave it the concern and attention Hannah and Olivia felt it required. Hannah and Olivia were not alone in having their fibromyalgia discredited. As participants told me of their experiences of diagnosis, they implied that through being diagnosed they had expected a greater response regarding what could be done, as Olivia and Jessica demonstrate:

*You're told what it was but you were nae further forward. (Olivia, Family 14, FM)*

*When I was diagnosed it was basically "Oh you've got it and your GP can deal with it, bye!" and that was it. And it was... there was no extended kind of assessment programme through it [...]. You were kind of left "That's it you've got it" and, you know, what do you do? (Jessica, Family 17, FM)*

Therefore, while diagnosis could reassure participants, I found that similarly to other studies (Boulton, 2019; Madden and Sim, 2016; Undeland and Malterud, 2007) a diagnosis was also dissatisfying as the condition is discredited by medical professionals. In turn, doctors' biomedical knowledge of how to treat fibromyalgia after diagnosis is exhausted, as also noted in the findings of Kengen Traska et al. (2012). Additionally, I interpreted a sense of being lost in translation. Participants said that they thought a diagnosis would lead to treatment and cure for fibromyalgia, and Jessica as noted above invokes a sense of loss at what to do when medical professionals do not provide answers. I suggest participants held a normative idea of acute illness and the medical profession reminiscent of Parsons (1951), where diagnosis of a condition entails some kind of progression towards its eradication. However, I suggest participants' understandings of what a diagnosis would entail did not match doctors' understandings, and this contributed to the theme of being lost in translation. Paul talks about how these discrepancies in understanding can have wider consequences for people with fibromyalgia being taken seriously:

*He [the consultant] was reading my notes when I was sat there so he didn't know anything about me anyway. [...] Eh and he turned round and said to his trainee consultant "That's fibromyalgia which I don't think is anything anyway, it's just a pain syndrome." He then turned round and said to me "So I see you have fibromyalgia." You know, and not only was that rude to do that, em but his attitude as he said it was, was condescending you know, and he got up and said "Oh hang on I gotta go get something." And I'm seething at this point and I thought how, how how can we get ahead with something that is now almost fully scientifically proven as a condition, you know? (Paul, Family 2, FM)*



Paul expresses anger and a sense of injustice that the consultant did not recognise his fibromyalgia describing him to be patronizing about an almost “*scientifically proven*” condition. In this instance the consultant is refusing to recognise and legitimate Paul’s condition, denying his experiences of chronic pain as having a valid and legitimate reason. By “*seething*” I interpreted Paul as feeling a sense of injustice at how the consultant was treating him. By disregarding the condition, I understood this as emphasizing how the consultant has the power to define what a legitimate illness is, while fibromyalgia is implied to not be a legitimate illness. Paul with “*how can we get ahead*” implies that not only is he in a less powerful position in this interaction, but that the consultant’s denial of fibromyalgia represents a wider collective marginalisation of those with fibromyalgia, and the issue of acceptance of fibromyalgia within the medical profession. I interpreted the medical profession as a sphere of legitimate power and those with fibromyalgia as campaigning to be allowed inside this sphere.

By saying fibromyalgia is “*almost scientifically proven*” Paul is drawing on the legitimating systems of biomedical ways of knowing which are being used by the consultant to undermine his experience. Again, I interpreted this as being lost in translation as the consultant and Paul are using similar language, yet through their different ways of knowing fibromyalgia, experiential and biomedical knowledge, they have different understandings of this language which is reflected in their actions e.g. the consultant dismissing fibromyalgia. I will reflect on the fluid use of knowledges and the power struggle between ways of knowing throughout the rest of this chapter. It is worth noting that this is similar to Blume's (2017) discussion of non-medical persons using medical terminology with medical professionals to discuss their experiential understandings of illness, as a means to obtain legitimacy.

Participants did not feel that doctors responded to fibromyalgia with the same respect as other illnesses. However, participants wanted fibromyalgia to be respected and understood by medical professionals as they felt this would enable their experiences to be acknowledged, and it would give the condition the same legitimacy as a condition such as cancer. GPs who did not acknowledge fibromyalgia as an illness could then be seen as a barrier to having one’s experiences legitimised, which I interpreted from my data as stemming from divergences in biomedical and experiential ways of knowing

fibromyalgia. The following interaction from Emily highlights how these divergences impacted her:

*But I remember doctors as well, my mum had a real hard time about it. Like doctors would say “It just doesn’t exist” and my mum said “Well I was told- I have been diagnosed with fibromyalgia.” “No no that’s all in your head” and things like that. I was told it was all in her head by a doctor, and I was like “I don’t know, that’s, I can see my mum’s in physical pain and you know what, see if it’s in her head or it’s no in her head, she’s in pain no matter what so.” (Emily, Family 14, Child)*

Emily states that her mother being in pain is more important to her than the doctors’ biomedical questioning of the source of her mother’s pain and whether fibromyalgia is an illness. I suggest this indicates how biomedical and experiential ways of knowing fibromyalgia can clash. I argue that the above highlights how the doctors’ and families’ understandings of fibromyalgia can at times be lost in translation as their different knowledges and understandings of illness give them different priorities. People could clash when using these two forms of knowledge, however, I did not interpret them as two dichotomous, epistemologically opposed forms of knowledge going against one another. I argue at times they could inform one another. As a means to conceptualise this I will turn to participants’ accounts of treatment for fibromyalgia.

#### 4.2.1 Pharmacological Medication

*See if you’re going to diagnose something, treat it, yeah? (Jessica, Family 17, FM)*

The above quote, though brief, captures the overall frustration felt by those with fibromyalgia and their families at the lack of treatment options that will eradicate the symptoms (Kengen Traska et al., 2012). Again, it emphasizes a Parsonian (1951) normative understanding of illness where diagnosis leads to treatment.

Before starting this section, I need to make clear that my participants’ experiences with doctors were not all the same. Some participants highlighted that doctors refused to explore different treatment options, while other doctors were willing to work together

with them to explore treatment options. This will be explored later in the chapter, but I will currently focus on where perspectives clashed.

Many of my participants had conflicted experiences with medication, as Louise told me:

*Int: [...] how you feel about the medication aspect?*

*Louise: I hate them, but I take them. I've stopped complaining about it in general. I take them and I'll deal with it em but I'm not happy about it. I'd rather not take any meds, because I know it's not good for my liver and my body to put these chemicals in. And if there was an alternative I would do it, but I've noticed, just, I've noticed I function so much better with them. (Louise, FM, Family 1)*

Louise implies she has no power in the taking of pharmacological medication as a means to manage her symptoms, and emphasises her anger towards this as they do not eradicate her symptoms and can cause other problems. Some of my participants avoided taking painkillers “*not that I take painkillers now because [...] I think I can't really rely on them for the rest of my life*” (Abby, Family 11, FM). However, the majority of my sample had to take some form of pharmacological medication for pain relief, and they expressed similar sentiments to those of Louise. For example, Hannah told me:

*I found that a lot of doctors were quite dismissive. Or you know they want to medicate you. “Just go and take paracetamol, go and take you know this painkiller.” Em and they kind of wanted you to go away because they didn't know what to do with you so. I'm kinda left feeling like [...] I was a burden on on the medical, or the NHS on the NHS and that I would complain about something that isn't real. Even though I went through phases of “Oh I just don't wanna engage with the medical profession I'm not.” But then you come away you're in so much pain you don't know what to do, so you're in that kind of catch-22 (Hannah, Family 15, FM)*

Bury (2012) highlights that many long-term chronic conditions require frequent engagement with health professionals over time, in addition to medication. Hannah notes, based on what she perceives as doctors' disparaging attitudes, that this type of engagement does not always happen when one has fibromyalgia. Hannah positions

herself as lacking the power to challenge her perception of her doctors' attitudes to her illness. I suggest that through Hannah's normative understandings of how illness is treated – with medication - combined with the impacts of fibromyalgia's impairment effects, people with fibromyalgia can lack the power to challenge treatment options for fibromyalgia, even if they do not feel they are what is best for them. As Cheryl indicates below, it could be difficult for her to determine if taking pharmacological medication was fruitful to helping her fibromyalgia:

*You go to the doctors, you say what the issues are and they throw pills at you. And you as patients' em, think that you're doing the right thing by going on all these things (Cheryl, Family 10, FM)*

I interpreted Cheryl as desiring to be a “cooperative” patient in a Parsonian (1951: 437) sense, accepting her doctor's authority and taking the medication given to her. However, Cheryl and Natasha point out that because of fibromyalgia's status as medically unexplained, this leaves space for doubts amongst some participants around whether pharmacological medication is really helping:

*But you, you, you always have a nagging doubt going “Are the side effects of these medications causing the side effects of the fibromyalgia to be emphasized?” (Cheryl, Family 10, FM).*

*They don't work, they just cause other problems. [...] my kidneys were affected by the drugs, pills just cause- like mask one problem, they cause different problems somewhere else. And [...] that's a medical fact the doctors will all tell you that. (Natasha, Family 16, FM).*

Natasha highlights that medication only “masks” the problem, and that it can have serious impacts on other parts of a person's body – in this case her kidneys. Similar to Paul's earlier statement “almost scientifically proven”, I argue that Natasha, by saying, “medical fact the doctors will all tell you” is interpreting and drawing on her understanding of biomedical knowledge to legitimate her EIK of fibromyalgia (Blume, 2017). I suggest that using biomedical language creates more authority and legitimacy to experiences than that of EIK, and that this supports Blume's (2017) argument that using biomedical language to frame one's experiences is a means to give more authority and legitimacy to

experiences than that of EIK. However, this could be problematic as I have suggested people are using language which can be used to marginalise them.

Some participants, though not all, told me they used things like massage, or vitamins, healthy eating etc. as they believed it helped ease their symptoms of fibromyalgia. These experiences were highly individual and personal, however they had a reoccurring theme where they felt these alternative treatments addressed their fibromyalgia in a more holistic manner, rather than the medication prescribed by their doctors and the NHS as Natasha, Louise and Claire highlight:

*I go to em yoga [...] I take a lot of em vitamin supplements so turmeric, and magnesium, vitamin D. So, things like that work for me. Em, I've got a wee machine em, to, it's a massager for the back, you know you get a kind of – I can use it for my calves and my shoulders, em a hot bath. So I try, I try to to em, I try to treat myself through vitamins and stuff like that rather than... all the drugs, although I do take them when I have to [...] but I think em, rather than prescribing tablets, if the NHS could prescribe me a wee bit of acupuncture or some kind of gentle massage therapy maybe once every couple of weeks, that would personally help me a lot more. (Natasha, Family 16, FM)*

*Like in [birth country] I got a massage every two weeks to keep my muscles [...] a bit more relaxed. Because of all the stress and the pain I tense up and the more I tense up the more pain I have, and those two weekly sport massages were so helpful. It's pre-emptive stuff that works so much better em, but it's a fortune I can't afford it here and in [birth country] it's part of the insurance because it saves me having to go the physiotherapy or to the pain clinic because with that and my painkillers I can manage. I didn't need any other help I was doing a lot better, but it doesn't work like that here so. (Louise, Family 1, FM)*

*I started taking a lot of like joint medications, iron, extra iron, em, proteins, and then I started a nutritional programme called [X][...] it's a three part system it's vitamins, a shake that you take four times a week,*

*and a patch that you wear that has like, that gives you energy all day. And I find that that has helped me become pretty stable* (Claire, Family 12, FM)

Natasha, Louise and Claire were not arguing these methods ‘cure’ fibromyalgia, the point to take is that participants drew on their own EIK of what they felt made them feel better and eased their symptoms. Not all the participants in my sample shared these sentiments, or believed they worked for their fibromyalgia, rather these are subjective to some participants similar to Kengen Traska et al.'s (2012) findings. For a more quantitative evaluation of strategies that those with fibromyalgia use to manage symptoms see Kengen Traska et al. (2012). The above findings could indicate Parsons' (1951) idea that participants were making demonstrative efforts to manage their health and avoid a flare up. However, Blume (2017: 99) argues that experiential knowledge is only viewed as “*authoritative*” insofar as that it is in sync with medical knowledge. The participants in my sample faced barriers in accessing things which they felt offered a more comprehensive treatment of their fibromyalgia symptoms than that of pharmacological medicine. I interpreted comments such as “*if the NHS could prescribe*” (Natasha, Family 16, FM), and “*it’s a fortune I can’t afford it here*” (Louise, Family 1, FM) as highlighting the barriers participants faced in easing their symptoms, as the ways they felt helped them the most based on their EIK were not biomedically proven, nor offered by the NHS or seen as legitimate and cost effective. I argue this suggests we have multiple ways of understanding and legitimising EIK, and that these findings indicate support for Bury's (2012) suggestion that there can be hierarchies in experiential knowledge. Additionally, I argue this further demonstrates how different ways of knowing fibromyalgia mean understandings get lost in translation.

Furthermore, the participants touch on a general theme that their perception of the medical profession’s approach to treating illness can be narrow. Regardless of whether alternative medicines had medicinal properties or not, participants felt them to have an effect. This was informed by their experience, and highlights the disparities in how their experiences and EIK is treated compared to that of pharmacological medication. Therefore, some forms of knowledge, such as medication for fibromyalgia, were more valued than others, despite participants’ personal experiences highlighting that medication did not always make them feel well. Paige and Claire illustrate this through the side-effects of pharmacological medication:

*Ma weight soared when Ah wis on a lot of ma medication, Ah wis huge, and that depressed me more than anything else and it wis like ugh!* (Paige, Family 9, FM)

*I found that the medications I was taking, em, it didn't really do much and also were making me eat more because that's what they do. So I stopped taking them and I'm better off now because I've lost that weight that I put on while I was on them which was- that's just a waste of time.* (Claire, Family 12, FM)

Paige and Claire highlight how medication's side-effects could impact their self-esteem. Other participants said certain medication would “*make me violently ill*” (Jessica, Family 17, FM), and Hannah highlighted:

*My hair was falling out and I was getting black marks on my face and they [doctors] were like [...] “Oh well isn't the weight gain and your hair falling out a lesser evil than you being in pain on a daily basis?” And I said “No it's not, because I'm still in pain, I'm just now in pain with 2 stones heavier.”* (Hannah, Family 15, FM)

Participants implied that medication's side-effects would not always outweigh the beneficial effects they could have on their symptoms. In effect, participants were using their EIK to evaluate and legitimise, or delegitimise the use of treatment as defined by doctors' interpretations of biomedical knowledge. Likewise, one family member commented on the side-effects of medication:

*When there's a day without her medication, em, she obviously she's in more pain em. So then like because she's in more pain she's able to do less things and like, she'll in discomfort and stuff like that. So when she does take the medication, um it completely like knocks her out so then, even though she like, she's not feeling the pain anymore but it has a a I think it has a... [...] The effect is worse cos like you feel like she's completely just not there with you at all.* (Eve, Family 15, Child)

Eve suggests that in taking strong medication her mother (Hannah) was simultaneously absent and present. Eve's account also highlights how medication does not just impact

the bodies and feelings of those with fibromyalgia. I argue it suggests that medication's side-effects could have relational impacts on families. Gordon talked about how medication could impact his EIK:

*When she's havin a flare up... especially with some of the medication that she's had, it's caused some arguments. And it's not that we're jist arguing, it wis the medication thit wasn't right fir her, do you know what a mean? It would really drag her mood down, so you could say anything and it would just escalate know what Ah mean? Now her medications totally changed... and we're probably getting on better than we have over the last few years, em only because her [Paige's] medication has totally changed.*  
(Gordon, Family 9, Partner)

Gordon implies that medication could bring about unpredictability in his relationship with Paige. I understood Gordon's account as demonstrating how medication for fibromyalgia, though conventionally seen to treat illness (Parsons, 1951), could make it harder for families to navigate their lives and relationships with one another. Medication, though an attempt to stabilise and manage fibromyalgia symptoms, could also be a source of uncertainty that families wish to avoid, as Ewan notes:

*Ewan: Ah don't like the idea of cha- changing yer medication every so often, you know maybe increasing or decreasing the dose and, especially when things are settled and stabilised. You know if they're settled and stabilised and it's a safe dosage yer taking why no just leave it like that?*

*Int: has has that happened in the past where?*

*Ewan: oh yeah yeah it has happened, yep.*

*Int: em, does that impact your relationships at all or?*

*Ewan: yes, it can do because if there's been a change in medication - obviously you'll understand it takes a wee while for the body tae adjust to that change in medication. So, for the few days or weeks, ten days whatever it may be until your body adjusts, everything is just up in the air and you don't know what you're walking into. (Ewan, Family 10, Partner)*



Ewan implies that medication changes create uncertainty for him and his family, and that these changes can impact the EIK families have developed to navigate life with the illness. Subsequently their EIK then has to adapt to the situation brought on by the medication. I argue this suggests that medication does not just treat fibromyalgia symptoms in an illness context, rather it can pervade and disrupt other aspects of personal life and impact people relationally. Additionally, participants implied that medication did not make it easier to meet the other social responsibilities and expectations placed upon those with fibromyalgia outside the realm of illness and medicine. Therefore, participants tried to find a balance between their own understandings of what works for them, and of taking pharmaceutical medication where they felt it was necessary and whose benefits outweighed negative side-effects:

*I take as little medication as I can because [...] I don't want loads of stuff rattling around my system making me feel more drowsy or out of it. Em but what stuff I do take I take because I think it helps me. (Heather, Family 4, FM)*

Heather notes that she uses her EIK and her understandings of biomedical knowledge to determine what medication to take for her fibromyalgia. I argue this demonstrates how her understandings of biomedical knowledge and EIK can work with one another. Looking at the example of medication can highlight how different forms of knowledge are systematically viewed as more valuable than others. Although participants had subjective experiences of what works to ease their fibromyalgia symptoms, there is a wider point to be made about the perceived inferiority of participants' EIK compared to the biomedical paradigm of illness.

I interpreted participants' examples of medical language as a means to legitimise their experiential symptoms within a biomedical context, and to me as the researcher. For example, earlier Paul asserted that fibromyalgia has almost been scientifically proven. Natasha drew on ideas of medical fact to legitimate her EIK that pharmacological medication for fibromyalgia made her ill. I also interpreted Natasha's discussion of taking holistic medicines in a very clinical manner similar to a prescribed medication regime which makes aetiological changes in the body to ameliorate physical symptoms. I interpreted that participants knew their EIK was devalued compared to biomedical understandings of illness, and that they were trying to translate and bestow legitimacy to

their experiences of fibromyalgia, and holistic medication, by drawing on biomedical language. I suggests this demonstrates that biomedical knowledge is valued more than EIK at a systematic level; as if experiences to their illness and treatment were just as valued and accepted by the medical profession then their assertion that massage works over painkillers may be more readily listened to.

Additionally, I interpreted participants repeated use of medical terms and imagery not only as a means to gain legitimacy, but as suggesting that biomedical language is the lingua franca of understanding, communicating, and legitimating illness. Participants' attempts to translate their EIK to biomedical language could get lost in translation as operating behind this use of language are systems which value biomedical knowledge and experiential knowledge disproportionately. The implications of this will be drawn on at the end of the chapter and expanded on throughout the remainder of the thesis.

### 4.3 Lingua Franca and Material Impacts

Participants' EIK would often clash with others' interpretations of biomedical knowledge which I related to the underlying epistemologies detailing how people could use these knowledges to understand fibromyalgia.

However, Abby highlights not all medical interactions were conflictual:

*The GP was, I say she was, I say she would be supportive because she listened to me and she... understood what I was going through I guess, but she couldn't really offer a, like a solution. (Abby, Family 11, FM).*

Olivia also felt that despite not offering a medical solution to her fibromyalgia, her GP was supportive by being someone who would listen to her and value her experience:

*I didn't want to change my GP but it was the best thing ken cos he said hiself "I don't know anything about fibromyalgia." But each time I went back he had writ- looked up or he had read up about something and he could help or- maybe no help but he could explain what was happening and why it was happening and I feel that he's he really has been great [...], and although he's no got the answers I still feel he's good to be able to go to. (Olivia, Family 14, FM)*

Olivia and Abby suggest being supportive is not about having answers to fibromyalgia, rather it is having their EIK acknowledged and listened to. This is similar to Juuso et al.'s (2014) findings. Here I understood participants and their GPs to be engaging in bilingualism where they found a common language to try and understand and bridge their differences in knowing fibromyalgia. This could lead GPs to acknowledge participants' experiences. Paige illustrates this when recounting her arguments with a medical professional over a type of medication that she believed caused her to have seizures, but the medical professional felt her seizures were due to anxiety.

*Paige: I went back to me GP em, and she's really good actually. [Clears throat] And she was like "Okay, let's trial your theory of take you completely off this types of medication" [...]*

*Int: did that, do you think that helped with the, when you were saying about the seizures and you thought it was a type of medication. Did you think that helped with them?*

*Paige: em the medication certainly when I stopped by six weeks later I had not a single seizure, em. I can't honestly say whether [...] I have decided it was the medication or whether the guy [other doctor] actually had a point. [...] It'll be a bag of it all I don't doubt. (Paige, Family 9, FM)*

Paige implied that her GP was supportive by listening to her worries and experiences of the medication, and allowing her to trial her theory. However, I argue "*let's trial your theory*" suggests Paige needed her doctor's approval to do this, which highlights the power disparity between her as a patient, and the doctor who occupies a position of authority as a "*technically trained person*" who can grant her the permission to trial her theory (Parsons, 1951: 441). I argue that this also demonstrates how doctors and participants could work together when navigating their experiences with fibromyalgia. As certain medical professionals listened to participants with fibromyalgia, the references to medical professionals and biomedical ways of knowing are not implied to represent 'the' medical profession as a whole, or to criticise the medical profession or individuals who draw on biomedical knowledge. Rather, similar to Campbell's (2014) discussion of structures being fluid systems built up of many processes and practices, I am arguing that there are multiple ways that medical practices are conducted by medical professionals.

Furthermore in conducting their practice they are drawing on different ways of knowing, such as experiential and biomedical knowledge, as Vicki informed me:

*There have been some very very helpful people and kind people, and some people in the medical profession who... were less than kind. However, my current GP is very supportive, and upheld information I had given to work and pensions for benefits. So, I feel settled in that there are those people who... understand on a really good level what, what it feels like. (Vicki, Family 13, FM).*

Vicki implies doctors have to recognise participants' EIK before they would support a person with fibromyalgia, and this could have consequences in other areas of their life as she later informed me:

*Dr [omitted] in [town], and she told me categorically there's no such thing as fibromyalgia and, when I asked for a supporting letter for benefits she wrote "She is, she says she has fibromyalgia, she attends a fibromyalgia group" and charged me £10 for the pleasure. (Vicki, Family 13, FM)*

I argue this highlights the power at play that values different forms of knowledge over others. Vicki needed a letter from her doctor to verify her illness status and support her benefits application. Vicki implies that the doctor is using her experiential knowledge of fibromyalgia "*she says she has*", not their professional opinion within this letter. I argue by using language that creates fibromyalgia as Vicki's experience, rather than a medical fact, and Vicki's subsequent conclusion that the letter was unhelpful suggests that medical language has an authority and power above that of experience when applying for support from external agencies. Her GP's letter was subsequently seen as so detrimental to the application, because of their refusal to recognise her fibromyalgia, that Vicki did not include it in the application. I suggest this example demonstrates the power of the medical profession in helping people access support, and that while some doctors can value EIK, others can devalue it and gatekeep services as Madden and Sim (2016) highlight. Additionally, I suggest doctors' ability to value and devalue participants' experiences in institutions outside of the medical profession through, for example, doctor's notes, highlights that biomedical knowledge, language, and the need for physical evidence

operate as the lingua franca not just for avenues of treatment, but for legitimacy in institutions outside of the medical profession.

#### 4.4 Conclusion

In this chapter I have argued that how we understand knowledge as a society is fundamental to understanding participants' experiences of fibromyalgia. I have presented two ways of knowing fibromyalgia: biomedical and experiential. The theme body talk argues that biomedically the fibromyalgic body is silent due to biomedical ways of knowing illness as something inherent within the body. Meanwhile, body talk argues that experientially for the person and those around them the body can speak volumes through physically being fatigued and in pain, or through observing looks, one's pace when walking etc. In this chapter I have also argued that once biomedical knowledge was implied by participants to be exhausted through a diagnosis, and pharmacological medication, people and families could develop experiential illness knowledge (EIK), which builds on previous work by Kengen Traska et al. (2012) and Armentor (2017) by incorporating and reporting the perspectives of family members.

Lost in translation, bilingualism and lingua franca deal with the communication of biomedical knowledge and EIK. Through lost in translation I highlight a clash between participants' understanding of diagnosis and treatment for fibromyalgia, and their interpretations of their doctors' understandings of these terms. I also demonstrated how participants' in using their EIK of fibromyalgia did not always interpret doctors' biomedical approaches to treatment e.g. pharmacological medication, as a means to treat fibromyalgia. Additionally, what participants' understandings of treatment entailed – such as massage – was not implied to be interpreted by medical systems like the NHS as legitimate treatment. In lost in translation I also argue that the language participants' used to justify their experiences was suggested to be used against them by medical professionals to delegitimise their condition as their experiences did not have an aetiological biomedically understandable origin. Through bilingualism I highlighted that in the minority of instances where doctors acknowledged peoples' EIK of fibromyalgia that these two ways of knowing can cooperate with one another. However, I went on to note that in instances where doctors were understanding of fibromyalgia, they were still implied to hold more power than participants.

Through *lingua franca* I suggested that medical professionals' biomedical language and objects – such as a doctor's note – operated as the main way to understand and legitimate illness outside of the medical profession – such as applying for welfare. Participants said that they required physical evidence of their illness from the medical profession to obtain support, however they also implied that if their experiences were not supported by the language of the medical profession – e.g. if the doctor's language suggested doubt over the veracity of their experience – then that support could be denied to them. I argue that underneath these themes of communication were two ways of knowing illness – biomedical and experiential – and that people and families' EIK was systematically devalued inside, and outside of the medical profession. Despite this, my findings highlight that these two ways of knowing are not dichotomous opposing sides, rather they inform one another e.g. fibromyalgia is subjectively diagnosed, and one needs a diagnosis of fibromyalgia to obtain EIK and understand their bodily experiences are a part of fibromyalgia. However, participants' implied when they and doctors' used these two forms of knowledge, they were often conceptualised as clashing rather than cooperating. I interpreted the systematic devaluing of EIK in interactions with medical professionals as having economic consequences for participants. Chapter Four will explore wider norms of illness, and the power of *lingua franca* outside of the medical profession, and how this impacts participants and their EIK in more detail.

## 5 Chapter Five: Introduction

In the previous chapter I suggested there was a biomedical way of knowing fibromyalgia, and an experiential way of knowing fibromyalgia. I coined the latter as EIK which was developed by people with fibromyalgia and their families' experiences with fibromyalgia. I argued these ways of knowing are not static, absolute opposites, rather they are more fluid and can inform, and be informed by, one another. I have suggested that participants' accounts give biomedical forms of knowledge more legitimacy and power within institutions, such as interactions with GPs and welfare officials, than that of their EIK. Additionally, the language used by the medical profession – underpinning its way of knowing – such as letters of support for welfare, appeared to operate as a lingua franca in speaking about illness, and affording legitimacy to participants' experiences.

In this chapter I move out of the realm of the medical profession to explore other aspects of society and social life that impacted participants in this study. Within this chapter and the one that follows I show how participants' perceptions of social norms impact their understandings of their experiences, such as understandings of what it is to be ill, to be a worker, a mother, a child etc. (Parsons, 1951; Campbell, 2014; Morgan, 2011; Jenks, 1996). Participants implied that these norms were held by other institutions and actors within the society that they interacted with, and by the participants themselves. In this chapter I also explore how participants understood their experiences and navigated these norms, and the emotional and physical impact on themselves and their relationships. I do so by looking at participants' experiences of welfare and work, and by dividing this into three broad themes: social gaze, injustice and loss. Social gaze explores participants' interpretations of feeling scrutinised by wider norms of illness and disability within social situations, as their fibromyalgia transgressed these norms. Injustice is explored in relation to receiving (or not receiving) welfare for fibromyalgia. Meanwhile, participants implied they felt and experienced emotional and financial loss by losing employment.

In this chapter I seek to move beyond a biomedical understanding of illness to highlight a wider societal understanding of illness that emerged in the interviews, and to demonstrate the challenges participants faced outside of the medical profession. Doing this is important, as participants strongly implied that society holds particular ideas of what an illness looks like, which impacted their lives outside of the medical sphere.

## 5.1 Social Gaze

Participants often spoke of the challenges they faced in getting people to understand fibromyalgia, attributing this to its invisibility. For instance:

*It's an invisible disability so people look at me and think I look young and healthy and relatively fit- and I am! But that doesn't take away from like the pain that I have inside my body, and the fatigue and um, it's it is it's very limiting you know. [...] I don't think the world is very fibromyalgia friendly it's like either you're really sick or you're not but I don't fall into either of those two categories. (Claire, Family 12, FM)*

*Int: em, so do you feel like the... Invisibility of fibromyalgia's like a barrier or?*

*Eve: yeah I feel like it is definitely... um in terms of like, so my mum has a disabled parking badge [...] and like when we go out, if we were to go to the shops and she parks in a disabled bay or whatever, like sometimes you can see the looks because people give her certain looks because they feel like "Oh how come she's parking there?" Because it's not like, they can't physically see like what's like wrong. Em, yeah. So like in terms of that yeah. (Eve, Family 15, Daughter)*

Claire and Eve suggest those with fibromyalgia are under social scrutiny for not fitting into “two categories” (Claire, Family 13, FM) of ‘ill’ or ‘wellness’. Jessica also suggests she faces this public scrutiny:

*So I got my blue badge for my car, made a phenomenal difference to me, it really has. I have had, maybe 20 confrontations where I've got out my car as a 5'10 built like a brick shit house woman who carries herself quite confidently and doesn't have an obvious disability. It was different when I got the stick, people sorta shut up when I got the stick. (Jessica, Family 17, FM)*

Jessica notes she is scrutinised in the same way as Claire or Eve's mother for not having a visible disability. However, Jessica suggests having a walking stick mitigated peoples' attitudes, she shows that a visual marker of illness/disability is required to provide



legitimacy. I argue this suggests that there are wider normative societal understanding of what illness and disability looks like – something visible (Parsons, 1951). Therefore, while participants faced issues in the medical field by being challenged on the legitimacy of their illness, they also faced pressures in a wider societal field through not looking conventionally ill. Michael gives an additional dimension to this:

*Michael: The way that Conservative government have been pushing this whole em strivers and skivers thing, that means that em we now both feel we have to em we have to to sort of answer to to to complete strangers [...] the fact that we have a blue badge. [...] You do notice the disciplining starts when you park the car in a disability bay, and then you get out of the car and you walk somewhere instead of you, um, crawl out of the car to your um your your your wheelchair that's in the back somewhere.*

*Int: Yeah*

*Michael: And that is stuff that does affect you*

*Int: so like the kinda, the visual I suppose markers are important in a way? Important to other people?*

*Michael: um, well in the fact that the the the, for a lot of people indeed disabilities em don't exist unless they are visible, and even then, em, a broken leg is okay but a broken leg isn't supposed to last longer than a few months and then afterword's you're um ready to run again. And if that's not the case then, em, what are you doing wrong? You must be something, doing something weird because em normal stuff heals within a few months. (Michael, Partner, Family 1)*

Michael implies that society has an understanding of illness as acute and visible – similar to that of Parsons' (1951) sick role. He was acutely aware of the political narrative that governs how disability and illness are perceived, and he felt this narrative combined with societal understandings of illness as acute, and both illness and disability as visible, contributed to the social pressures he and Louise faced (Briant et al., 2013). In mentioning societal attitudes to illness, the UK government's narratives of illness, disability and how this links to welfare entitlement and in implying that he and Louise are excluded from

this, Michael creates a sense of having to ‘prove’ and physically demonstrate illness similar to the evidencing of aetiological illness within the previous chapter. Michael creates a sense of constantly standing trial, in which being ill is something that can always be contested. This is similar to the findings from Åsbring and Närvänen (2002) where their participants always felt themselves to be challenged in their experiences of being ill.

Additionally, Michael points out ableist assumptions of the human body by highlighting that he and his partner become suspect for their chronic conditions as their bodies not only do not appear normatively ill, they also do not return to a tacitly implied wellness (Campbell, 2009; 2014).

Overall, in wider society participants’ encountered ideals around what it is to be ill that did not match their own experience. Despite not matching their experiences, these ideals still influenced them as they implied it created them as outsiders but not *ill* in the eyes of the public. As such, participants interpreted their lives not only under biomedical and personal understandings of fibromyalgia, but also through wider societal ideals of what illness looks like. I understood these interactions to be reflective of Campbell’s (2014) microaggressions. Participants implied that public, government and disability narratives understood illness as Parsons (1951) did, thus it was acute, visible, and curable. As such, they looked upon and evaluated fibromyalgia through this understanding of illness and the biomedical understandings of illness that this position entails. In this thesis I refer to this understanding of illness as the social gaze, an interactional concept comprised of people interpreting biomedical and societal understandings of illness to create their own idea of illness. Such an interpretation can then delegitimize those who are not seen to meet this ideal. As we will see, this in turn impacts participants’ access to certain areas of systematic power (welfare benefits). I argue this social gaze can also effect personal and social interactions with friends, employers, family. My aim for the rest of this chapter is to show the impacts of this judgement in institutional settings, focusing on welfare and work.

## 5.2 Welfare Narratives, Good Citizens and Injustice

Within my sample some participants had experienced applying for welfare as a means to supplement their income and provide additional support. Within this section the following UK welfare benefits are mentioned: Disability Living Allowance (DLA), Employment Support Allowance (ESA), Personal Independence Payment (PIP), and Housing Benefit.

DLA is being replaced with PIP, however both come at a higher and lower rate and are benefits providing money to supplement costs of living for those with a chronic illness or disability (Citizens Advice Bureau., 2019). ESA is an income supplement for those with chronic conditions and disabilities who are unemployed and looking for work (Crown., 2019b). Recipients are placed into a category of those actively seeking work, or a second category of those with severe impairments who are in a support group and do not have to actively seek employment (Garthwaite, 2014; Crown., 2019c). Housing Benefit is a monetary sum designed to help people who are unemployed or who receive a low income or other welfare benefits to pay their rent (Crown., 2019d).

Participants were not excluded from institutional levels of recognition – as highlighted in the Section 5.1 several had blue badges recognising that they were disabled. However, there were other forms of recognition, such as receiving disability benefits, which participants implied they had to fight for. Participants suggested that receiving welfare was dependent on welfare officials' views on fibromyalgia which are informed by the social gaze. For instance, Samantha recounts the following:

*Int: I was gonna ask do you see the government – meaning Westminster in this case – like as supportive in that sense or unsupportive?*

*Samantha: em I would say unsupportive. Because, em, it just, it just gets me angry that the the times when Greg was having- I keep going back to his seizures. When we tried to get DLA for him, the things that we had to do eh the forms we had to fill in it was absolutely ridiculous. Em and even then, em see trying to keep his money as well, all the time. Cos I don't know what we would have done if we didn't have that money, I needed some money coming into the house. (Samantha, Family 6, Partner)*

*Int: do you ever feel like doctors don't listen because of fibromyalgia or?*

*Samantha: I do think, em, uh huh away back, away back when me and Greg were trying to get em, DLA for Greg, [...]I felt that as if they were going "Yeah yeah yeah, aw here we go again." You know as if we were trying to rob the system. And that's no the way it was at all, until we tried to- until we started delving into "Oh my husband's had cancer and this has all happened about his fibromyalgia and blah blah" and then that's*

*why they started to listen to us “Aw this guy really is and has been sick, he’s a genuine guy that that really is trying to get on with his life, trying to get what’s due to him.” Em, and I felt that that was when people started listening. (Samantha, Family 6, Partner)*

Samantha and her husband Greg encountered various barriers in getting welfare for his fibromyalgia. Samantha says not only were the bureaucratic systems complex to navigate making financial support hard to access, but that keeping this support is difficult. In particular Samantha mentioned the financial difficulty this placed on her family and earlier in the interview she mentions that in order to get this support and avoid scepticism from “*people that specialise in it [fibromyalgia]*” that she and her husband had to recourse to his experience of cancer to be seen as legitimate. This implies that institutionally participants’ experiences and understandings of fibromyalgia were denied and that they were not viewed as ill enough for support

This denial could have created further financial consequences for the family by potentially limiting their access to welfare. However, it also implies normative consequences through denying support for illnesses not seen as institutionally legitimate. Within the UK disability benefit is awarded based on how one’s daily life is limited by impairment, rather than whether one’s impairment is a recognised disability (Barber et al., 2019). However, participants still felt the lack of knowledge and awareness of fibromyalgia by the public and welfare officials was a barrier to them obtaining support. Participants implied that society valued normative understandings of illness that could delegitimise their understandings of illness. Additionally, within micro-welfare encounters participants repeatedly noted a feeling of having to prove to welfare officials that they were legitimately ill, and provide evidence for it, as Hannah highlights:

*Your day to day functioning is highly impacted on them not understanding or not having enough knowledge of what the condition is. [...] With fibromyalgia it’s almost [...] “Oh you don’t look sick!” You know and they ask “Why do you have a walking stick?” “Oh the doctor said that I should get one” and then they will write down literally “Oh the doctor suggested it, she bought it at the chemist.” It almost undermines why you got it, and that you bought it yourself so you could justify you needed it, it wasn’t a medical need. [...] I’ve said to these ESA professionals*

*beforehand, “I’m not being disrespectful and I’m not being pompous, but when I’m working I am quite well. Why would I purposefully put that down to- for £72 a week or whatever it is?” It makes no sense so obviously if I’m applying for it at this time because I need it, and when I don’t need it I won’t take it I’ll go back to work! (Hannah, Family 15, FM).*

Similarly to Vicki in Section 4.3, Hannah implies the welfare assessor is using her EIK to undermine her need for a walking stick by framing Hannah’s need as a suggestion and stating the walking stick was not medically provided. I understood this as delegitimising Hannah’s physical need for a walking stick while also demonstrating how the welfare official can interpret and value biomedical knowledge over Hannah’s EIK and how it impacts her. Subsequently, I understood Hannah’s interaction with the welfare official as an instance of an ableist microaggression (Campbell, 2014).

I argue this highlights the power and legitimacy of the medical profession outside of the biomedical domain as marked ‘signs’ of disability are not always legitimated if they are not obtained through a medical domain. Similarly to Paul and Natasha in Chapter Four, Hannah is drawing on medical narratives to legitimise her need for the stick. However, I suggest the institutional actors she is engaging with are using their own understandings of what illness looks like, and their own biomedical interpretations to delegitimise Hannah’s needs and deny her support. This in turn impacted her family’s finances and physical resources – as will be discussed later.

Additionally, Claire was angry that she could have claimed benefits which would have helped her financially when she was not working:

*I was like jipped out of thousands of pounds [for housing benefit], and physically couldn’t work, paid my taxes into the system when I moved here you know as did my family that were British so, yeah it’s it’s frustrating. I feel like there isn’t yeah, there isn’t a lot of support there isn’t a lot of voluntary- unless you’re, you know, full on disabled, but I am disabled I’m just not disabled enough so... it’s it’s very very frustrating. (Claire, Family 12, FM)*

Hannah and Claire both imply they are responsible citizens who are deserving of support from the government. Hannah states she needs the support, but when she does not she

will go back to work, while Claire argues she is deserving of support because she paid her taxes. They create a deserving and undeserving narrative, whereby they are, or have been, good working citizens and are therefore deserving of support. Not receiving it is then viewed as an injustice.

Although Emily's mother viewed her employer as being as supportive as they could have been with her fibromyalgia, Emily highlights the power disparities in the relationships between those with fibromyalgia, their employers, and welfare professionals:

*My mum was told she couldn't work and then... for her to have to fight to get anything at all, constantly justifying herself constantly trying to go "I can't do this I can't do that". And "Well how far can you walk, and can you do this?" So she's not, she doesn't get support in that respect, it's a constant, it's a horrible system of trying- I mean it wasn't my mum that said she couldn't work, it wasn't even my mum that went "You know what I don't want to go do this anymore." I mean she was the one, she was medically retired and and I don't like the way... that my mum's having to get put through gruelling assessments and stuff like that and I don't think that's fair. (Emily, Family 14, Daughter)*

Emily suggests that her mum (Olivia) is a good citizen who wanted to work and that the decision not to work, which is at the heart of the welfare scroungers narrative, was not made by her mum, rather it was her employers. By saying her mum wanted to work, Emily implies a theme of injustice as it was her mother's employers who decided she was not able to work. At the same time I argue that the social gaze that defines what illness looks like continually challenges whether she is ill enough for support. I reason that this demonstrates how ableist processes disempower participants through systems such as the welfare system and employment. Participants implied it was their employers who decided whether they were able to work and welfare officials who decided whether they could get financial support. These were not decisions that people and families' could make, demonstrating again how normative and ableist accounts of illness can impact the choices people and families can make, and subsequently the material resources available to them e.g. money (Campbell, 2014).

### 5.2.1 Conclusion

In this section I expanded on ideas I discussed in Chapter Two and Four around the types of illness knowledge in institutional settings. I drew on the social normative ideas that suggest disability is visible, that in illness one is either ill or well, and highlighted that the valuing of biomedical over EIK formed a social gaze that I interpreted as participants feeling pinned and constantly under trial by. I argue this social gaze demonstrates how participants can be institutionally disempowered outside of the medical profession, and constructed as able, and undeserving bodies in the realms of welfare.

It is important to keep in mind Michael's "*strivers and skivers*" comment which helps to contextualise participants' accounts and experiences, and demonstrates the wider contextual pressures of a social gaze encompassing public scrutiny and the challenges it brings to participants' experiences. I argue that participants, in creating a narrative of injustice through being denied work or denied access to systems (e.g. welfare) that they contributed to while in employment, tacitly implies that employment is central in being able to claim this narrative of deserving of support. Therefore, participants could assert they had had an injustice committed against them by having paid tax, or having had been in employment reminiscent of Campbell's (2014) unencumbered worker.

However, similarly to Chapter Four, I suggest that in linking employment and deservingness, participants were drawing on and interpreting the very narratives that they mentioned were used to institutionally delegitimise them and reinforced ableist ideas of work (Campbell, 2014). As such, they were also perpetuating these ideals and narratives themselves contributing to the wider ideal. The following section will look at this more closely and address the ideals and narratives around work, and how they relate to participants' experience of employment.

### 5.3 Experiences of Employment: So what do you do? Work as Normal.

Drawing on the narrative above in which work created one as being deserving of welfare, I interpreted that in participants' accounts there were wider norms around work that influenced their attitudes towards work. Participants' experiences of work varied depending on whether they were full-time, part-time, a student, currently unemployed, or retired.

At the point of interview only one participant with fibromyalgia was currently working full-time in a manual labour job:

*Greg: I was diagnosed [with fibromyalgia] and then about [...] a year after that I decided right I need to try and get back to work and try to get a normality back if you like. And it really did help getting back to work and getting a normality in my life, but it's still is kinda dragged me down a bit em,*

*Int: in what ways?*

*Greg: em just wi' tiredness, lethargicness, emmm soreness being on medication and I just feel dragged me down (Greg, Family 6, FM)*

Greg touches on an important aspect of social norms and work. He highlights that despite the mental and physical cost work could have on him due to his fibromyalgia, he associates work with an idea of normal.

The idea that work was a benchmark for 'normal' was reflected in other participants' (with and without fibromyalgia's) accounts as well. For instance:

*[on daily routine] On a normal basis it would be working obviously, but Ah think since November I've been out of work so, I'll [...] be looking for work again (Benjamin, Family 12, Partner)*

*We're all defined by our bloody jobs aren't we? It's the first thing you ask somebody when you meet them "What's your name? What do you do?" It's really embarrassing if somebody asks you "What do you do?" and you say... So I generally launch into a spiel about what I used to do. Cos it feels as if you've got to prove that you did, you were able you know, but that's about that's about proving you've got the mental capacity to do something, cos you say you don't do anything I think people just make the assumption that... "She's no that clever". (Heather, Family 4, FM)*

*You just feel a total... total reject really. That you know you're still young and you should be em, still working age you should still be working. And*



*people do look doon on ye, that don't understand this [fibromyalgia].*

(Andrea, Family 5, FM)

For Benjamin, work is seen as part of a normal routine. Heather highlights the challenges and societal norms around work through the example of the frequency in which people ask about work. She interprets and associates not working as reflecting badly on her. Meanwhile Andrea highlights that not working makes her feel like a “*reject*”, implying how important work is in daily life and sense of self. Additionally, Andrea invokes ideas that one can only be legitimately exempt from work through older age.

The accounts of Heather and Andrea also draw on this idea of social gaze by highlighting how social understandings of illness, and what illness looks like, can impact participants who are perceived and assumed to be able-bodied. Heather and Andrea suggest that others feel they look able-bodied and the scrutiny they feel is placed on them by others leads Heather and Andrea to feel they should be working. By retelling her employment history Heather demonstrates that she had an able body and was once a productive worker to avoid this perceived judgement and to be allowed the space to now be ill and unproductive (Campbell, 2009; 2014).

However, this idea of productivity and looking well impacted participants in employment as well and the following section will address this through looking at participants' experiences of part-time and flexible employment.

### 5.3.1 Part-Time and Flexible Employment

Similarly to other studies on fibromyalgia, some of my participants were not well enough to engage with paid employment, while other participants were (Juuso et al., 2014; Ashe et al., 2017). Some participants highlighted that they were given the option to work part-time. Studies of fibromyalgia and employment have found that part-time flexible work where employers are understanding create the best environments for participants with fibromyalgia to work (Juuso et al., 2016).

In this section I use part-time work to refer jobs where participants worked set days,<sup>1</sup> and flexible work to refer to implied zero hour contract jobs - an employment contract where

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<sup>1</sup> The participants I state who worked part-time informed me of the days they work, and as they did not mention 0 hour contracts I took this to mean they had contracts specifying work for those particular days.

one works when their employer needs them, but does not have to accept this work, and their employer is not obligated to give them work (Crown., 2019a).

Most participants in my sample who worked, worked on a part-time basis:

*But I went down from full-time down to part-time three days a week, em and the days are are split throughout the week which gives me an opportunity to recover in between. (Cheryl, Family 10, FM)*

*I work four days of the week and on a Friday that's my rest day so I usually can't do much on a Friday. (Natasha, Family 16, FM)*

*So we agreed on a Wednesday off, so I'm only ever working a maximum of 2 days at a time which is been a real godsend. And that's probably been the last 2 years Ah've done that, em so it's only Monday Tuesday, break and Ah mean ma Wednesdays are literally doing heehaw because Ah need tae completely rest. (Paige, Family 9, FM)*

In allocating a day for rest when working part-time I interpret this as participants using strategies based on EIK to manage work and fibromyalgia. This supports the previous literature that highlights the need for formal work support (Juuso et al., 2016) along with the need for a diagnosis and EIK to know one's limits. I argue this also highlights how people's employment and their EIK can work together to help those with fibromyalgia navigate work. However, participants implied these strategies can come with costs as others' perceived normative ideas of work and able-bodiedness impacted them, as Paige suggests:

*Still Ah hold this little idea "One day I might get back up to 5 days". Realistically that's just pie in the sky because I couldn't, I couldn't do 5 days. And Ah and Ah felt embarrassed at- for a long time expressing that to people because they were like "Oh you've dropped your hours, and oh why's that?" And I'd have to be the whole story and then it's other people's opinions because not everybody's convinced that it's a valid condition (Paige, Family 9, FM)*

Paige's part-time status allowed her to maintain her work, and is similar to Juuso et al. (2016) and Palstam and Mannerkorpi's (2017) findings that part-time work gives legitimacy and recognition to people with fibromyalgia in the workplace – as their employers allow them to work part-time and take rests. However, Paige implies there is uncertainty in social interactions over who will accept fibromyalgia as a legitimate reason not to work full-time. Paige feels that she is scrutinised not only by a social gaze informed by norms of illness because she does not look normatively (visibly) ill, but also by established norms within society such as work. I interpret Paige's need to explain her part-time status to others as an indication of others' ableist attitudes towards her fibromyalgia, and as demonstrating the ableist microaggressions that people with fibromyalgia can face (Campbell, 2014). However, as Paige describes that she felt embarrassed explaining her decision to go part-time to others, and the hope that she has to eventually return to full-time work, I understood her experiences as similar to that of Heather's in Section 4.1.1. I interpreted Paige's embarrassment at explaining this and her hope to return to full-time work as indicative of Paige's own ableist attitudes towards her body. Similarly to Heather, I understood Paige as knowing through her EIK how much her body can physically work, but that this can interact with her social relational self of what she feels she ought to work. I appreciate this as being based on Paige's own ableist ideals of her body, and others' social gaze informed by normative understandings of illness and ableist understandings of work (Campbell, 2009; 2014).

Although part-time work benefitted participants, I suggest that not all forms of flexible working were beneficial. For example, Hannah discusses her experiences:

*I did go back to [job], back as a temporary member of staff so if I do have a flare up I can say “Okay I need to go” and it doesn't impact on my work history in the way a second dismissal, or you know. It's a case of I leave, they don't pay me, I don't get any pay, and then I get well again and I phone the agency and they let me know which office needs staff members and that's how I've been working. Em but [...] you don't get any of that support and when you do go back to work, you don't get any of that in work support that you would do if you were a permanent member of staff [...] you just get “Oh you're ready to work? Great! You're back on the normal case load the normal”. You know it's that kind of thing which*

*sometimes doesn't work when you're coming out of a flare up [...] and you hit the road running, it's very easy for you to relapse back into a flare up within a couple of months.* (Hannah, Family 15, FM)

Although Hannah was working full-time at the time of interview, she worked for an agency with a flexible contract. She highlights flexible working through an agency is good for her in that a flare up does not affect her work history. She implies her employment is less secure as she has less rights and support to protect her and help her return to work. Subsequently her flexible employment and lack of rights and support impacts her fibromyalgia.

Hannah reported that her work had been supportive in supplying adjustments and that particular colleagues and bosses were supportive. However, she implies the full-time nature of the work and lack of support in returning post-flare up makes work difficult. Hannah felt she had to work harder than her colleagues in order to demonstrate to her employer that she was a valuable member of staff, in order to be retained and accommodated:

*I need my manager to feel like "She's an excellent member of staff em and so I'm gonna support her through the flare up." Em and that's what's put me in good stead. So in that last few that I've had whereby they're like "Okay, what can we do for you? You can work for home a day or two?"*  
(Hannah, Family 15, FM)

I see Hannah as engaging in planning and strategizing based on EIK to navigate working with fibromyalgia. I interpreted Hannah as trying to push herself to perform, similarly to Campbell's (2014) ableist unencumbered worker, to compensate for asking for support for her illness, and to demonstrate to her boss she is a valuable (able) member of staff despite the physical and emotional costs this can have.

I understand this as demonstrating the systematic disadvantaging of participants with fibromyalgia in the employment market, as Hannah had to take flexible but insecure work to avoid the punitive, ableist consequences of absences in more secure and stable employment.

In the next section I highlight that some participants within the sample challenged normative ideas of employment and what it is to be a good worker.

#### 5.4 Unemployment and Alternative Narratives

So far I have argued that normative ideas of work and illness seem to influence participants' and society's attitudes to work. I interpret these norms to be encompassed by a social gaze that had a pinning effect, whereby I understood participants to feel constantly on trial through implying they did not meet the wider normative expectations held by others. However, some participants challenged this by challenging the norms surrounding work as Claire indicates:

*Claire: I was doing [omitted] sales and I was doing really well but, um, they make you work six days in a row or nine days in a row and I just physically couldn't do it. But I was doing really well like I wasn't doing any worse in terms of sales so and my boss said to me "I can't manage your absences anymore." And I was like "What do you need to manage? I'm still making the company money." [...] just cos you're not working 37 hours a week doesn't mean you can't get everything that you need to get done done. When I'm sharp and I'm on my A game I can get more done than people probably do do in a whole week, but I need time to rest, and sleep and recover as well so that I can be sharp.*

*Int: It's like maybe breaking down the idea that 36 hours of work is like the?*

*Claire: Beginning and end all and that it has to be between 9am and 6pm or whatever, it's just, it's just such an archaic way of working. (Claire, Family 12, FM)*

Claire suggests that despite meeting her own expectations of what an able worker is within her job performance, she does not meet the ableist expectations of her employer due to her absences (Campbell, 2014).

Rather than blame her illness, Claire points to what she perceives as wider systematic ideals of work which are imposed on her (Campbell, 2014). In this instance I understood Claire as staring straight back at the norms and social gaze which try and dictate how her

body should be. I interpret Claire as challenging the microaggression being enacted against her (Campbell, 2014). However, although Claire views herself as an able worker, similarly to Emily's point earlier, Claire demonstrates that it is her employer who can decide what conditions need to be met for her to be an able worker. I interpret this as indicating how hard it can be for people with fibromyalgia to alone challenge the ableist codes and microaggressions which can dictate who should and should not be within certain environments (Campbell, 2014).

Louise also challenged the ideals of work:

*I would give the world to be able to work again, but mentally and physically it's just, it's just I can't every time I try I just crash and fail and it's become so frustrating that I put it off because it's causing me so much anxiety, it's just not worth my energy. I can better spend my energy doing some volunteer work and at least being there for my friends when I can be. (Louise, FM, Family 1)*

Louise highlights the emotional significance she places on work and the emotional impact and loss that she feels at not being able to work, along with the stress that this causes her. I argue this stress needs to be considered within the wider societal norms and discourses around welfare and work as mentioned earlier. However, Louise rationalises her decision with her EIK of how her body reacts to the confines of a working schedule. This returns to the idea in Section 4.1.1 of energy as a resource which needs to be managed. What this suggests is that despite her frustration at not being able to work, when managing the resources she has, it is better for her to be there for people and volunteer.

I take this to be an alternative narrative, Louise is making an active decision against trying to force herself into work despite the normative attitudes around work in order to protect her health. Louise reasons that she can contribute more by being there for those close to her and volunteering. While this could still lead to the idea that we need to be 'productive' within society, I argue it is more about managing one's energy and making sure one has the energy to spread across various aspects of one's life by re-evaluating what is meaningful fulfilling action (Juuso et al., 2016; Asbring, 2001).

However, alternative narratives did not make participants immune to financial constraints which could hinder the sustainment of these narratives, as Claire demonstrates:

*I'm in this strange limbo right now of trying to force myself to go back to work even though I don't really feel physically capable of going back to work. Um, but I only get £400 a month on disability so it's like what do you do? I can't live off that. (Claire, Family 12, FM)*

While earlier Claire challenged normative assumptions and the social gaze around working, in practice this challenge was harder to sustain. In the above extract she states she has to comply with the current state of the employment market and work around it as relying on the welfare system alone puts her at a material and financial disadvantage – which as I stated earlier happened to other families. Despite the power of alternative narratives in redefining societal norms and ideals, it can be difficult to uphold these narratives due to the emotional and financial cost to people and families that constrains their agency and their options in how they can redefine and find new values and meaning. Therefore, participants imply that wider institutional understandings of illness are not just a difference of values, rather they can have real material consequences for people's and families' lives. I argue this demonstrates how hard it can be to change ableist codes (Campbell, 2014).

Additionally, the emotional costs of losing work were, for those with fibromyalgia, significant. I will now discuss this loss and how it impacted participants.

## 5.5 Work and Loss

### 5.5.1 Emotional Loss

Work is important to having a sense of self and purpose. Despite the alternative narratives expressed in the previous section, there was a sense of emotional loss when one lost work, as Andrea highlights:

*That's my communication my pets. From em, no having any eh no going out and having friends or socialising really. Em and when you dinnae work, I feel so guilty that em you know you haven't got anything to talk about and you know a lot of people look on you look down on you when you're no working, and em, so you dinnae wanna get involved in those kinda situations. So fibromyalgia has got a lot to answer for really. (Andrea, Family 5, FM)*

Andrea implies losing work was not just about losing a job. It also impacted her social relationships as she withdraws from social interaction where she feels she might be judged for not working. Jessica expands on the impact this could have on one's relationships:

*I was devastated. Absolutely devastated when it happened. I had professional pride I wanted to complete my 30 years, I wanted to be someone who had achieved that. [...] And that had a big impact- you're talking about the personal relationships and things, your personal life that had a big impact on my relationship with my colleagues for me from my perspective cos I felt I was getting hung out to dry. And em, that's hard. To to suddenly be told "You can't do this anymore because of what's wrong with you." It's really really hard. (Jessica, Family 17, FM)*

Jessica expands on the sentiments from Heather in Section 5.3 and Andrea above. Although Jessica explains that losing her job was emotionally difficult for her, she implies that what makes this loss so challenging is her comparison between how her colleagues treated her for having fibromyalgia, and how she tries to reconcile this with the relational histories she shared with those she worked with (Smart, 2011).

Not all family members saw a discontinuation of work as a loss, particularly when it meant their family member was no longer in pain through having to work. For instance, Duncan was happy that that Heather obtained early retirement:

*Heather would be really in depths of despair, really the pain was ripping out her you could see how uncomfortable she was. The stress and worry would grow on her mind because she was continually off work and then when you're off work for so long going back to work becomes an issue. What will they be saying about me? (Duncan, Family 4, Partner)*

Duncan suggested the demanding nature of Heather's job caused her a lot of physical stress, but that being absent from work caused her emotional stress. He highlighted that both of these states aggravated her fibromyalgia. Despite the loss of work being devastating to Heather, Duncan implies her retirement was a relief as he did not have to see Heather in pain or stress. Söderberg et al. (2003) highlight how losing work can cause financial strain on the partner without fibromyalgia. However, my findings suggest family members could also be relieved at not seeing their family member in pain.



As I mentioned in Section 5.2, alongside an emotional desire to work, work also played a role financially in families' experiences. When the person with fibromyalgia lost work, participants' suggested they experienced a financial loss in this regard and this subsequently impacted them relationally. The following section will discuss financial loss in more detail.

### 5.5.2 Financial Loss

Despite Duncan's relief at Heather's early retirement in the previous section, because of the emotional and physical impact working had on her, he had been concerned about their financial situation:

*Heather's on a great pension for somebody who's retired early. It's enhanced, it's not what she would have got at 65 but it's more than she would have got at [age] right. She could have only had half of that, partial disability pension and I was gauging that income thinking "That's a problem". Anyway, the fact she got the full thing was super. (Duncan, Family 4, Partner)*

Therefore, despite the emotional benefits involved in being retired, Duncan says that not receiving this pension could have caused financial problems. While in this case it ended positively, where money was tighter for participants, it could have significant consequences for the families' finances:

*I've even at times had 2 jobs, eh cos Greg couldn't work, em, he was incapacitated he couldn't work. I had to take up 2 jobs so I was coming home, em to young children, em having to go back out again to work eh 2 jobs because we needed the money you know. (Samantha, Family 6, Partner)*

*So like in terms of he's feeling more like tired and stuff like that because while my mum's not at work at the moment he's bringing all the money, stuff like that. So, um like he worked from the weekend as well, so like during the week and the weekend as well, so he probably feels he doesn't really get a break either. And then on top of that like em he helps out around the house and stuff like that yeah. (Eve, Family 15 Daughter)*

Eve and Samantha demonstrate how the partners in the family had to take on an increased workload to help pay for family expenses, this is similar to what was noted by Söderberg et al. (2003). In Samantha's case this was while Greg was receiving benefits – highlighting how the money provided was not sufficient for the needs of their family. In Eve's case, her mother Hannah was repeatedly found to be ineligible for welfare support. I argue this demonstrates the precarious position that a lack of finances could have on families, and the impact that a lack of governmental support can have. This in turn had consequences for families' personal relationships as Heather also speculates:

*If that was the case [not receiving a pension] I would have packed a bag and left by now because I couldn't be financially dependent. So, I'm very very lucky that I managed to get my pension because I don't know where we would be as a couple, I would not have been able to cope with that. He probably would, I wouldn't. [...] I suppose from that point of view we are much luckier as a couple than lots of couples would be that have got somebody with fibromyalgia because if you're not fit enough to work... Money is the root of all evil if you're not bringing money into your house everyone starts fighting and you know that's where it all goes wrong so I suppose we're lucky from that point of view that I did manage to get my pension. Em I don't know how rosy the picture would be if we weren't in that position, I think it would be a lot worse. (Heather, Family 4, FM)*

Despite having an extreme sense of loss over her employment, Heather feels that by obtaining the support she did upon leaving work, the financial support contributed to preventing her personal relationships from suffering. Similarly to what Claire hinted at earlier (“*I only get £400 a month on disability [...] I can't live off that.*”), Heather feels that financial independence, and having a source of income when one cannot work while experiencing fibromyalgia, is incredibly important. This was not only for one's sense of self, but also to maintain wider family relationships and help people support themselves through meeting their own, and potentially their family's, basic living costs. Arnold et al. (2008) and Wuytack and Miller's (2011) participants expressed similar worries and difficulties with finances owing to the difficulties they faced in managing work and their fibromyalgia symptoms.

Other participants in my sample also implied how fibromyalgia flare ups could cause financial difficulties and subsequently impact their personal relationships, as Paige and Hannah discuss:

*It changed financially our situation changed and Gordon then backlashed into doing loads of extra work, and I felt it was him pulling away but it was really just him trying to practically fill the financial void because Ah had decreased ma hours. So that was hard financially the impact was was difficult, and, and we're still recovering from that. (Paige, Family 9, FM)*

*He's [partner] working 7 days a week so [...] his energy levels are low, you know when he comes in he's very, very tired because he's been doing a- since half five. And then if he has to come in and handle the baby, put her to bed, or bathe her, or feed her, or whatever then you know the energy that you have left at the end of all of that to have a general conversation with me, or to you know, it's not always going to be there [...]. And visa versa, you know he'll coming in from a long day at work and you know I- where I should be doing the doting partner thing, but I've had the baby all day, I'm in pain, I'm exhausted so I might miss out on that "How was your day?" or "Do you need a shoulder rub?" (Hannah, Family 15, FM)*

Paige implies that financial issues brought about by being unable to work impacted her finances and relationships. Meanwhile, Hannah highlights that as her partner must work extra hours, and because her fibromyalgia symptoms are in a flare up, it does not leave them with the time or energy to spend time together as a couple. This is similar to Corbin and Strauss's (1985) discussion on the work families have to do when balancing family life and chronic illness.

However, I argue these accounts add another dimension of normative roles through family relational norms as Hannah suggests she "*should be doing the doting partner thing*". I suggest this highlights Hannah's perceived expectations placed on her in being a partner, and the difficulties of juggling this with childcare, illness, and financial need. I argue, as in Section 4.1.1, that this invokes the idea of energy as a resource, and as Hannah was in a severe flare up at the time of the interview, it highlights how energy becomes something the whole family needs to manage to navigate the other social expectations

placed on them – such as work, parenthood etc. again as highlighted by Corbin and Strauss (1985). I suggest it also demonstrates how financial loss can impact more than a family's finances – such as their personal relationships, and how labour is negotiated within the household.

In summing up this section, I argue that my findings highlight the emotional and relational loss that losing work could have on participants. Participants implied they did not just experience an emotional loss in relation to no longer being able to work, but that they experienced a loss of the relational histories they shared with those they worked with. Participants noted that they faced a financial loss with the loss of earnings from them/their partner. Some family members stated that no longer working was a relief, as it meant they did not have to see their family member in pain. However, I suggested this relief was related to the ability of these families to obtain other sources of income which could support them.

## 5.6 Conclusion

In this chapter I have explored participants' experiences of fibromyalgia through welfare and work. Participants implied that society's view of illness was similar to Parsons' (1951) acute visible illness, and the biomedical logic that underpins this understanding, which I interpreted as creating a pinning social gaze. I argued this social gaze in turn impacted participants' experiences of welfare and work.

I interpreted themes of the injustice as characterising participants' experiences of welfare as they created narratives of deserving and undeservingness where they were good citizens deserving of welfare. However, I understood in participants' accounts that to be deserving of welfare one must have previously been an able worker (Campbell, 2014). I take participants' understandings of their experiences of work to be influenced more by ableist notions of what it is to be a worker, and that to work is normal. Participants said that losing employment came with emotional and financial losses which impacted their relationships. By using EIK some people were able to challenge wider norms around work which reflected Juuso et al.'s (2016) suggestion that those with fibromyalgia who cannot work should be helped to find new values in life. However, my findings suggest that changing peoples' personal values and outlooks towards employment does not nullify their need for financial resources. These individual approaches also do little to address the wider systematic devaluation of participants' EIK, and the wider institutional

discrimination they could face through a lack of rights, normative understandings of illness, and ableist understandings of work and the body which had a greater impact for their material and emotional wellbeing. Additionally, participants implied that losing one's job was not just about losing a job and thus finding new values, but that the shared relational histories one had with co-workers were also impacted.

I concluded this chapter by looking at the disempowerment that the systematic devaluation of participants' experiences could have on them emotionally, financially and relationally. I argued that this systematic disempowerment did not just impact isolated aspects of participants' lives, rather it can have relational consequences for personal relationships and households, in addition to the impairment effects fibromyalgia has as an illness (Thomas, 2004). In Chapter Six I will explore in more detail the ways in which this disempowerment and fibromyalgia's impairment effects impacted households divisions of labour, and I will follow on with the themes of EIK, and the sense of loss experienced in an emotional and financial way within this chapter.



## 6 Chapter Six: Introduction

I ended Chapter Five arguing that reduced working, or ceasing to work, could impact different aspects of families' relationships in regard to finances, the division of household labour, and that this in turn would impact their personal relationships. I argue essential to this idea are social negotiations and social expectations, similar to that of Finch and Mason's (1993) terms of social expectation and negotiating responsibilities. In this chapter I will first explore how participants with fibromyalgia navigate household tasks by discussing what I refer to as adaptation. From there, drawing on my discussion of loss in Chapter Five, and the normative expectations that framed participants' lives, I will discuss the theme of missing out in relation to the costs I interpreted as being associated with these adaptations, and the sense of loss participants implied they felt in their personal relationships. I will then discuss the theme of balance which I use to conceptualise how families managed fibromyalgia in their social relationships to one another, using their EIK to adapt, compromise and plan their social and personal relationships and days out. Lastly, I will explore how the support detailed throughout this chapter reflects a privileged position, and particularly normative understandings of families as reflected within policy discourse. I demonstrate that this family support was not an experience all participants shared, but that the assumption of its existence had a significant impact on their lives.

### 6.1 “*You just get on with it*” The Multidimensionality of Care

Ewan (Family 10, Partner) when asked about the support he provided to his wife Cheryl responded with: “*You just get on with it*”. Rather than viewing it as something he begrudged or found wearisome, I argue it represents a wider aspect found within participants' accounts whereby they supported one another due to their interpretations of their lives as being part of a family. I argue it signifies an attitude of no questions asked, this is what one does. Throughout this section, I will make this sentiment evident. Participants within my sample frequently spoke of negotiating their daily lives in relation to fibromyalgia and the wider needs of their household, and the social expectations placed on them through their perceptions of their roles as parents, mothers etc. This is similar to findings from other studies on family support and chronic illness (Richardson et al. 2007; Corbin and Strauss, 1985). In this chapter I have organised the negotiations participants make under the headings of Adaptation, and Balance. I argue these negotiations were essential to shaping participants' social expectations of their lives in the context of

fibromyalgia and embedded relational histories and biographies that they lived with, and the wider norms of family that they implied they lived by (Smart, 2011; Gillis, 1996). Before exploring in more detail the theme of adaptation, I would like to highlight that within my sample there was no ‘one type’ of adaptation, instead there were multiple different understandings depending on people’s situations. While I recount various ‘types’ here, it is not my intention to create a typology from qualitative data. Rather, it is to highlight how people used the agency they perceived was available to them to navigate life with fibromyalgia.

### 6.1.1 Stable and Flexible Adaptations

Regardless of the type of adaptation, or how participants perceived it, participants implied it was a part of juggling the needs of the person with fibromyalgia and that of everyday family life:

*Family life has to go on you know, there’s things I have to do on a daily basis like put on a washing. I know it exhausts me I know I’m going to have to sit down after I do it, I can’t not do it because it makes me tired you know. (Heather, Family 4, FM)*

Heather implies that life goes on regardless of how the impairment effects of fibromyalgia may impact, this was also noted by Corbin and Strauss (1985). I suggest her EIK can help her navigate these social responsibilities by letting her know how doing laundry will impact her, and how she can recover from doing it. Paul and Cheryl demonstrate how they adapted their routines below:

*I rarely meet friends in public, this is rare for me to be out in a [interview location]. There’s two reasons for that [...] 1) because I find it really difficult to hear when there’s background noise 2) I’m still petrified in case I get bumped into because the pain can be so excruciating it just stops me in my tracks and I can’t do anything I gotta wait you know, and I don’t find that an enjoyable experience anymore. (Paul, Family 2, FM)*

*I tend to find I have to pull the line down so I don’t have to lift my arms as high. Em, things like, boiling a kettle, just simple things like taking*



*washing out of a machine. You know where if you bend down, stand up and yer feeling dizzy as anything, or ye've no goat the strength. Ah've adapted the way that Ah do things an awful lot tae make sure that Ah do them instead ay.* (Cheryl, Family 10, FM)

Through Cheryl stating “*You know where*” she is recalling a previous experience of doing a household task, and how by using her EIK she can determine how it may impact her in the future. In Paul and Cheryl’s accounts, I interpreted adaptations to be things which they have known to do from experience, and known to do for a while. This restates my point in Section 4.1.1, that obtaining EIK is a temporal process and something people can use to navigate their lives, and the needs of themselves and their families. Additionally, I interpreted an ordinariness in Cheryl, Paul and Heather’s accounts. Therefore, I conceptualised these adaptations as stable, as participants implied they were ordinary parts of their daily routines and practices rather than something extraordinary.

These adaptations were not limited to participants with fibromyalgia, partners also adapted their life around their partner’s fibromyalgia. For example:

*There is still the odd occasion I say “Aw naw I’ll drive” but Samantha generally does all the driving now. And it’s not because I don’t like driving, it’s just because of the way I feel, it’s because I maybe feel drowsy, I maybe feel tired. Em so she’ll do it. Em, so, there has been subtle changes like that that I’ve no even kinda thought about that just happened because of fibromyalgia.* (Greg, Family 6, FM)

*When it came to the coming home, the shopping coming in from the car, I had to carry, if I wasn’t- if I was away for a week working Heather wouldn’t do a big shop because I wouldn’t be there to carry it in the car.* (Duncan, Family 4, Partner)

I interpreted Greg and Duncan as demonstrating how they and their family members developed their own EIK which caused renegotiations over time on aspects of the division of labour in their house. I argue this suggests renegotiations do not have to be done by physically communicating with someone, rather by living with them over time and that this demonstrates Elden's (2016) ordinary complexity of care. Greg implies an ordinariness in Samantha taking on more driving. However, Greg also implies that the

reason for this is complex, involving fibromyalgia's impairment effects, and Samantha's EIK telling her how driving will impact him negatively. Emily also implies this ordinary complexity:

*There are certain things I know- If she wants to make soup I'll come down and say "Mum leave the turnip, I'll do the turnip" cos it's too hard on her hands. So there's certain things like that that I know she'll struggle with.*  
(Emily, Family 14, Daughter)

Emily, like Greg, implies this adaptation is an ordinary daily practice, but I argue again that the reasons and processes behind knowing that one should do this adaptation are complex. Participants also implied that although they did more in the house now than before the onset of their family member's fibromyalgia, they did not feel resentful, or burdened by these adaptations, as Paulson et al. (2003) and Arnold et al. (2008) have suggested. I interpreted these adaptations as similar to Briones-Vozmediano et al.'s (2016) study in which her participants with fibromyalgia explained they adapted their life and housework around fibromyalgia. My findings suggest participants' EIK could be used to help them manage the impacts of fibromyalgia and meet the wider needs of the household. However, I argue there was more to this than simply meeting household needs, or doing something for someone because they could not do it themselves. Participants implied that the extra work they took on was not always reciprocally returned. However, they also implied that this lack of reciprocity was acceptable, if it meant their family member was not in pain. This finding is different from other studies on families, care and chronic illness (Corbin and Strauss, 1985; Richardson et al., 2007). I understood participants as undertaking this because they loved and cared for one another, which is an idea that I will return to (Smart, 2007).

Although participants implied some adaptations were more 'stable' in a longer term, others suggested there was a high degree of flexibility amongst others due to the differing needs of the household and variability of fibromyalgia in day to day life, as Benjamin states:

*Normally we will have a list of things that we want to do during the day, Claire's really good at writing things out "Right we need to get this this this and that done." Em, so if we have that list, the things that I would*

*normally do on that I would do, and then if there's anything on that list that she can't now do, I'll make sure I do them as well – like picking things up from town, [...]. Some days it has impact, other days it doesn't, I guess it just depends what we have planned for the day. (Benjamin, Family 12, Partner)*

*Int: [...] How do you feel about like em doing like housework when your mum's ill and looking after your sister sometimes?*

*Eve: em... how do I feel about it?*

*Int: yeah*

*Eve: Sometimes I feel a bit sad that I have to do it, but em in a way I know that I have to do it and it needs to be done because my mum- if my mum could do it she would, but the fact that she can't it makes me want to do it even more [...]. She's not one of those parents that would force me to do it, she would try and do it herself but em, she's not physically able to do it so she's putting herself through more pain. So I just do it cos I know that if I don't do it she's going to try and do it when she can't. (Eve, Family 15, Daughter)*

Benjamin and Eve detail adaptations that I interpret to being flexible in daily life, based on the needs of the household and the impairment effects of fibromyalgia. I understood this renegotiation to be constantly in progress as Benjamin and Eve used their EIK to know how their family member might be impacted by fibromyalgia, and how their household responsibilities might change daily. These findings are similar to findings from Corbin and Strauss (1985) on how families manage illness. However, I suggest my findings build on this; I interpreted that families' EIK did not only help them navigate their practical needs, but also their emotional needs as family members without fibromyalgia did not want to see their loved one in pain.

It is also important to note that participants' negotiations of who did the housework were not always related to fibromyalgia:

*My doing the housework probably precedes Vicki's contraction of fibromyalgia, eh not by a long way. There was a time where we used to share it, but then it, it mainly was driven by Vicki's work in [City] [...]. It meant she had no time. And eh so therefore it was left to me and, it was like topsay- it's stayed with me. Eh, and then she got fibromyalgia and that was that so. (Daniel, Family 13, Partner)*

*If I had my day off, and I would always tidy up, do the dishes, clean up and eh, I just got into a routine of doing that through the routine. But now it's more a case of... eh trying to take the strain off Natasha, eh take the pressure off her like do the house, do the washing, hang the washing up. Now and then she'll say to leave her own stuff and she'll do her stuff. Eh, I'll do eh, eh Noah's [son], myself. Eh a lot of the time I will do the washing, hang it up, bring it in. So I try and do everything to make her life easier. (Jacob, Family 16, Partner)*

Daniel and Jacob imply that some adaptations were not started because of fibromyalgia, rather they originated historically from other reasons. With the advent of fibromyalgia, Daniel and Jacob explained how these existing habits were continued to accommodate their family member's condition. I suggest that while not all family negotiations started due to fibromyalgia, the onset and knowledge of the condition could change participants' reasons/motives for continuing or not continuing to do certain tasks. I argue this supports an ordinary complexity of care, and a dynamic conception of family relationships and shared histories, which are continuously moving and changing in reference to the relationships of those around them (Smart, 2011; Morgan, 2011; Elden, 2016).

### 6.1.2 Short-term Adaptations

Participants' implied that not all of the adaptations they made were sustainable in the long-term. Where a person had an extreme flare up of fibromyalgia symptoms, it could strain families both physically and emotionally, and families implied these were harder to navigate as Hannah and Gordon demonstrate:

*I'm also aw- noticed that when you're when you're sick for 2 months or 3 months you can have that help [informal support] that's great. But when you're going into 8 months 10 months that's, and everybody starts to kind*

*of go back to their normal life because it's not sustainable indefinitely. It's like a short-term fix. And we're at that point now where it can't be sustained any longer. So... yeah.* (Hannah, Family 15, FM)

*She stopped working while these seizures were happenin, em Logan [son] was goan ay nursery cause before he started school, Ah wis huvin ay come down from ma work on ma breaks and take him tae nursery. And on ma breaks Ah'd then pick him up from nursery, and that wis and that wis hard tryin a fit that intae 15 minutes in the morning and then in the afternoon.* (Gordon, Family 9, Partner).

Hannah and Gordon detail the strains that a flare up of fibromyalgia can have on people's informal support networks. Hannah implies this support is not a permanent solution in an extended flare up as people return to "*their normal life*". I suggest flare ups within fibromyalgia are not perceived by those around Hannah as something which should last longer than a few months. I interpreted this as indicating a Parsonian (1951) understanding of flare ups as acute period of illness. Gordon talks about the strain that being ill can have on other social obligations, e.g. taking children to school, and who is able to do this while also balancing the financial needs of the family. I understood Hannah and Gordon's accounts as demonstrating how intensive adaptations can be on families' resources and informal support networks. Families were not only juggling the impacts of fibromyalgia's impairment effects, but also the wider needs of their household.

I argue that short-term adaptations highlight that adaptations families with fibromyalgia can make are not always sustainable physically or emotionally. Additionally, as mentioned in Section 5.2 Hannah noted in her interview that she faced a lot of barriers in accessing assistance from the government, and that being denied access to support placed further strain on her informal support network. Although in this section I have been speaking of instances of support that family members engaged in within daily life, I am mentioning this here to remind the reader than they could take place within a wider context of a lack of state support. I suggest this is reminiscent of Bury's (2012) argument that there is an assumption in policy that families will provide informal support. I suggest these findings also support Elden's (2016) argument that care can be undertaken for complex reasons relating to socio-economic necessity. I will expand on this lack of state support later in the chapter.

### 6.1.3 Conclusion

Overall, I suggest that families adapt to the impairment effects of fibromyalgia, and that these adaptations could take various forms. I argue that these were undertaken to address the needs of the household and various family members which were at times external to fibromyalgia, but which fibromyalgia could impact. I interpret participants' EIK to be more valued in navigating their daily lives than that of biomedical knowledge of fibromyalgia. However, as I argued in Section 4.1.1, having EIK of fibromyalgia required a diagnosis highlighting the fluidity of these two forms of knowledge. I interpret participants' navigation of daily life as involving participants changing the social expectations they, and at times others, held over who is responsible for domestic work. I suggested that this involved a wide array of social negotiations between them to manage their needs and the needs of their household. I suggest these adaptations present multidimensional and context specific instances of care as an ordinary complexity which are done by families to navigate their household needs and relationships. I will expand on this multidimensionality of care later in this chapter.

Prior to this I am going to explore the wider social norms that participants implied influenced their feelings about adaptation. I will explore this through the theme of Missing Out.

## 6.2 Missing Out: The Long Shadow of 'The Family'

At the start of this chapter, I suggested families negotiated their daily household tasks through adaptation, which was sometimes as a result of fibromyalgia. I suggested adaptations were ordinary complex acts undertaken by family members out of love for one another as people with shared relational histories (Elden, 2016; Smart, 2011). I also implied that adaptation could be a response to needs unmet by policy. I argued that key to adaptation was for families to change the social expectations of who is responsible for tasks in daily life, for example household tasks. I mentioned that this could come with physical costs when a family member was in a flare up of fibromyalgia. However, I argue this renegotiation could also come with emotional costs as firstly, participants felt they missed out on what 'normative' families do, based on their interpretations of wider social norms of family roles. Secondly, I interpreted families as missing out on wider relational experiences which were important for their shared relational histories and their relational selves.

### 6.2.1 Adaptations and Alternative Narratives

Before discussing how participants felt they were missing out, some participants framed a redistribution of housework as an equitable distribution as Cheryl and Jessica highlight:

*We all live in this house so we all should work together, shouldn't just be one person's job tae dae it despite what everybody thinks.* (Cheryl, Family 10, FM).

Jessica also suggests something similar:

*We have quite a bit of, you know, equality in this house and Jack [husband] carries his share and so does Lucy [daughter].* (Jessica, Family 17, FM).

Cheryl implies housework was previously perceived to be her job. In both instances Cheryl and Jessica are redefining the expectations of who is responsible for doing certain activities in the house. I interpreted this process as creating alternative narratives of equity as other family members engage in housework, and in these instances, participants implied the changes to come about with the onset of fibromyalgia.

However, as we saw in Chapter Five, participants' accounts straddled multiple, and sometimes contrasting, ideals and narratives. Although Morgan (2011) and Smart (2007) highlight that families practices can be dynamic and fluid, Morgan (2011) and Gilding (2010) also remind us that certain family practices endure over others. I understood Cheryl and Jessica's accounts above as alternative narratives, similar to those mentioned in Section 5.4, because I understood Cheryl, Jessica, and other participants to be fighting against a stronger theme of missing out. I constructed the theme of missing out as I understood participants to compare their changed family practices to their perception of normative understandings of their roles within the house around femininity, motherhood, family and childhood, which they felt fibromyalgia disrupted. I will now discuss this.

### 6.2.2 Family Ideals and Lived Realities

Despite the existence of alternative narratives, I interpreted wider normative ideals of what it is to be a child or a parent and how this related to fibromyalgia in participants' accounts of household life, as Jacob and Ewan mention:

*You're talking about maybe 10 years ago so you know like 13/14 eh even younger 12... eh so it's very difficult for them- if I don't understand it then kids really won't understand it [fibromyalgia] (Jacob, Family 16, Partner)*

*We kinda want the kids to have as normal a childhood as possible and, Ah you know I'm an adult [...] I can understand you know what I am going to get let down at times but the kids shouldn't have to get let down. So we try and give them as normal a childhood as we possibly can. (Ewan Family 10, Partner)*

Jacob and Ewan imply their children will not have an understanding of fibromyalgia, similar to Wuytack and Miller's (2011) findings when their participants spoke about their children. Ewan suggests he and his wife's role as parents is to prevent their children from being impacted by fibromyalgia. In both accounts, Jacob and Ewan demonstrate normative, minority world ideas of childhood (Jenks, 1996), and in Ewan's case, a desire to maintain this state of childhood. Jessica wrestles with this understanding of childhood, and her own perceptions of motherhood:

*My daughter does everything herself in the morning, and she's 12. She gets up, she feeds herself, she has a shower, she gets dressed, she packs her bag she's ready to go. Now, she's 12. [...] I worked when she was younger so she was taught to be self-reliant but eh... she has to do you know, and a lot of children don't and she notices where other kids like... for example, a really good example is the school pick up, where the mum walks up to the gate even though the kid's a teenager, and takes the bags and puts the bags in the boot of the car. I couldn't do that for Lucy. Lucy walks up to me. Now, I think at almost 13 years old she's perfectly capable of walking down the hill to the carpark on her own (Jessica, Family 17, FM)*

Jessica suggests a conflict between what she and her daughter can do, and what she feels they ought to do based on her perception of unwritten normative rules of getting ready and coming home from school. Jessica implies Lucy is too young to be doing what she does. However, Jessica also creates an alternative narrative of childhood where she is teaching her daughter to be independent (Jenks, 1996). Jessica suggests she is missing out



on being a 'normative' mum to her daughter through not collecting her bag. I interpreted this as an example of the multiple, competing, and at times ableist, narratives and norms that participants perceived and navigated within their lives, and the emotional toll they could have. Hannah makes a similar point when discussing the impact of her fibromyalgia:

*It makes me feel like I'm failing as a mother em it makes me feel like I'm an extreme burden on my family em... yeah. Cos you know if you, if I'm, if that thinking that if you're gonna be a stay at home mum, then your gonna do all a stay at home mum things. You're gonna take you know the child to the stay and plays, and you know you're gonna do their ABCs with them, and [...] the older kids and your partner is gonna come home to a cooked meal and the house is gonna be clean and the washing is gonna be- you know all those kind of things! But I'm a stay at home mum whose not always able to do that. So, you know they come home after a busy day and they're having to do the cooking at 6 o'clock in the evening, or they're having to, you know, and then they have to take over from the baby [...] because I physically can't manage. (Hannah, Family 15, FM).*

Hannah contrasts what she feels she ought to do as a mother, and what she and her family actually do instead. While she highlights the physical costs to her family, she also invokes a sense of a failed motherhood, and a clash between the norms of an idyllic childhood and family. This is similar to the account of Jessica, both participants seem to compare and evaluate their experiences to a family role structure, similarly to Parsons' (1951) account of the nuclear family, with what actually happens when a fibromyalgia flare up occurs. However, the norms discussed by my participants have an internal ableist logic as they assume a life without illness (Campbell, 2014), yet I interpret that participants seemed to use these norms like an evaluative framework of what their life ought to be like. When expectation did not meet reality, participants implied feeling as though they and their families were missing out on what they felt other families did and/or what they once did. I suggest this demonstrates the power of Campbell's (2014) concept of comparison that I mentioned in Section 2.5. More importantly, I argue that this highlights how loss in the context of fibromyalgia can be experienced not just individually but relationally, and in reference to families' shared histories and wider perceptions of family norms. I suggest

this incurred another type of emotional loss which concerned the emotional and relational change participants perceived missing out had for their personal relationships.

### 6.3 Missing Out: Family Relationships

For some families, fibromyalgia had caused a lot of relational changes and this created a sense of loss:

*Int: How would it make you feel if they just announced they're [adult child and family] coming?*

*Andrea: Oh you know there's been times, that's happened a few times you know and I've had to pretend that I wasn't in. I've been in my bed and no answered the door cos Ah- It's not the fact him and her that's- it's the three kids that I wouldn't want them to see me in some of the states that I've, or the tiredness or no being able to play with them or talking to them like a normal Nana [grandmother] so I've had to ignore the phone or no answer the door. I never in my wildest dreams would I have thought I would ever do that. (Andrea, Family 5, FM)*

Andrea, in feeling that she can't interact with her grandchildren like a "normal" grandmother, invokes ideas of idyllic childhood as she implies she is less uncomfortable with her adult child and their partner seeing her when she is unwell. She creates an ableist ideal of a grandmother by positioning having fibromyalgia as not meeting this ideal, implying it is not just understandings of parenthood and childhood which are impacted. However, I want to draw out the emotional implications within her act of distancing herself from her family. Andrea implied she was missing out through losing family time together as a result of fibromyalgia, which caused her emotional pain and social isolation. Lucy also discusses this idea of missing out:

*Other people in my class will be talking about how they go on walks with their mums and they like go runs, and they do all these things that my mum can't really do so it's quite unfair I guess. (Lucy, Family 17, Child)*

Lucy argues that she and her mum (Jessica) are missing out on engaging in wider implied normative activities that the rest of her classmates can do. She also highlights the

emotional pain she feels at not being able to do this due to her mum's fibromyalgia. Hannah also demonstrates this pain:

*Even now she's got prom coming up and I've not been able to go do dress shopping with her. We've looked online, but you need like to go to the shop and try the dress and you know, those little things, you know, you know that mothers and daughters do they go and they bond over shopping together or whatever. And we're not doing that cos... physically I'm restricted. (Hannah. Family 15, FM)*

I am suggesting that participants felt they were missing out on experiences of spending time with their family members, in ways that are emotionally valued by participants' normative understandings of how these relationships work. For example, Hannah's account of being unable to go prom dress shopping with her daughter Eve. Before I discuss the implications of this, I will detail how I understood missing out to impact relationships between partners.

### 6.3.1 *Missing Out: Partner Relationships*

The majority of my sample were in relationships, and within my sample some mentioned a distinct feeling of missing out and loss in relation to what they had previously been able to do before fibromyalgia. For instance, Duncan states:

*We moved in together [...] we were young, we were healthy, we had lots a things ahead of us you know [...]. I'd love us to be able to go camping. Not that I'm a big camping- but just like go on we're gonna go with my mates for a while and go on the bike away and we'll go in a tent or something. We canny go we've got to find a bnb or something. There's just things that are parallel to my other friends friends are doing at our age that we we can't, that's what kinda, you always miss something that you canny do. Probably wouldda never have gone camping, probably would have never have gone sailing whatever, but then I know that we can't now. You know what I'm saying, you kinda taking away and you think there were times you wouldda done those things you know. And it's also when you come home and your wife is really no well, you're, and there's nothing*

*you can do you're so helpless, you feel so helpless.* (Duncan, Family 4, Partner)

I interpreted Duncan's excerpt as being filled with emotional pain at missing out on his expected life trajectory with Heather. Duncan emphasises this loss is not just his own rather the loss of a relational we. By saying "*we had lots of things ahead of us*" Duncan implies that he and Heather are sharing a loss of relationally shared practices and future expectations that his friends are doing that he implies are normative, and that he emotionally values which creates emotional pain. However, Duncan also implies the emotional pain comes from more than missing out on normative activities, and that it is also about having time spent together with someone you love taken away. This is similar to the account given by Natasha:

*Int: Why do you think family members might like well struggle initially with em understanding fibromyalgia?*

*Natasha: because the change in us, quite simply because the change in us. We are no longer that person they married. Em, we no longer perform to the same level we did in our day to day life. Em, the change is so profound. At times em, I come back to sex. Sex, em was a huge part of my relationship, em, you know... something that you know every weekend we could look forward to a wee glass of wine, holidays and stuff like that. And, and it was something we were kind of guaranteed. And then all of a sudden I became so unwell it was like "Please just leave me alone." Em now my body's telling me this is how I'm feeling but his body's still the same and his mind is still the same, his desires are still the same, whereas mine have dropped.* (Natasha, Family 16, FM)

Natasha mentions the difficulties associated with missing out as her (and she implies those with fibromyalgia) relational wants and needs change, while her partner's stay the same. She also highlights it is not just the present that fibromyalgia impacts, rather it also impacts the practices which have historically maintained and supported these relationships, as well as the emotional wellbeing these activities offered. I argue this indicates the emotional value in certain activities is not just because they are normative, but because they are embedded in participants' wider emotional and relational histories

(Smart, 2011; 2007). However, Abby suggests there are ways to work around this:

*Abby: I can't do the spur of the moment – like ma husband like if he came home and said "Let's go to the cinema." I'd say "Haha!" I couldn't like just do that. Em kind of thing em. You have to be quite organised about it [...]*

*Int: Does he ever expect- does he ever sometimes do that?*

*Abby: No no I think he's got used to that now that you know we'd need to sort of plan things quite sort of in advance kind of*

*Int: Did he used to do that?*

*Abby: Mmm maybe sometimes we would. [...] Em but like if we were like gonna go go out like- we actually went- we actually came to the theatre here in [City] a couple of weeks ago. But like we actually came to see it as a comedy we went to see, so but we'd had the tickets since before Christmas so I knew it was going to happen and I knew in advance that maybe I wouldn't do so much the afternoon so in the evening I'd be okay.  
(Abby, Family 11, FM)*

Abby implies that she and her partner miss out at the lack of spontaneity afforded to them. However, she contrasts this by arguing that if they plan in advance she can often accommodate her day to provide her with the energy to, in this instance, go to the theatre. I interpret that Abby has using her EIK to do this. I also view this as an instance of people finding alternative ways to do things which enabled families and partners to spend time together. This occurred frequently within my sample, in different contexts. However, the general theme of it remained the same; if you cannot do something one way sometimes you can reach a compromise or find another way.

#### 6.4 Balance: Living by those we live with.

In this section I return to the multidimensionality of care discussed within Section 6.1. The title is taken from ideas expressed by John Gillis (1996; 1997) and Carol Smart (2011; 2005) of having family ideals that inform our idea of how we feel families ought to be, and the daily people who constitute our family that we live alongside. In this section I

explore how these ideals were balanced against the people my participants lived with. In particular, I explore how participants negotiated their relationships with one another, and their wider social lives in relation to fibromyalgia and their EIK. I understood this primarily through the theme of compromise which explores the communicative process between people and family members to renegotiate social expectations. In discussing the theme of compromise, I will explore how participants balanced their relationships as partners, and within their families.

#### 6.4.1 Partners and Balance

Within this chapter I have discussed how families adapted to fibromyalgia, how this clashed with normative ideas which they implied informed their ideas of what it is to be a partner, family, mother, parent etc. thus creating a sense of missing out in their relational lives, and the emotional pains around this. Additionally, family and partners' activities had a normative and emotional significance where being unable to continue these activities as people had done previously could contribute to a feeling of missing out. Despite this, their lives were not solely characterised by ideas of missing out, and, like adaptation, families engaged in what I interpreted as compromise. Here compromise is a temporal process concerning itself with families' social relationships, juggling fibromyalgia, with families' wider social needs/wants, as Natasha demonstrates:

*Int: [...], what is it about... not wanting to go to your bed and just leave him sitting watching TV is that like just?*

*Natasha: I [sighs] it's a guilt because em, you know I'm trying to consider my husband's feelings and.. as well. Em, I'm tir- I don't want him to be lonely and unhappy. Sitting there at night you know, at night, because I I I I can't be bothered I just want to go to bed. But Ah don't want him to be sitting here every night on his own, so I just stay up and chat, bletther, watch a programme with him or something like that. (Natasha, Family 16, FM).*

Despite Natasha feeling guilty at not always staying up with her husband, I interpreted this as a compromise. Some nights they would spend together and other nights they would not as Natasha notes she has to compromise and balance how her fibromyalgia makes her

feel alongside the feelings of her partner. Compromise was not restricted to participants with fibromyalgia as Jack demonstrates:

*I'd said to Jessica we could go out, you know, go for a walk round the [...] and eh... I could see she really didn't want to go. Really didn't. So I said "Well we-." No I said "Maybe we could go another night, and I'm gonna take my time cos I like photography I'm just gonna go out and I'm going to take some pictures" [...]. So I think... she didn't know that I was changing it you know, so I went out and took photos but, you know... I really would have preferred if she'd come out. (Jack, Family 17, Partner).*

Jack demonstrates here what it is to compromise. I understood Jack as using his EIK to see Jessica was in pain, and then changed his plans and expectations by going out on his own. I understood this as highlighting how compromise could be an ordinary but complex act of care (Elden, 2016). Jack implies it is ordinary, as he is talking about a single interaction between Jessica and himself. However I argue it is complex as he is managing the needs and wants of his wife, and the emotional pain he feels at missing out on spending time with her, and the emotionally significant relational practices that constitute their daily relationships (Morgan, 2011). I understand this as their relational *we* who do things together. However, Jack did not dwell solely on the loss that this compromise entailed:

*Int: Do you mind me asking how it makes you feel em... that... she didn't come with you or?*

*Jack: Well it's not a big deal, we will go another night I'm- you know, maybe tomorrow or something we'll go. We can do these things... you don't, you can't put your life in a rigid calendar, I don't think it's helpful at any stage of life to do that. You need... humans are social creatures and whilst it's good if there's some routine in people's lives - it's better if it's more flexible and exciting and you just go with what's right at the time. (Jack, Family 17 Partner)*

I interpreted this as Jack balancing the missing out of going on a walk, with his reasoning that there will be times where fibromyalgia will not impact and other times in which they can spend time together. I suggest this does not lessen the emotional pain in that moment.

However, I did interpret it as a means of managing the emotional costs fibromyalgia can bring and the importance of compromising within intimate relationships even if it hurts one person to do so. Jack's implication that people need to be flexible in their daily lives when adapting and compromising is reminiscent of Smart's (2007) argument that love and commitment are ongoing processes, constituted, performed, and inseparable from everyday actions which maintain relationships historically and prospectively. I also understood Jack's account as reasoning to himself that there will be other times he and Jessica can be a relational *we*.

Duncan also suggested the importance of flexibility:

*It would be a kind of date night we would spend together that could just be going a walk, just going, I don't know, a train to [Town] or like, going to the cinema type of thing. Or often just not doing other jobs just whatever a bit of time together but I'd say the kind of, we've kinda with Heather not doing date nights as much but I've had a lot of my plate with doing up, I've done a lot to this house since we moved in and em, you know we've, maybe more of our date nights now a days are sitting in and watching whatever she wants to watch on the telly. (Duncan, Family 4, Partner)*

Earlier Duncan mentioned a sense of loss at what he and his wife did before she had fibromyalgia, what they could do now, and how this compared to their friends. Here he implies new ways to maintain spending time together while accommodating for fibromyalgia. In this case Duncan implies they changed what a date would entail to ensure it still happens, based on fibromyalgia, their EIK and other commitments they have in their lives.

Despite the emotional pain participants could face with missing out, in this instance I understood compromise as enabling important emotional and relational work that keeps the relationship going.



## 6.5 Families and Balance

Partners were not the only ones who had to balance their relationships with fibromyalgia. Lucy demonstrates how families could also balance their relationships and fibromyalgia's impairment effects:

*Lucy: [...] I am really grateful for everything I do have, but... it's just like it's very special spending time with your mum, and I feel like we just have to do different things [...]*

*Int: I suppose what do you mean by different things? Doing different things?*

*Lucy: em, so probably like let's say, I dunno my friends mum they walk the dogs all the time [...]. My mum and I will probably go and sit and have something to eat together or, go for a drive. Em, sometimes we cook [...] that's about the stuff that we do. I know there's a lot more we could do but we don't know what... like we've not really tried it so I don't know, there's lots of different options but.*

*Int: what were you thinking?*

*Lucy: I don't know we could go um... sightseeing? We could go to castles, museums [pause] small museums, um... (Lucy, Family 17, Daughter)*

Lucy implies, both here and earlier, that she is missing out by comparing her experiences to her peers, and saying she is unable to engage in the normative activities “*they*” do “*all the time*”. By discussing alternative activities I understood Lucy as compromising what she and her mum (Jessica) could do to create a balance between the impairment effects of fibromyalgia, and the desire to engage in shared relational activities with her mum which is very important to Lucy. The emotional pain and feelings of missing out on normative activities is not negated by compromising and balancing as Lucy stated earlier missing out was “*unfair*”. However, these activities highlight a wider desire participants had to spend time together as this time was important to them. I suggest this indicates the importance of spending time together as a *we* can have for participants, as they interpret it within their normative understandings of family life, and their shared relational histories with one another (Gilding, 2010; Smart, 2011). Subsequently participants found ways to

engage in relationship building and maintaining regardless of fibromyalgia, as Hannah points out:

*[Places she likes to go] Em, the local restaurant I can go out, I can do something with my family, with my partner that feels normal. But it's not so taxing because it's local, so it's not a long hard drive, you know. We could do that and come back and it doesn't feel like I have to be out for three days because we had a meal because actually it was local. (Hannah, Family 15 FM)*

Hannah highlights the proximity of the location is important, and it is reminiscent of the theme from Section 4.1.1 that energy is a resource. She likes the restaurant as it enables her and her family to engage in a normative family practice of having a meal at a restaurant, suggesting this act had an emotional relational value. Gillis (1996) highlights that by being able to take part in family rituals such as Christmas, we can be reaffirmed of the families we live by even if our own family practices do not resemble these values. I understood Hannah and Lucy as interpreting activities like going to a restaurant, or in Lucy's case walking a dog to be means of upholding, or being unable to uphold as in Lucy's case, activities which could reaffirm the values of the families they live by with the families they live with. Therefore, I argue certain activities with families can be emotionally valued over others, and I suggest Lucy's account demonstrates the difficulty she and her mum could have in finding alternatives which mean the same.

In this section I aimed to highlight that participants were informing me of relationships within their lives that have emotional significance to them and a history where fibromyalgia is but one aspect. Participants felt there were aspects of family life they missed out on which were important for maintaining their relationships and a sense of multiple relational *we* who do things together. However, they also attempted to find possible ways to maintain these relationships and multiple relational *we* in the context of fibromyalgia. I understood participants as compromising because they valued their family relationships and these relationships have emotional significance and importance to them. I suggest that, despite the sense of missing out experienced in the last section, the emotional care, love and shared histories that I understood my participants to have for one another helped them negotiate the ideals of the families they lived by with those they

live with (Gillis, 1996; Smart, 2011; 2007). However, family relationships were one type of many relationships in participants' lives, and we will now briefly discuss participants' relationships with friends.

### 6.5.1 Social Life and Balancing/Getting Out

In the previous section I explored how participants found balances within their personal and familial relationships, which I interpreted as a way to navigate and try and mitigate – though not eradicate – the emotional pains I mentioned earlier in this chapter. However, this does not address physical and emotional pains participants implied they felt and where they stated they needed a break from fibromyalgia and their household. My data supports previous studies on fibromyalgia emphasising that people's social circles/groups of friends become smaller after diagnosis (Söderberg et al., 1999; Rodham et al., 2010; Briones-Vozmediano et al., 2016). Participants like Jacob highlighted the importance of going out with friends and maintaining a social life:

*Int: [...] As a... partner of somebody with fibromyalgia in general is it kind of important to have like maybe activities outside of the house? Does that make sense or?*

*Jacob: Definitely, definitely [...], I've always believed this, you've still got to have other people's company. And the partner with the fibromyalgia has to realise that that they have to have their time. Not, not all the time but they've got to have their time. Eh and then they can come back refreshed and then give you more help, [...] But I think that's just a way of life, I mean I've always had that way of life, and me and Natasha have always had this way of life too. Don't lose your friends, eh, don't don't fall out with friends [...]. You've got to have other friends, other things in your life. (Jacob, Family 16, Partner)*

*Wi ma work mates and ma darts mates ye kinda ye can switch off fi' family life wi them. Em, and the same, ay the close family, cousins and all the rest ay it. Ye kin jist kinda get intae a different world and switch off fae everything else that's happening, fir that length of time that yer with them (Gordon, Family 9, Partner)*

*My other friends that I've, that I still love to socialise with all the girls that I used to - cos I used [work in sport] - and all the girls and they're still all you know running half marathons every third week and all that kinda jazz. It's really really difficult to socialise with them because I don't fit in anymore, but I force myself to do it sometimes because they're great company [...] I just have to pick and choose what thing's I join in with. [...] I'm trying to think of a kinda, it's a wee kinda... happiness rucksack that I have on my back that I just if I go I just go out with them even if it's only twice a year it just kinda tops up my wee happiness rucksack again and kinda reminds me that I can still have fun like that I just can't do it every week. [...] I think the pros still outweigh the cons so I still make myself go yeah, and they would really miss me if I didn't go. (Heather, Family 4, FM)*

Jacob places an importance on having a social life outside of the household so that family members are then able to support those with fibromyalgia. I understood this as people and families valuing the historically embedded relationships and activities they had previously done before the onset of fibromyalgia. Gordon demonstrates Jacob's point mentioning that a social life outside of the house is important to help him switch off from family life and, as mentioned later in the interview, from fibromyalgia. As Heather chose what events she would attend, I saw this as compromising the impairment effects of her fibromyalgia with her and her friends desire to socialise. Within this excerpt I also interpreted her "*still have fun like that*" to suggest it acts as a return to life without illness or where illness can be forgotten about for a few hours:

*Cheryl: [places she likes] And the local pub because Ah like goan in an seein' everybody and huing a chat and catch up wi' people. So you kind a feel that yer still, yer still involved with people yer showing face "I'm still here" you know what I mean?*

*Int: what do you mean still involved?*

*Cheryl: Just em, I used to go out, you know and em now yer no as capable you know, you just try an keep, ye go out to try and feel normal. You know, you put the brave face on you maybe put a bit of make up on you know you*

*go “Right, my whole body could be aching, and I might not be able to do much, but I can get down ay that pub and Ah can sit there and pretend that everything is awright”. (Cheryl, Family 10, FM)*

Cheryl mentions – more explicitly than Heather – this idea of an attempt to return to her perceived normality through the acts of putting on make-up and going to the pub to “*pretend that everything is awright.*” This act of pretending could be interpreted as Goffman's (1990) passing, as Cheryl is trying to conceal a condition which could discredit and stigmatise her. This analysis would support other findings within fibromyalgia studies where people engage in impression management to avoid being stigmatised by others (Åsbring and Närvänen, 2002; Armentor, 2017). However, I argue ableism offers a more comprehensive understanding of Cheryl's account (Campbell, 2009). In going to the pub and acting as though she does not have fibromyalgia, Cheryl is using her agency to perform the ableist ideals that she perceives as her normal. For instance when she says “*I can get down ay that pub*” and “*I used to go out*” she implies this informed her sense of self and a relational self prior to fibromyalgia, and that these activities have an emotional value to her with “*ah like goan in an seein everybody.*” I argue that understanding Cheryl's experience in terms of stigma and passing undermines the complex emotional ties, ableist ideals and agentic possibilities that Cheryl herself viewed as available to her. I understood Cheryl as continuing to practice her relational self who could still go out and to do activities that historically maintain relationships which are meaningful to her, similarly to Heather (Campbell, 2014). I interpreted Cheryl as balancing the impairment effects of fibromyalgia, with her need to socialise for her mental wellbeing and to see people to avoid isolation. As Heather highlighted earlier, to do this she needs EIK to know how fibromyalgia impacts her, and how the act of travelling and being in a public place can impact her body. I suggest EIK can be used not only to assess how one's body feels and what it can do on a daily basis, but also to help maintain wider relationships and relational selves.

Again, I suggest EIK was not just limited to those with fibromyalgia, family members also implied that they used it when navigating social interactions and relationships. However, these relationships were suggested to be different to that of relationships with family members. While family relationships in adaptation were implied to not always be reciprocal – at least in relation to the doing of household tasks, relationships with friends

were implied to be reciprocal and requiring give and take on both sides. As Jacob indicates when talking about a night out with friends:

*And so what we'll do is, we'll go out and I'll explain right away "Right this is how it is, we're going out but we're going up the road early, we're meeting you at 2 o'clock but we're going up early cos Natasha is no up for staying out til 11 o'clock at night so I'll pick up at 7 o'clock 8 o'clock if I must, that means we'll be out for 5 or 6 hours that's plenty of time. I'm telling you right away that's what we're doing" (Jacob, Family 16, Partner)*

Jacob implies this act is reciprocal, as while he and his wife will go out with their friends, their friends will respect the terms (hours) they plan to stay out. I interpret this as offering a give and take within the relationship, and a compromise between the different wants and needs of the people involved. Jacob implies he has EIK of his wife's illness by knowing she will not want to stay out until 11pm, and here he is demonstrating the value of having this knowledge not just as a means to navigate family and intimate relationships, but to maintain wider social relationships outside of the household. This is important as the wider literature within Chapter Two, highlights how hard it can be to maintain social relationships with fibromyalgia (Söderberg et al., 2003; Rodham et al., 2010). Jacob is using his EIK to support the needs of his wife, and also using his EIK to support them both in getting out of the house to see their friends and maintain their reciprocal friendships.

Ana also highlights this idea of compromise and reciprocity:

*So, mostly it's very hard to admit that I'm tired let's say and ask my friends to change the plans or something like this. I mean as a group, but of course the close ones who are aware of the details and know of the pain they would, we would from the beginning plan things which are within our, you know, limits in terms of you know like to balance between my own maximum effort I can put and their whatever they want to do on the day. (Ana, Family 3, FM)*

I interpreted Ana's difficulties at balancing her EIK with the social obligations she felt were placed on her when seeing her friends as similar to the difficulties Heather faced in

Section 4.1.1. Ana implies that she and her friends work together to compromise the expectations of a day out beforehand as a means to navigate what they are able to do. I interpreted this interaction as reciprocal, like Jacob, as both parties do something for the other. Ana also suggests that this might not be easy to do with friends who are less aware of her fibromyalgia.

I argue that in order to compromise, people and families need to use their EIK to plan how the impairment effects of fibromyalgia can impact their family member, and evaluate how the event they are attending may impact their family member. While Jacob compromises with he and his partner's friends over how long they will stay out, he does this through using his EIK of his wife's condition and how long she may want to stay out for. Ana suggests she plans with friends who know about her fibromyalgia about what she is able to do on a given day, and what her friends want to do. Duncan details how he navigates a night out:

*You go out with your friends you have to think ahead "Right where are we going?" "We're going to [town] to go to some pubs." "Right what pubs would these friends like to go to?" "Eh they're busy and there's no any seats, right, how are we gonna fix this, right "Heather, we'll go there early and get a table." And then in the evening I gotta say "Right well Heather there's six chairs at this table what one looks comfortable? Where do you want to sit? There's the bench seat, or is it the seat on its own?" Gotta kinda think ahead, you know before you just go and meet your friends and you would never give it a second thought you know that type of thing.*  
(Duncan, Family 4, Partner)

In Chapter Four, I highlighted that the EIK held by two family members (one with fibromyalgia and one without) could be different kinds of knowledge as each person interpreted fibromyalgia differently – one as a lived bodily experience, the other as a person observing it (subjectively) from the outside. However, here Duncan implies how he and his wife can use their EIK to navigate wider social situations. He mentions earlier in the interview that he and his wife could disagree on what the best course of action could be to do in a social situation – highlighting the difference in interpretation. However, it is important to note they, and the other participants within my sample, are using this EIK, which they did not gain from the medical profession, as a means to

manage the wider social relationships, expectations, and obligations within their lives. In other words, they manage life more holistically than is implied by the medical perspective in Chapter Four, where illness is a set of symptoms requiring medication and an alteration to diet and lifestyle (Bury, 2012).

Lastly, it is important to note that participants' relationships were not just about managing fibromyalgia, as Gordon highlights:

*Gordon: Ah... a lot ay the time tend tae not try and think about it. Because it's kinda found it, as Ah said earlier, Ah don't like seein her with it and having the flare ups so Ah tend try and not tae think about it so it doesn't, kinda, git in the headspace.*

*Int: Yeah so you're not thinking about it... it's Ah suppose Ah could be wrong here, but like it's so you're not thinking about it if you're interacting with her and stuff like that?*

*Gordon: yeah... [pause] it's not that, Ahm not doing it out of badness Ahm jist doin it outta, Ah don't want it it, it does have an impact on our life... but we- we're tryin tae huv it in the background instead ay the forefront.*

*Int: so like it has an impact but there's jist, there's also other things goan on likesay parents night or something?*

*Gordon: yeah*

*Int: yeah*

*Gordon: yeah, so we always try an' have... have it there rather than there, know what Ah mean but*

*Int: have at the back rather than the front?*

*Gordon: uh huh, we can beat it rather than it's beating us type ay attitude.  
(Gordon, Family 9, Partner)*

Although I have looked at how families navigate fibromyalgia in this research, Gordon implies it is one aspect of their experiences of family life, not everything. Therefore, from



the above excerpts, I understood compromise within my data to be about maintaining a balance between relationships. Compromise is the social act of renegotiating the social expectations placed on people within daily relationships. This could help people and families balance relationships and activities that they value, and the various needs and wants within peoples' and families' lives, one of which is fibromyalgia, without continuously having to sacrifice one or the other.

I have suggested in this section that families responded and dealt with the earlier theme of missing out through compromising and balancing within their personal relationships. I argued that most families spoke about finding other things to do and other ways to spend their time to navigate their social relationships. I contrasted this by highlighting how participants compared themselves to their perceived wider social norms of family, suggesting that these perceptions did not completely eradicate the sensation of missing out (Campbell, 2014). I argued that participants placed more importance on spending time with their friends and loved ones, even if the activities were different from before. Most participants implied these relationships were important to them emotionally - many of which had a history before fibromyalgia. I understood this as participants engaging with multiple relational *we* who spend time together and do activities together which are emotionally significant to them because they share relational biographies which are embedded with emotional significance (Smart, 2011). As a result, I suggested that families would use their EIK of fibromyalgia, as previously noted in Chapter Four, as a way to navigate and maintain these relationships, and create a balance between their experiences of fibromyalgia, and their experiences of the other responsibilities, relationships, and roles within their lives. I argue this contributes to the multidimensionality and ordinary complexity of care within my participants' lives.

## 6.6 Adaptation, Balance and Compromise as a Privileged Positions

In aiming to highlight how people, families and friends could adapt to fibromyalgia and strike compromises, I also want to highlight that this was a privileged position. In Section 4.1.1 I argued through Abby's account that not all families had EIK of fibromyalgia, nor did they always acknowledge their family member's illness. Andrea highlighted, in Sections 5.5.1 and 6.3, that her friends left after the onset of fibromyalgia and her unexplained symptoms. Here she tells me that her children did not acknowledge her illness:

*I suppose one of the reasons I did move to [local district] I suppose was I thought I might get a bit of family support but, I suppose if I'd said to them "Aw look I've, I've got something that's recognised." And they might have thought "Aw better rally round and help her a wee bit." But when you've when you've got something that's no recognised and nobody knows anything about, different scenario, different situation. Especially when you look okay you know. (Andrea, Family 5, FM)*

I interpreted Andrea as having a normative assumption that family would provide support for her in her illness, and felt disappointment when they did not. She attributes this to a lack of knowledge of fibromyalgia, and its invisibility. She repeatedly stated that she felt the invisibility of fibromyalgia was a barrier to informal support throughout the interview. I interpreted this as coming from assumptions based on a social gaze that defines what illness looks like (acute and visible), and suggests that Andrea is able as fibromyalgia is invisible (Campbell, 2014; Parsons, 1951).

Paul highlights how his daughter would not compromise on activities to accommodate his illness:

*It [conflict] only kicked off because of a Christmas discussion em [...] cos I said I wasn't coming round one Christmas because I would have had to sleep on the floor and I said "I can't physically do that, I'm not you know well enough as you should know". Em [...] she doesn't believe it [fibromyalgia] exists, she thinks it's in people's heads like many consultants. (Paul, Family 2, FM)*

Andrea, Paul above, and Abby in Section 4.1.1, imply that their family relationships could be emotionally detrimental and physically unsupportive in daily life. While previous studies have mentioned that family may not understand the symptoms and impacts of fibromyalgia and that this can cause emotional pain (Arnold et al., 2008; Juuso et al., 2011), I argue that we need a more nuanced approach to this which highlights people's relational experiences. I argue it is important to acknowledge the complexity of these relationships as I suggest the sadness over a lack of support may not just come from a denial of fibromyalgia, but from the message it then sends to the shared relational histories participants are embedded in. Where I interpreted participants with fibromyalgia as not

having supportive family relationships, participants still implied that they were embedded in these relationships through the shared emotional relational histories of – in Andrea and Paul’s case being parents to their children – and in Abby’s case as being the partner to her husband. I argue these findings highlight negative aspects of relationality as they had shared historical connections with unsupportive family members who they implied to be unsupportive due to normative ideas of illness (Smart, 2007). I also argue that these accounts demonstrate that the concepts of adaptation, compromise and balance and the multidimensional ordinary complexity of care experienced by some participants were privileged positions.

Lily highlights the difficulties of managing her fibromyalgia and the demands of family life (her children have additional support needs) without formal or informal support:

*It’s taken me six years to get where I am today but I still struggle everyday with my routine and every day with my routine I have to go to bed. I have to be so disciplined to the point where I won’t see anyone, I won’t speak to anyone, I don’t go to people’s houses, people don’t come to mine. I hardly see any, I hardly see anybody because my priority are my daughters. (Lily, Family 8 FM)*

In relation to the other participants, Lily had particularly severe symptoms and was at times bedbound with fibromyalgia. Lily mentions that despite lacking support she still lives relationally with her daughters and has to balance their needs against her own. Lily implies her understanding of her role and identity as a mother provides her with agency to define her priorities “*I won’t [...] I don’t [...] my priority*”. However, Lily also implies she is constrained by these relationships, her perceptions of her ideals of motherhood and by her perception of the ideals of professionals who do not understand the relational obligations of care she feels she has to meet for her daughters:

*It’s, it’s like you’re expected to look after yourself and your health, and look after you know everyone and be, you know, like, you know they say at the doctors I’ve had to do a lot of research myself, about my health, and the thing is the doctor will just say to you, you need to look after yourself and that’s it. (Lily, Family 8, FM)*

Lily was frustrated at doctors' advice that did not consider the various relational demands within her life such as childcare, household and fibromyalgia symptoms, which could impact her performance as an active patient who takes their doctor's advice to get better (Parsons, 1951). I interpreted that motherhood for Lily was a means for her to exercise her agency in looking after her daughters. However, I perceived Lily's understandings of her experiences, which interacted with normative ableist understandings of family support in policy and doctors' disregard for the relational obligations people have, as demonstrating how people's relational lives with their family could be just as constraining as the previous sections imply them to be empowering.

I presented these aspects of my data to highlight that the adaptations and compromises as a means to obtain balances in families lives were privileged positions one could only engage with when one had informal social networks. In this section I demonstrated how relationality could be experienced negatively when family members did not receive formal or informal support despite having multiple needs which they struggled to address themselves. I argue that this highlights concerns raised within the literature of the tacit role families are implied to play in providing support for ill relatives, and ableist assumptions of parenthood and motherhood, which in Lily's case were very constraining (Dalley, 1996; Bury, 2012). Additionally, Lily's situation supports Briones-Vozmediano et al.'s (2016) findings that roles such as femininity and motherhood play a part in how people negotiate their day with fibromyalgia with and without informal and formal support.

## 6.7 Conclusion

In this chapter I have explored how people and families navigated the impacts of fibromyalgia on a daily basis. Through the multifaceted concept of adaptation participants implied they renegotiated their daily tasks in relation to their EIK of fibromyalgia and wider histories of household domestic labour. I suggested that adaptation did not mitigate a sense of missing out on activities that participants implied to be socially valued and normative to them, nor those which had historically maintained their relationships. Drawing on this, I suggested that within chronic illness not only could there be a loss of self, but also a loss of a relational *we*. I then explored how families renegotiated their daily lives and activities and how they maintained their family practices and multiple relational *we*. Additionally, I explored how people and families maintained relationships

with friends through using their EIK. What this suggests is the value that having EIK could have to navigating and renegotiating relationships with friends and family in relation to fibromyalgia. However, I understood that instances where friends and family were supportive of fibromyalgia was a privileged position that not everyone within my sample had. This finding highlights the tacit role that policy makers presume families play in providing support to those with chronic illnesses and how this can impact participants who do not have this support and are simultaneously having to meet other social roles such as that of motherhood.



## 7 Chapter Seven Discussion

### 7.1 Introduction

In Chapters Four, Five and Six I aimed to highlight that people and families with fibromyalgia found themselves caught between two non-dichotomous, amorphous ways of understanding fibromyalgia within their lives. I understood participants to use the understandings of both biomedical knowledge and what I termed experiential illness knowledge (EIK) when they felt it was appropriate, to understand and navigate their lives with fibromyalgia. I argued that for one to develop EIK, one must have a medical diagnosis of fibromyalgia to know that the experiential knowledge one is gaining concerns fibromyalgia. Additionally, I suggested that knowledge was given legitimacy by those with more power within interactions. After exploring EIK within participants' experiences of the medical profession, I then explored how dominant biomedical models of understanding illness resulted in participants' experiences being discredited within social and institutional interactions. I related this dismissal, and participants' struggles, to Parsonian (1951) and ableist Campbell (2009) understandings of norms around illness and legitimacy as held by welfare officials, members of the public, and the participants themselves. Lastly, Chapter Six explored how biomedical ways of knowing and EIK mentioned in Chapter Four shaped families' experiences of their personal lives in addition to their perceived norms of family, motherhood and childhood, and their shared emotional and relational histories with one another. I found that some families found alternative ways to do emotionally valued activities together, and with friends, and that this was negotiated by their EIK. I suggested that this enabled a continued performance of a relational we. However, I also highlighted that not all participants had families who were supportive of them, and that family members developing EIK and providing support was a privileged position of some of my sample. Through exploring this, I unpicked some of my participants' normative assumptions around family, detrimental aspects of relationality, and the practical and physical impacts a lack of family and formal governmental support could have.

In this chapter I will discuss the findings presented in the previous three chapters with more detailed references to the literature that I discussed in Chapter Two. I will discuss the findings under the research questions that they address:

- 1) How do people with fibromyalgia and their family members understand fibromyalgia?
- 2) How do people and families with fibromyalgia understand their experiences of life outside of the home?
- 3) How do people with fibromyalgia and family members navigate everyday domestic and social life?

Using my findings, and the theories that I have employed to contextualise them, I will address each of the above questions, relating the relevant findings to them and highlighting where they agree, contest and originally contribute to the existing literature. I will then summarise the implications of the main findings, clearly stating my original contribution to knowledge, and discuss some limitations with the present study. Finally, I will discuss the theoretical, and practical contributions of my thesis before giving a brief conclusion.

## 7.2 How do people with fibromyalgia and their family members understand fibromyalgia?

Diagnosis was central to my participants' understandings of fibromyalgia. Similar to Armentor's (2017) conclusions from her interviews with women with fibromyalgia, diagnosis acted as a framework of meaning for those with fibromyalgia and families to contextualise, understand and explain their experiences. Armentor (2017) argues that by having a diagnosis the reputational stigma her participants faced in their family and social life through not performing their previous expected social roles could be lifted. However, she also argues this could come with the stigma of being diagnosed with a contested illness (Armentor, 2017). Armentor (2017) uses stigma to highlight how those with fibromyalgia may not communicate their illness to others, and hide from social interaction to manage the stigma that comes with fibromyalgia. Conversely, she argues that communication is important for people with fibromyalgia and their loved ones to understand the illness (Armentor, 2017). My findings support her work; as by interviewing families I found that for many a diagnosis helped frame families' experiences of unexplained, invisible symptoms, affording them a legitimacy that was not there prior to diagnosis, and helped participants communicate the impacts of fibromyalgia.



However, Armentor (2017) understands her findings through Goffman's (1990) stigma, I argue that by focusing on stigmatised and the stigmatiser, we overlook theoretical perspectives that can challenge the episteme in place that facilitates the production and reproduction of stigma to particular groups of people. I argue that when considering the epistemological and normative understandings of illness internally and externally to the medical profession, ableism can demonstrate a wider network of power relationships and legitimation processes operating to impact the lives of those with fibromyalgia in a way that exploring the impacts of stigma cannot (Campbell, 2014: 2019).

Stigma offers an insightful view of the challenges Armentor's (2017) participants faced, and why those with fibromyalgia may be reluctant to communicate how their condition impacts them for fear of being stigmatised. However, by focusing on stigma, Armentor (2017) leaves unexplored the ways that some of her participants mentioned their family members could see and be supportive of their fibromyalgia. In Chapter Four, I interpreted diagnosis not just as an individual categorisation but as a relational process. Participants did not just think of themselves in relation to diagnosis, but also to how it might affect their families now their unexplained symptoms had a name and were categorically defined as an illness. Therefore, for some participants diagnosis was considered relationally (Smart, 2011). Although diagnosis may present itself to be something which happens to individuals (Bury, 1982), by exploring my participants' relationships with others my findings add to studies on fibromyalgia by highlighting that for them diagnosis was experienced relationally in reference to those around them (Smart, 2011). While I am not denying that illness does not come with unique changes and disruptions which are personal to individuals (Asbring, 2001), I argue that it also comes with implications to one's relational self. By highlighting how a diagnosis might affect other members of their families, I argue that a diagnosis is more than just an individual disruption or reinforcement of identity in reference to a group (Bury, 1982; Carricaburu and Pierret, 1995). Rather, that it can be relational and that biographies are experienced and situated relationally in the context of others within emotionally and physically intimate relationships (Smart, 2011; 2007).

However, despite a diagnosis becoming a category and naming 'fibromyalgia', I demonstrated in Chapter Four that this did not lead fully into what Jutel and Nettleton (2011) understand as the organisation, treatment and direction of an illness. Despite

diagnosis acting as a means for participants and their family members to understand their symptoms, as I mentioned in Chapter Four not all participants were satisfied with the diagnosis due to the lack of cure and treatment options (Boulton, 2019; Undeland and Malterud, 2007; Madden and Sim, 2006). I suggested that participants' frustration at the lack of prognosis, treatment, and respect for fibromyalgia by the medical profession deviated from their normative understandings of illness and diagnosis. I understood participants' dissatisfaction as implying that they viewed the medical diagnosis of illness as a linear way forward to uncovering a cure to return to the able symptom free body one had (Campbell, 2009; 2014; Parsons, 1951). This is possibly because of how we view illness and medical science within the 21<sup>st</sup> century, as something which has a cure, which also highlights the ableist logic underpinning this – that there is a “*species-typical*” ideal in which we can return to (Campbell, 2009: 6). By exploring how a diagnosis did not meet participants' expectations through leading to a cure and treatment, I interpreted participants' expectations of a diagnosis, and of illness, to be similar to ableist notions of the body and Parsonian norms of acute illness.

Therefore, for participants to understand their experiences of fibromyalgia and navigate the remissibility of the condition and the uncertainty that it entailed, they drew their own experiences and information from others. Participants suggested this helped them to manage the condition. Although participants' were dissatisfied with a fibromyalgia diagnosis due to the limits of medical knowledge and treatment of fibromyalgia, I argue a diagnosis was essential for them to understand the illness. I argue that the labelling of their symptoms provided legitimacy to their illness, and a basis from which experiential knowledge of the illness could be generated by people and families, suggesting diagnosis has more use than some studies have previously intimated (Boulton, 2019; Undeland and Malterud, 2007; Madden and Sim, 2006).

I understood this as experiential illness knowledge (EIK) which is a temporal process where participants with fibromyalgia and family members without fibromyalgia know what they/their family member with fibromyalgia is capable of on a daily basis based on their symptoms. In relation to individuals with fibromyalgia, Kengen Traska et al. (2012) has written about the context of self-management strategies for fibromyalgia as pacing oneself. Paulson et al. (2002) refers to it when speaking about their male participants with fibromyalgia doing hobbies and daily activities at their own pace. Briones-Vozmediano

et al.'s (2016) female participants with fibromyalgia employed this strategy when trying to do housework and meet their perceived gender roles and the needs of the household. Armentor (2017) hints that the family members of the women she interviewed with fibromyalgia might have this knowledge, as her participants informed her that those closest to them – friends, family and at times work colleagues – were able to tell if they were unwell and change their actions accordingly.

My findings in Chapter Four expand on these aforementioned studies through interviewing family members, and highlights that not only do certain family members have EIK of fibromyalgia, I document throughout the thesis – particularly in Chapter Six – how family members repeatedly use this knowledge to inform their practices of daily life. My findings highlight that experiential knowledge of one's illness is not just gathered individually, but also relationally within the context of others and interpreted by family members in different ways. This has already been documented in the field of medical sociology and lay knowledge of illness. For instance, Pols (2014), in looking at people with Chronic Obstructive Pulmonary Disease (COPD), found that they developed a knowledge called 'know-now' in conjunction with others with COPD to diagnose when their body might have a flare up of symptoms, and how their body would react to the social-environmental contexts around them. For example, how they might react to a loss of air pressure in a thunderstorm, or by walking quickly and becoming short of breath (Pols, 2014). Pols (2014) argues know-now could be used to develop general strategies to help others with COPD. However, Blume (2017) criticises Pols (2014) use of know-now by highlighting the dilemma of how one values something that is inherently subjective and personal. Additionally, he questioned which knowledge is more valuable, that of the person with the illness, or the family member (Blume, 2017). Meanwhile Bury (2012) highlights, in his discussions on the self-management trend within chronic illness care and treatment policy in the UK, how self-management has been redefined from academic understandings where it was a means that people navigated their daily lives with reference to their personal contextual specific knowledge of illness (Corbin and Strauss, 1985), to that of skills people with chronic illnesses can acquire to understand their illness and reduce demand and costs on the NHS.

My understanding of EIK, and the views shared by my participants, concur with Bury's (2012) understanding and with Blume's (2017) assertion that trying to quantify something

that is so inherently personal and variable as experiential knowledge is fruitless. Importantly, Blume (2017) highlights, similarly to my findings, that studies in the sociology of health and illness need to take a more critical view of what lay knowledge is, and that lay knowledge is not one body of knowledge but a multitude of knowledges epistemologically opposed to quantification. This does not mean we cannot learn from EIK, but as Blume (2017) argues, and Bury's (2012) insights inform us, we need to be very clear on how we use it, define it, and value it. We also must be acutely aware of the power disparities of those who have illnesses. Particularly as Blume (2017) highlights first how some may have more power and resources to articulate their experiences of illness over others. Secondly that experiential accounts which engage with biomedical models are often afforded more legitimacy than those which do not (Blume, 2017).

One thing my participants repeatedly stated was that fibromyalgia is not an illness which universally affects people in the same way, people have different symptoms, and different severities of symptoms – something wider literature supports (Boulton, 2019). EIK in this instance is something that personally helps families, and is aided by a diagnosis. It is not something to be quantified as ‘these are the experiences’ of fibromyalgia, nor is it hierarchical knowledge. Rather, it is something that people use to make sense of their own experiences. Chapter Four also demonstrated that families interpret EIK differently, for example when two partners highlighted they need to remind their partners to rest. Therefore, while families could use it to work together, they could also disagree on how symptoms were affecting a family member. This knowledge was important to help them navigate daily life and wider social relationships, but these findings support Blume's (2017) point that the knowledges people were drawing on were multiple and not quantifiably hierarchical. I argue that what is more important for people and families is making people consciously aware that they can develop experiential knowledge of the illness. It can help make invisible illness visible within lived everyday contexts. However, when considering Bury's (2012) point of the shift in understanding of self-management, I argue EIK should not be used as a means to refuse support to families with fibromyalgia under the guise that they can get by with informal networks alone. My data highlights that not everyone had access to informal networks, and that even those who did still required more support within their daily lives. In other words the reach EIK can have is not boundless, nor is it a green light for a withdrawal of state support.

Therefore, I argue that people with fibromyalgia understood their experiences of fibromyalgia in relation to the EIK they obtained about their body. I also argue that some families understood their experiences of fibromyalgia within their own personal experiences of close-knit relationships which helped them develop their own subjective EIK.

Although this offers an answer to the first of my research questions, it does so only partially. Excluded from it are the wider implications from my findings about the systematic devaluation of EIK in a social context obsessed with physical evidence of illness (Boulton, 2019; Thompson and Parsloe, 2019). Despite this systematic devaluation of EIK, the two forms of knowledges (biomedical and experiential) are not dichotomous. My findings support Boulton's (2019) findings and suggest doctors' diagnosed fibromyalgia through subjective interpretation of participants' symptoms in the absence of positive medical tests. This is important, as it brings a new context to the injustice and frustration families expressed to me in interviews when their EIK of the illness was refuted by medical systems who had limited biomedical knowledge of fibromyalgia. Particularly as, despite a lack of biomedical knowledge on fibromyalgia, medical legitimacy is an important means to validate and legitimate their experiences. Participants did not just understand fibromyalgia in relation to their lived everyday experiences; they also understood it within wider social systems involving things such as a diagnosis, which they needed to understand and legitimise their condition but that also devalued their own personal understandings of fibromyalgia.

Through the theme of lost in translation in Section 4.2, I highlighted how people and families with fibromyalgia, and medical professionals had different understandings of what diagnosis and treatment of fibromyalgia entailed. Wider norms of illness – reminiscent to Talcott Parsons' (1951) sickness model – informed participants that illnesses get treated and cured. However, this was not the case with fibromyalgia. Kengen Traska et al. (2012) informs us that people with fibromyalgia can be reluctant to take medication due to the side effects it can have on one's body. My research expands on this through looking at the impacts that medication can have relationally for people and their families. Participants implied that pharmacological medication can at times cause tensions in their relationships and impact the EIK they use to navigate their lives and relationships. However, these relational aspects are not often considered within medical

encounters, despite being important to participants. Additionally, when participants implied they had input into decisions on medication – such as stopping certain medications – their doctors were still suggested to hold the power in this situation. My findings indicate that more attention needs to be paid to not only the individual physical impacts and side-effects of medication, but the social relational impacts (Kengen Traska et al., 2012). The implications of this are that treatments for fibromyalgia can be counterproductive to helping people and families get on with their lives, and participants' experiences of the impacts of medication should be considered within medical encounters.

My findings highlight that there is a systematic devaluation of EIK over biomedical knowledge – however understandings of how this devaluation operates are contested in the literature (Boulton, 2019; Åsbring and Närvänen, 2003). Boulton (2019: 812) conceptualises this devaluation as being informed by the medical professions' "*doctor as detective*" perspective requiring the doctor to search for physical proof of illness within the body. However, a minority of the doctors interviewed in Åsbring and Närvänen's (2003) study suggest having a visible source/marker of illness is not the only condition required for a diagnosis. My participants encountered more doctors who dismissed fibromyalgia, rather than acknowledging it. Using Campbell's (2014; 2019) concepts of purification and translation as mentioned within Section 2.5 I argue that the difficulty for doctors to translate fibromyalgia into a coherent category of ill or well could be due to its transgression of normative codes of illness and its elusiveness within doctors' biomedical ways of understandings illness. This continued denial of fibromyalgia at an interactional level can lead to the idea of a wider structure of a medical profession in which those with fibromyalgia are marginalised. I interpreted participants tried to place themselves within their understandings of biomedical categories and terminology to mitigate the discrediting of their condition and experiences. I suggested this was denied to them creating the idea of being lost in translation as their normative understandings of illness and diagnosis did not meet the medical professionals' understandings of purification and translation. However, as some participants had positive encounters with medical professionals, and by Campbell's (2014) understanding of how codes indicating who and what is meant to be in particular spaces can change, I suggest that people's understandings of biomedical ways of understanding illness are not concrete systems, rather powerful forces malleable to change over time.

Through the theme of lingua franca in Section 4.3, I explored how language, definitions and objects – such as a doctor’s note – could impact the legitimacy of participants and their access to support outside of the medical profession. Dyck (1995) in studying women with multiple sclerosis (MS) and Madden and Sim (2016) have highlighted how doctors can act as gatekeepers to services. Crooks et al. (2008), in Canada, demonstrate that being defined as disabled by doctors could help their female participants apply for support from their insurance companies. Madden and Sim (2016) have also shown that by refusing a diagnosis of fibromyalgia, services and help can be denied – suggesting again the power of translation and its significance to the state (Campbell, 2014; 2019). Therefore, rather than just looking at how norms of illness can stigmatise and marginalise people in micro-interactions (Goffman, 1990), ableism provides us with a framework in which we can transform this by viewing ideas of power as fluid and interdeterminate (Campbell, 2014). I argue that Campbell (2014) provides us with a framework in which to understand how people and families’ experiences and EIK of fibromyalgia can be marginalised, but also how we can transform this. The wider literature, and my own findings, highlight that what is understood as ‘valid’ knowledge relates more to who has power within an interaction to define what is legitimate, and therefore ‘right’ (Årestedt et al., 2014; Castiel, 2003). My findings suggest, in the case of fibromyalgia, legitimacy is given to whichever force has the most power in an interaction, which leads to an access or denial of access to resources. I suggest this could offer a more critical and empowering theoretical perspective to explain medical encounters of people with fibromyalgia. I argue this understanding goes beyond notions of stigma which do not question why norms of illness are there, nor do they problematise the existence of a tangible able body (Juuso et al., 2011; Armentor, 2017).

### 7.2.1 Summary

Within this section, I have addressed how people with fibromyalgia and their families understand fibromyalgia. My findings support the previous literature on fibromyalgia, highlighting how a fibromyalgia diagnosis can lead to relief at having symptoms named, and frustration at the lack of medical knowledge of fibromyalgia. Additionally, my findings imply participants used both their interpretations of biomedical and EIK of fibromyalgia to help them learn how to manage their fibromyalgia, and negotiate daily life. However, participants also understood fibromyalgia as a tense relationship between themselves and the medical profession. Participants implied that the medical profession

could exert power over their lives in obtaining a diagnosis (and subsequently developing EIK), in obtaining medication, and through the denial of certain forms of treatment and welfare based on their understanding of illness and what constitutes treatment. In using Campbell's (2009; 2014; 2019) theory of ableism, I demonstrated that fibromyalgia does not fit into a conventional biomedical model of illness. However, I also used ableism to show the fluidity of what I understood as biomedical knowledges and experiential illness knowledges as they were both contested in different contexts, they were operated in different contexts, and they were not always used in antagonistic opposition to one another. Through focusing on these forms of knowledge I wish to highlight in the subsequent sections how power and interpretations of what is legitimate knowledge pervaded aspects of participants' lives.

### 7.3 How do people and families with fibromyalgia understand their experiences of life outside of the home?

The end of Section 4.3 argued that medical language acted as a lingua franca to obtain access to services outside of the medical profession, as it was the means of communicating dominant, legitimated, biomedical ways of knowing illness across the medical profession and welfare system. I attributed this to the wider valuation of scientific expert knowledge over experiential knowledge – as mentioned in Chapter Two. This is important as it suggests the power disparity between these ways of knowing extends beyond the medical profession (Blume, 2017; Disability Benefits Consortium, 2019; Crooks et al., 2008). When looking at my participants' experiences outside of the medical profession, they implied that they encountered two attitudes which delegitimised them; their fibromyalgia, and their EIK. The first of these I interpreted in a theme of a social gaze. The second was a continuation of the devaluation of their EIK over what was implied to be others' perceptions of legitimate biomedical knowledge. Both of these understandings related to and informed one another.

Some participants mentioned that when using public disabled spaces and resources, they felt judged and held accountable to strangers' normative assumptions of what illness and disability ought to look like. Furthermore, participants highlighted that within the context of the UK, this gaze was supported by wider moral narratives of welfare deservingness which are intrinsically linked to the foundations of the UK welfare state (Englander, 1998). In short, I understood this gaze to marginalised participants through using



normative understandings of illness and disability as visible. For example, it could be used when welfare officials felt a person did not look ill, or when someone questioned a participant's decision to work part-time when they did not appear visibly ill. Participants implied feeling as though they were under trial by this gaze, and I argue underpinning it is an internal ableist logic that one is healthy until proven otherwise (Campbell, 2009).

The second aspect of participants' experiences was the continued devaluation of participants' EIK over what they felt others' perceived as legitimate biomedical knowledge. By biomedical knowledge, I mean that participants felt people evaluated their bodies based on what they interpreted as evidence of legitimate illness. This often required aetiological understandings of illness, or visible signs that one was ill. In the case of welfare benefits this could be a doctor's note or a diagnosis of cancer, for the general public this could be assessing how someone looks after parking in a disabled parking space. I interpreted this as an underlying epistemology which we subjectively interpret, yet by its very principles gives us the impression of something objective. I discussed within Section 2.2 that Thompson and Parsloe (2019) found that when lay people try to determine whether a family member is faking an illness, they will often collect their own evaluated evidence as proof. Thompson and Parsloe (2019) indicated that evidence consisted of participants' normative understandings of how they thought an ill person should behave, and relied on evidence of medication, medical tests, and the consistency of one's illness performance over time. My findings highlighted, alongside previous studies, that fibromyalgia subverted these expectations (Juuso et al., 2014; Armentor, 2017; Rodham et al., 2010). However, I argue what is important here is the underlying epistemology used by Thompson and Parsloe's (2019) participants which they perceive is a means to objectively determine and know the illness status of their family member even though this evidence is subjectively interpreted.

Where my participants interacted with welfare officials, I interpreted them as encountering this pseudo-objective-actually-subjective epistemology, which with its social valorisation could serve to deny them access to support. Campbell (2014; 2019) highlights that governments, through purification and translation, try to categorise populations into able and disabled. We know from other studies on fibromyalgia that diagnosis can enable the provision of support (Madden and Sim, 2016). Within micro-interactions such as that of welfare, participants are either coded and categorised as

deserving of support or marginalised. Therefore, by not being neatly translated into a state of illness or wellness, people and families with fibromyalgia could be denied support by welfare officials, and receive hostile treatment from members of the public. I understood this as cases of Campbell's (2014) microaggressions which were conducted against participants as they did not meet people's understandings of what it is to be legitimately ill, and therefore must be 'able'. Campbell (2014) argues that these microaggressions occur as there is a dichotomous constitutional divide between what is healthy and what is ill, and the State has a desire to classify disease and its population (Campbell, 2014). My findings suggest that similar to Thompson and Parsloe's (2019) study, that part of what maintains this constitutional divide is an amalgamation of normative ideas of an able body and an ill body, alongside the processes and power relations that determine what equates to legitimate knowledge.

In response to perceptions of having been miscoded, participants felt a sense of injustice at the lack of understanding by others, particularly when they were denied financial and physical support from the government when they were ill. This is similar to senses of injustice felt in other studies at a lack of public and medical understanding over the impacts fibromyalgia can have on people and their partners (Rodham et al., 2010). Within this sense of injustice participants engaged with narratives of morality and welfare by situating themselves as good citizens deserving of support, by comparing themselves to an imagined undeserving other. Campbell (2014; 2019) highlights that comparison is important as it gives us an indicator of wider norms reflected within society. For example, participants' comparison of those deserving and undeserving of welfare can reflect wider UK-based ideologies of welfare entitlement (Englander, 1998). However, this is where *lingua franca* again becomes important. In Section 4.3 I highlighted that the *lingua franca* to communicate medical conditions was implied to be that of biomedical language supported with physical evidence of doctors' notes etc. to legitimate illness. Repeatedly participants referred to themselves in these terms, as a means to legitimise their condition and to frame themselves as deserving of welfare and as good citizens who had worked and had justly contributed to society. However, as some participants were rejected or challenged when applying for welfare, in these instances officials did not define them as citizens deserving of welfare and as being translated by the state into a disabled condition that would engender support. As within the Chapter Four, I suggested that the language participants used to legitimate themselves was part of a rational that contributed to their

discrimination and the social gaze that constrained and delegitimated them. I understood that those who had the most power in these interactions (medical professionals and welfare officials) were using their biomedical ways of knowing and legitimising illness to justify this delegitimation. The implications of this are that what is legitimate is subjectively defined by those with the most power in micro-interactions, and then classified as objective to maintain the able/disabled dichotomy (Campbell, 2014; Castiel, 2003). This could possibly then contribute to the stigmatisation people with fibromyalgia experience (Åsbring and Närvänen, 2002; Juuso et al., 2014; Armentor, 2017).

I previously suggested that for participants to conceptualise themselves within a deserving welfare category, they required a pre-requisite history of being an able-bodied worker. I suggested that underpinning many participants' understandings is an idea of an able bodied worker, and a need to prove to others that at one point one was such a worker to avoid stigma and judgement about one's moral character (Goffman, 1990). Åsbring and Närvänen (2002) use Goffman's ideas of stigma and morality as they highlight how the moral character of their female participants with fibromyalgia and CFS was called into question by those around them. Owing to the invisibility of both conditions, their participants felt that those around them felt they were not legitimately exempt from their responsibilities (Åsbring and Närvänen, 2002). Paige touched on this stigma in Section 5.3.1 when speaking about her experiences of dropping to part-time work and facing other people's reactions, as she did not appear ill. Stigma has often been used to describe people with fibromyalgia's experiences' with those who do not understand the illness (Armentor, 2017; Åsbring and Närvänen, 2002). However, I argue participants' experiences are better conceptualised through their implied internalised ableist ideals concerning how much they felt they should work, and how much their bodies were able to (Campbell, 2014). Paige implied that she encountered stigma for not working full-time because of the ableist presumptions others made of her body and what illness ought to look like. I argue ableism better conceptualises these experiences as the people in my sample were not being stigmatised for looking ill, rather they faced negative social attitudes for looking able but occupying spaces and positions which deviated from the presumed ableness of their bodies (Goffman, 1990). In other words they only received stigma for not having a visible stigma which would legitimate them to use a disabled space, or work part-time. I argue that this suggests they were impacted more by the wider notions of an able-body within the micro interactions in which they were engaged (Goffman, 1990; Campbell, 2014).

Importantly, my findings highlight how difficult it can be to challenge ableist thinking as participants themselves could reproduce ideas of an able-body through narratives of welfare, contributing to wider ideals which then marginalised them.

In exploring Hannah's flexible working arrangements in Section 5.3.1 where she could leave when she was ill but had to return to full-time work when better. Hannah implied she was compelled in these instances to perform like Campbell's (2014) unrestricted worker who is constantly available and able to work to maximum capacity. Hannah said she did this to be given allowance by her employer to be off sick without getting a bad reputation/record. However, this example emphasises the ableist nature of work, as she has to take flexible work to avoid repercussions of absences, but in doing so this comes with the physical and emotional costs of feeling the need to appear well and perform the able worker ideal (Campbell, 2014). The implications of this are that people with chronic conditions need support beyond flexible contracts and that we need to challenge more broadly ableist ideals of what productivity and a good worker are to address the ableist microaggressions that people with chronic illness can face.

Whether employing stigma or phenomenological approaches, studies on fibromyalgia have historically taken fibromyalgia as deviant as its starting point, then exploring how people manage having a body that is socially deviant and what accommodations others should make (Åsbring and Närvänen, 2002; Paulson et al., 2002; Juuso et al., 2014; Armentor, 2017). However, within recent years some have started to focus on the systematic power that can affect people. Crooks (2007) touches on macro level inequalities such as low payments of welfare as a cause for hardship in her female participants' lives. Boulton (2019) highlights how medical categorisation can exclude people with fibromyalgia as it is unexplained by medical science. My thesis contributes to people and families' understandings of the public sphere by using Campbell's (2009; 2014) theory of ableism and understandings of microaggressions to suggest how the systems that stigmatise those with fibromyalgia and their families could be produced and reproduced on a daily basis.

Campbell (2014) argues that we cannot rid ourselves of ableism, only challenge it, and my findings indicate participants were not passive to instances of being coded or categorised by welfare officials and norms of work. When looking at some participants who were unemployed, they at times challenged this and the ableist standards which they

felt they were held up to. Highlighting the ableist notion that working certain times and hours equates to productivity, and by valuing volunteering and maintaining social networks over the ableist worker ideal, the codes which generally dictate experiences of unemployment – such as those expressed by other participants that work equated normality – could be subverted. However, challenging these ideals came with emotional costs of not adhering to wider norms of work, highlighting, like other studies (Wuytack and Miller, 2011; Arnold et al., 2008), the importance of work within participants' lives and the financial and relational problems that reduced employment and unemployment could cause.

### 7.3.1 Summary

Through using Campbell's (2009; 2019; 2014) theory of ableism, I have discussed how wider preferences for biomedical positivist epistemologies, and powerful actors, can marginalise people's and families' accounts of illness in micro-interactions. This impacts people's, and their families', experiences of the public sphere as through media discourse of welfare, ideology, biomedical ways of knowing and normative ideas of illness they are evaluated and judged by a social gaze that marks them dichotomously as either legitimately or illegitimately ill. By using Campbell (2009; 2019; 2014) I expanded on previous studies which have looked at social norms and stigma, by looking at how participants exist within ableist systems and experience microaggressions, and at times how they reproduce in micro-interactions the ideals used to oppress them (Åsbring and Närvänen, 2002; Juuso et al., 2016; Armentor, 2017). Conversely, as participants gave accounts which challenged implied dominant normative ableist assumptions of welfare and work, they were able to subvert at times the ableist norms in which they felt judged by, highlighting Campbell's (2014) point that we can challenge and subvert ableism.

In answer to the question: How do people and families with fibromyalgia understand their experiences of life outside of the home? Participants again found their EIK discredited as I interpreted, and participants implied, wider public attitudes and welfare systems favoured scientific, biomedical visible ways of knowing illness. Additionally, participants came up against ableist understandings of the body that at times they themselves had internalised and reproduced, and at other times they challenged. I argue that using Campbell's (2019; 2014) ableism to understand participants' experiences contributes to our knowledge by letting us move beyond experiences of stigma to look at

the norms which can create the conditions for stigma to occur, and detail how we can resist them.

#### 7.4 How do people with fibromyalgia and family members navigate everyday domestic and social life?

The previous two questions largely focused on participants' experiences with institutions in society such as the medical profession, welfare, and work, and I argued Campbell's (2009; 2019; 2014) theory of ableism has been invaluable in conceptualising their experiences. In this section I discuss how people with fibromyalgia navigate everyday life, and despite the contribution of ableism to helping us understand how people and families can be marginalised, ableism does not let us explore the depth of the emotional and relational experiences that participants informed me of. Therefore, in this section I focus on these emotional and relational aspects of people and families' lives, drawing on wider norms of family, concepts of relationality, care, and emotions.

My findings concur with previous studies that participants felt a sense of loss around losing employment, and the relationships with colleagues which work facilitated (Juuso et al., 2016; Crooks, 2007). Some participants implied they were not only impacted by the loss of their job, but by how the treatment they received contrasted their perceptions of the shared emotional and relational histories they had with their colleagues. I suggest this highlights the importance of exploring one's relational histories when exploring experiences of loss and employment. Participants also highlighted the financial impact of losing employment and how this could impact their relationships (Wuytack and Miller, 2011). Crooks (2007) highlights that her participants were restricted from seeing friends not only because of their fibromyalgia, but also because of their low welfare payments meaning they could not financially afford to meet friends. My findings add to this by highlighting that losing work did not just impact the person with fibromyalgia, but their family, in that family members would have to work extra hours, and the loss of income could strain relationships as the energy of family members with and without fibromyalgia became drained trying to meet the needs of the household. This highlights how adverse experiences in employment and in applying for welfare could be experienced relationally within families, impacting not just the person with fibromyalgia but their whole family – as Söderberg et al. (2003) hinted at.

My findings suggested that family life is dynamic: there is a doing of housework, a doing of days out, a doing of cooking etc. and that participants adapted around this in various ways. In my findings I attempted to group these into categories, though this list was not an attempt to quantify family practices, rather I wanted to give some shape and structure to the amorphous practices that families engaged in to facilitate analysis of them. Families' adaptations – stable and flexible – were situated in the context of relationships with histories informing who has previously done what, and who now does what, when, and where. Similar to Finch and Mason (1993), some of my participants with fibromyalgia implied there were social expectations placed on them to perform housework, however that these were renegotiated with the onset of fibromyalgia. The person with fibromyalgia still engaged in housework, even if it was not viewed by participants as a 50/50 split of housework. This is similar to findings from Richardson et al.'s (2007) study on families with chronic illness where ill family members still engaged in acts of care and domestic labour, but at their own pace. This is also similar to findings from studies on fibromyalgia where pacing oneself while balancing the needs of the household, such as housework, is something that those with fibromyalgia have to juggle (Kengen Traska et al., 2012; Briones-Vozmediano et al., 2016). My study contributes to this as I argue using family sociology, and the idea of family as a fluid doing of family activities, allows us to see how these practices were relationally and historically situated, and not always related to fibromyalgia in ways that other illness studies have not explored (Richardson et al., 2007; Briones-Vozmediano et al., 2016). My findings highlight that families adapted their behaviour based on their EIK of fibromyalgia. Therefore, families knowing of fibromyalgia discussed in Section 4.1.1 changed their actions and responses to their loved one's fibromyalgia. This expands on Armentor's (2017) findings in which some of her participants with fibromyalgia highlighted that their family members and those close to them could recognise their fibromyalgia symptoms and help them to make her participants' lives easier. It also highlights how experiential knowledges can be used to navigate aspects of daily life in unpredictable illnesses.

However, I understood participants' accounts of their household responsibilities and day lives as not only fluid doings of practices, but as related to their normative understandings of what they felt they should do as families, children, mothers etc (Morgan, 2011; Gilding, 2010). I demonstrated how this clashed within their daily lives. For example, mothers within my sample expressed anguish at not meeting their perceived responsibilities of

motherhood such as picking up their child from school, or doing the housework. Partners' expressed loss over not being able to exercise together, spontaneously going out, or having changes to their sex life. For most of the children, and some participants, within my sample who did not know their family member with fibromyalgia prior to onset, I understood this loss to be normative as they compared their experiences to their peers, as these activities were not always things they had historically done (Campbell, 2014; 2019). I argued that by exploring what I understand as normative loss, it could give us an insight into participants' normative assumptions and perceptions of family roles, gender, age, and childhood and how this impacted their understandings of their experiences (Chambers, 2012; Jenks, 1996). Through looking at these norms, I argue they have an internal ableist logic that shaped what participants felt was normal, but which could also be harmful to participants who compared their lived experiences with these norms (Campbell, 2019). This is important as many prior studies on fibromyalgia have not explored how people's understandings of norms and roles of family, childhood, work, illness can all interact and impact people's lived experiences (Juuso et al., 2016; Armentor, 2017). Norms were only one aspect which informed my participants' lives. However, by exploring them it gave important insight into the emotional impacts that transgression of these norms can have in informing the everyday *doing* of family (Morgan, 2011).

Participants highlighted how practices that had historically maintained and supported their relationships, and their emotional wellbeing, were no longer available to them as they once had been. Many studies on fibromyalgia have explored this idea of loss in relation to control over the body and one's freedom to act, a loss of identity, social life, and activities with partners (Söderberg et al., 2003; Wuytack and Miller, 2011; Rodham et al., 2010; Briones-Vozmediano et al., 2016). My findings in Chapters Four, Five, and Six highlighted how Campbell's theory of internalised ableism could help us understand our experiences of the ableist assumptions we hold about our bodies, and what we feel we should be able to do. I argued that internalised ableism created a sense of loss in people with fibromyalgia as they compared what they could previously do with what they could do now with fibromyalgia. Furthermore, I argued a sense of loss was extended to family members who missed doing shared activities and interacting with their loved one with fibromyalgia as a relational we, and missed engaging in activities which were either biographically significant to them, or viewed by themselves as culturally normative



family activities. However, in Chapter 2 Section 2.5 Ableism I argued that Campbell's (2009; 2014) theory of ableism does not account for people's emotional relational experiences of illness. I argue that Campbell's (2014) internalised ableism, and Smart's (2011) notion of shared relational biographies can explain people's feelings of loss to their prior biographical selves and relational we. However, similarly to the previously cited studies on fibromyalgia, the loss felt by people and families in these instances came from the impairment effects of fibromyalgia (Reeve, 2012; Thomas, 2004). Participants were not always restricted by the ableist assumptions of society, at times their impairment effects impacted them. I argue my findings evidence the physical and emotional impacts that impairment effects can have on the lives of people with a chronic illness like fibromyalgia, and for the people around them through an inability to engage with their biographical relational we (Reeve, 2012; Thomas, 2004). Loss, pain and emotional impacts are then both individual and shared. When previous studies have looked at loss, they have often conceptualised it as individual losses to individual people, rather than what it means to lose the "*we-ness*" that these activities implied (Edwards et al. (2012: 736).

I argue that when looking at experiences of chronic illness, it is imperative to include this *we* and consider the wider relationships beyond the ones between people and their *selves* (which are in part constituted by those around them) to explore how chronic illness impacts people. By conceptualising relationships as a process, we can see that these activities were embedded within participants' relational histories with one another (Smart, 2011). I do not want to downplay the individual pain and sadness felt by participants in relation to fibromyalgia. However, I argue a contribution to our knowledge of families understandings' of their experiences of fibromyalgia is the loss of a relational *we*, which was constituted (done) and maintained historically by normative and emotionally significant and enjoyable activities (Smart, 2011; Morgan, 2011). I argue this contributes to the literature by exploring how fibromyalgia impacts more than a person's individual identity, and that we should explore not only how social *selves* are shaped by chronic illness, but the social biographical *we* (Asbring, 2001; Bury, 1982; Bell et al., 2016). Bell et al. (2016) have discussed biographical disruption in relation to families across the life course. They conceptualise illness trajectory as oscillations across the life course that interact with our imagined (hoped) normative life trajectories, and the realities that illness presents for us (Bell et al., 2016). However, in their research, biography is still

largely something that individuals reassess within the context of their families. I argue based on the findings, that it would be interesting to see future research looking at biographical disruptions and oscillations where biographies are relationally informed, and where multiple relational *we* and *us* can be explored.

Although feelings of loss were strong within participants' accounts, some participants highlighted that they found other ways to do family, and this "*we-ness*" within the context of fibromyalgia (Morgan, 2011; Edwards et al., 2012: 736). Participants spoke of finding ways to balance the social impacts fibromyalgia could have in spending time together and with friends. Spending time with one another was often conceptualised as doing different activities which were manageable for the person with fibromyalgia, as primarily what was important was the spending time with one another – highlighting the emotional significance of doing relationships (Morgan, 2011; Smart, 2011; 2007). Within Section 2.7 I discussed many aspects of care: as a burden, care as worry, care as rewarding, as an expression of love, as an interdependent reciprocal relationship (Paulson et al., 2002; Cheung and Hocking, 2004; Finch and Mason, 1993). My findings suggest care was more multifaceted than being simply a burden, rewarding, or as expressed through worry. Rather, when families spoke of care it was similar to Elden's (2016) understanding of care as an ordinary complexity. Using this, adaptations, compromises, finding balances between family and friends were constructed as ordinary features of people and families lives with fibromyalgia, but at the same time, underpinning these were complex reasons and relationships. I understood care to be multidimensional as participants provided physical and emotional care which was embedded within their shared relational histories. Participants suggested that these aspects of their lives were not necessarily reciprocal, as family members could take on more domestic work than their family member with fibromyalgia. However, I argue superseding participants' lack of perceived reciprocity was a sense of the emotional bonds, and shared relational histories between participants, which they implied was more important to participants than getting something back (Finch and Mason, 1993). I argue that by exploring families' relationships in chronic illness from a relational perspective it can highlight that reciprocity takes a cold transactional view of care that does not acknowledge that forms of care are emotional and ordinarily complex aspects of people and families' lives.

This brings back the notion of the families we live with, and the families we live by, and Smart's (2005) findings on families experiencing divorce that providing help to the family one lives with has more importance than maintaining the ideal of the family one lives by (Gillis, 1996; 1997). Being flexible and willing to adapt around the illness was essential to this— similar to findings from Årestedt et al.'s (2014) study on family experiences of illness. It also highlights that while participants' perceptions of family norms were important in informing their lived experiences and relationships, they were only one aspect whereby families could redefine these understandings, and still engage in emotionally rich, fulfilling relationships.

Families were not just involved in relationships amongst themselves, some participants' spoke of the benefits of getting out and seeing friends, spending time away from family life and, at times, fibromyalgia. For participants with and without fibromyalgia, getting out and seeing friends contributed to mental wellbeing, and could also be instances of compromise between how fibromyalgia impacted someone on that day and what their friends wanted to do. EIK was important here as participants repeatedly spoke of planning days out with groups of friends based on how they knew fibromyalgia would impact them. Particularly interesting was how partners spoke of accommodating and supporting their partners' symptoms with the needs of the group of friends they were with, highlighting again the presence of care as an ordinary complexity within participants' lives (Elden, 2016). I interpreted that norms impacted their friendships as engaging in social activities were seen by some participants as maintaining a normality similar to that that they had from before having fibromyalgia. Spencer and Pahl (2006: 64) in their qualitative study on friendship suggest there are different types of friendship and that some friendships can be "*fun friends*" who enjoy having fun and socialising together over various activities. I suggested that by going out and doing activities with friends it not only helped to actively maintain participants' wider relationships, but also acted as a means for people and families to have a break from fibromyalgia. My participants also suggested that reciprocity within their friendships was very important, and it is something they placed more emphasis on than that of Spencer and Pahl (2006). In order to achieve this reciprocity, and as a means to maintain their friendships, families implied their EIK - which was so devalued within wider systems within society - was integral to managing their informal day to day relationships between families and friends. EIK enabled people to obtain a sense of balance within their relationships and emphasized the emotional

importance family and friendship could have for people. Many of my participants had lost some, or all, of their friends with the onset of fibromyalgia which supports wider research on fibromyalgia and friendship (Paulson et al., 2002; Crooks, 2007; Rodham et al., 2010) However, my findings also highlight how some people and families were able to maintain their friendships through using the EIK.

My findings are similar to findings from Årestedt et al.'s (2014) interviews with families with an array of chronic illnesses and who argued that their participants adapted to chronic illness by changing their activities to suit the pace of the person with the illness. Their participants also highlighted how they had to be flexible over what they did, and that by talking about the illness families found ways to manage life with it and act together (Årestedt et al., 2014). The findings from Årestedt et al.'s (2014) study are illuminating in acknowledging the emotional importance familial relationships had to their participants. However, although Årestedt et al. (2014) is an empirically robust study, they do not challenge wider norms surrounding what a family is, and how this might impact participants. For example, they state that chronic illness is a “*family affair*” (Årestedt et al., 2014: 29). Yet, at no point do they critically engage with normative ideas around family or family roles and life, and how this might shape families’ experiences. Their work, though very valuable, supports an ideal of family that theoretically and ideologically goes unquestioned, and does not exist for everyone. This is particularly important in the context of my findings in Section 6.6 and the wider debates around families within the literature (Smart, 2011; Gilding, 2010; Edwards et al., 2012).

Årestedt et al.'s (2014) findings, and my own concerning how families manage their close personal relationships and household responsibilities, creates a cosy picture of families who love one another and care for one another. However, I am concerned that by focusing on this idea alone it reproduces ideas of families that were not uniform across my sample. I highlighted in Section 6.6 that some people did not feel they had support from family or friends. Therefore, I understood that having the means to adapt and compromise was then a privileged position of people who were in relationships with those around them, who were in turn willing and able to do this. In this instance, even having EIK can be seen as a privileged position if some peoples’ family members deny the existence of fibromyalgia – something that occurred within my sample and the wider literature (Juuso et al., 2014; Briones-Vozmediano et al., 2016). Armentor's (2017) female participants indicate this

contrasting picture in her own findings, that while diagnosis could lead to more support over time, it could also lead to stigmatisation and a lack of support. For some in my sample, family and friend support did not exist. I argue that this demonstrates negative aspects of relationality where people can live with others in embedded and relational lives with shared relational biographies, and still have their experiences of chronic illness be denied or unacknowledged by these people. Therefore, we do not necessarily have positive relationships with the families we live with even though we may have shared emotional and relational histories with them (Smart, 2011; 2007). Additionally, my findings suggest that participants' perceptions of family norms informing how they can be positioned relationally to others could impact their health and access to support. For example, Lily in Section 6.6 was unable to receive state support, but also had children with additional needs and struggled to manage this with her own symptoms of fibromyalgia. Lily implied her role as a mother was both a source of agency, and something which constrained her ability to look after her own health. I interpreted her perceptions of wider social norms, and the needs of her household and relational self as constraining her agency to look after her own health, which was compounded by a lack of formal and informal support.

I argue that without discussing the detrimental aspects of relationality, I am reproducing an account of family life that supports wider policy assumptions the family is a source of informal support (Smart, 2011; Edwards et al., 2012; Smart, 2007; Gilding, 2010). I want to be clear that many families in my sample were supportive to their family member with fibromyalgia. However, I had other participants who implied their families did not provide them with support. In drawing out the existence of family support as a privileged position I am acknowledging the tensions and contradictions of family life experienced by my participants and which are characteristic of qualitative data. I argue that Section 6.6 highlights that family forms are fluid rather than uniform, and cannot be an assumed starting point for some level of support when formulating policy (Morgan, 2011; Dalley, 1996). This point is particularly salient given the wider UK austerity agenda in which people and families live and which could deny them support (Disability Benefits Consortium, 2019). By reporting the contradictory elements of my findings on participants' experiences of family life in Chapter's Five and Six I hope to maintain a critical view of families within studies of chronic illness. While some of my participants

lived with families that engaged in family practices, and an ordinary complexity of care in which illness was one part of their lives, others did not.

#### 7.4.1 Summary

To answer my third research question, people and families navigated their lives through various strategies. Sometimes this involved utilising informal networks, in which families adapted and changed what they did within household divisions of labour. Other times this involved compromising within their social activities – such as seeing friends - to meet the needs of their illness, and the expectations of others. People and families also navigated their everyday domestic and social life in relation to wider norms of family and historical activities they once did, and some people and families felt an overwhelming sense of loss at not being able to do what they used to. I argued that by viewing this through Campbell's ableism and Smart's relational biographies, we could explore how participants with fibromyalgia understood their bodies through an ableist lens, and that they were comparing their current experiences with their biographical experiences prior to the onset of fibromyalgia. I also argued that this evidences instances of the emotional impacts that impairment effects, theorised by Thomas (2004) and Reeve (2012), could have on people. Participants could not live up to their ableist ideals and expectations, and the expectations of others, as a result of their impairment effects. I argued this demonstrates how impairment effects can personally, physically, and emotionally impact people with fibromyalgia, and how it can impact families relationally through being unable to undertake certain family practices that they had done previously, or that those around them do, as a shared relational we. Despite this, I would like to stress that the limitations people experienced as a result of fibromyalgia's impairment effects were only one part of the wider discrimination and oppression they faced by the ableist assumptions and biomedical models of illness which I interpreted from participants' accounts of their interactions with certain doctors, employers, and members of the public. In the context of prior studies which focus on how fibromyalgia's impairment effects limits people, I urge the reader to remember that participants' also navigated their lives through multiple systems where actors had their own interpretations of illness, family, and legitimate knowledge, which could also marginalise them. Lastly, I highlighted that people's personal lives were still informed by wider understandings of illness as visible, and ableist assumptions of ability – similar to my theme of social gaze. Therefore, families who developed EIK and provided informal support were in a privileged position to participants

who did not have this informal support, and who implied their family members understood illness through the lens of the aforementioned social gaze. I argued it is then important to consider how wider policy and normative understandings of illness and family can impact those not within this privileged position, and how this highlights the detrimental aspects of relationality. Prior to drawing out the conclusions, and theoretical and practical contributions of this research, I will briefly discuss the limitations of my study.

### 7.5 Limitations

I conducted an exploratory study of families' understandings of their experiences of fibromyalgia within the UK. I will now present some limitations to the current research.

It was beyond the scope of this research to obtain the perspectives of medical professionals who worked with people with fibromyalgia. However, it became apparent during the data collection that medical professionals' attitudes and understandings of fibromyalgia had significant impact on my participants – particularly as most participants spoke of negative experiences when trying to obtain medical help. Therefore, future research on medical professionals' (doctors, nurses, physiotherapists, occupational therapists) perceptions of fibromyalgia within the UK is required to see how professionals understand, and experience fibromyalgia within their work. Additionally, further research is required within a UK context on what support people and families with fibromyalgia feel would help them manage life with fibromyalgia, and who would be best placed to provide this.

I did not research the perceptions and understandings of fibromyalgia from welfare assessors, employers, or the wider public. However, participants noted that the attitudes and perceptions of these people had serious impacts on their financial, physical and mental wellbeing. Future research should explore how actors such as welfare assessors, employers, and the general public view fibromyalgia. This could help us understand how medically unexplained illnesses are understood by wider public bodies and in micro-interactions, and help us learn more about norms of illness and the operation of ableist practices within the UK.

A further limitation to this research was the lack of perspectives of children whose parents have fibromyalgia. In only three out of the 17 families I interviewed were children

interviewed, and in only two of these instances were the children under 18. Future research should look at families with younger and older children's experiences of fibromyalgia to see how they understand the illness within their lives and families. Of particular interest would be to see whether onset of fibromyalgia and the older age of adult children may change their views compared to that of younger children who have only known their parent as having fibromyalgia. Within my limited findings, the older children within my sample did not report memories of their parents' pre-diagnosis. However, when exploring fibromyalgia relationally, and with norms of family, it would be interesting to explore in more detail whether a larger sample of children would result in divergences.

## 7.6 Conclusions and Contributions

In this thesis I have demonstrated that people interpret chronic illness not only in relation to their lives, but in relation to the lives of those around them, and through the multiple socially constituted *we*. In Chapter Two I highlighted that historical shifts in how we understand and know illness relegated experiential knowledge to having less value than that of biomedical knowledge of illness. I then explored the medically contested condition of fibromyalgia, and how it challenges this biomedical knowledge through only being known experientially. I then highlighted the problems that could occur for people living in a society where biomedical knowledge was implied to have more legitimacy than that of experiential knowledge in relation to welfare and employment. I evaluated theories of illness, disability and ability, exploring how they could conceptualise people's experiences with fibromyalgia, enable a critical perspective of how we claim to know illness, and what perspectives we may marginalise based on this claim. I drew on Campbell's (2009) theory of ableism to conceptualise the aforementioned issues. However, I argued that missing from this was understandings of the families which people live with. By drawing on sociological studies of families within the UK (Morgan, 2011; Smart, 2011; Gilding, 2010), I argued it was important to consider how families experiencing chronic illness may be impacted not only by the impairment effects of illness, but by their perceptions and wider policy assumptions concerning what is a family, and what a family ought to do. I indicated that in the UK there are particular policy assumptions of the role of families and family roles of motherhood, fatherhood and childhood that could impact people's lived experiences, and how they view care within their lives. Lastly, in reviewing what we know about families' experiences of



fibromyalgia, I argued we do not know the experiences of families and how their understandings of their experiences might be informed by not only their illness, but wider ideological understandings of family and care. I argued it was important for us to know how this may impact families materially and relationally.

The arguments in Chapter Two were drawn from multiple disciplines detailing peoples' experiences of fibromyalgia, of chronic illness and disability more generally, and of peoples' experiences of family life to explore different things which could inform people's and families' understandings of their experiences of fibromyalgia in the UK. As there is an absence of studies on fibromyalgia within the UK, I drew on literature internationally and domestically from a variety of sources to create picture of what might be the case for families experiencing fibromyalgia. In doing so I identified gaps in the literature around families' experiences of fibromyalgia, and I wanted to find answers to the following questions:

- 1) How do people with fibromyalgia and their family members understand fibromyalgia?
- 2) How do people and families with fibromyalgia understand their experiences of life outside of the home?
- 3) How do people with fibromyalgia and family members navigate everyday domestic and social life?

To answer these questions, I interviewed 29 people (16 with fibromyalgia, and 15 of their family members equating to 17 families in total), using a mix of phone and face to face interviews and thematic analysis. In answering these questions, I propose several contributions to our understandings of families' experiences of chronic illness. I will present them in the sections Theoretical, and Practical Contributions and discuss what we know now that we did not know before.

#### 7.6.1 Theoretical Contributions

In Chapter Two I highlighted that it was unclear whether families understood their family member's fibromyalgia. In Chapter Four I detailed that post-diagnosis, people and family members of the person who has fibromyalgia could develop Experiential Illness Knowledge (EIK) of fibromyalgia. This is a subjectively interpreted knowledge which

could inform them of what they could and could not do on a given day either through their own experience of their body, and through observing and/or directly communicating with their family member. Through using Campbell's (2009) concepts of purification and translation, and the need to categorise illness, I argued that families also understood fibromyalgia and their EIK of fibromyalgia as being continuously devalued to that of biomedical knowledge and acute understandings of illness which marginalised their understandings and experiences. This expands our knowledge of families' experiences of chronic illness by highlighting that illnesses can be experienced relationally. It raises awareness to disparities in how we value knowledge about illness (biomedical and experiential), and how these disparities can systematically marginalise illnesses with limited biomedical knowledge but a wealth of experiential knowledge such as fibromyalgia.

Previous studies have explored the idea that people with medically contested conditions can find it hard to access welfare (de Wolfe, 2012; Disability Benefits Consortium, 2019). Participants implied that doctors, welfare officials, employers, and the general public understood illness as being visible and acute. Participants also implied fibromyalgia contrasted this understanding, as participants stated they looked well despite being ill. My thesis contributes to our knowledge by arguing that the disparities in the value of experiential and biomedical knowledge and understandings of illness can systematically marginalise families from obtaining support in welfare and employment. This finding contributes to our knowledge as I argue that participants were constrained and materially marginalised by systematic barriers and societal understandings of illness, rather than solely by the impairment effects of their illness.

However, despite the systematic barriers that impacted my participants, my thesis contributes to our understandings of the emotional impacts of impairment effects as theorised by Carol Thomas (2004; 2007) and Donna Reeve (2002; 2012). Previous studies on fibromyalgia have stated that people feel a sense of loss over their lives prior to fibromyalgia, and what they can physically do now (Briones-Vozmediano, et al., 2016; Asbring, 2001). Using Campbell's (2009; 2014) understanding of internalised ableism, I expanded on this by theorising that participants with fibromyalgia felt a sense of loss when comparing what their body could do now, with what it could do previously and what they felt they should do. Furthermore, I used Smart's (2011) understanding of

relationality and biography, and I drew on Morgan's (2011) understanding of family practices, to demonstrate how impairment effects can also impact family members of those with fibromyalgia. I argued that fibromyalgia's impairment effects do not just stop the person with fibromyalgia from doing things, rather they can stop families from engaging in culturally normative, historically shared and emotionally significant practices that have defined their shared biographies. My thesis contributes by highlighting that fibromyalgia did not just disrupt individuals' biographies (Bury, 1982), but the shared relational biographies of families as they had to change and adapt what they did with the onset and progression of fibromyalgia. Drawing on biographies and practices as relational, I theorised that when doing activities as a family, participants were engaging in relational we. I argue that future research should explore ideas of relational we in more detail when researching experiences of chronic illness.

#### 7.6.2 Practical Contributions

In this thesis I offer some practical contributions from the findings presented above. Before detailing them, I want to emphasise that people and families cannot challenge the ableist assumptions, microaggressions and marginalisation they face on their own. Services need to support people and families with fibromyalgia and challenge their own ableist assumptions of illness.

First, medical professionals should receive more training on fibromyalgia, and be aware of how their biomedical and people's experiential knowledge of the illness can work together to support the person experiencing fibromyalgia and their family. Medical professionals should be made aware of EIK, and the value that it can have for people and families in managing their illness, such as making decisions about medication, or completing household tasks. Furthermore, having support from medical professionals was important to participants when trying to get help from welfare officials. Doctors should be made aware of the authority they have to influence welfare officials and to offer support to their patients who have fibromyalgia.

Second, healthcare professionals like doctors can play a role in helping people and families develop EIK of their or their family member's fibromyalgia, as this was found to help support people with fibromyalgia and helped families maintain their relationships. Supporting family members to obtain EIK could help diminish the number of people whose family members did not accept or understand their fibromyalgia. Additionally,

fibromyalgia was experienced relationally between my participants, and some family members in my sample wished they could receive counselling, or skills sessions to help them process and manage the impairment effects of their loved one's fibromyalgia. Therefore, I recommend that healthcare professionals and families work together on an individual basis to work out what kinds of guidance and support family members without fibromyalgia may require.

Third, despite highlighting the importance of EIK in helping people and families navigate life with fibromyalgia, EIK should not be a reason to deny wider governmental or healthcare support to families under the policy rhetoric of self-management and the tacit assumption that families will provide informal care for family members with chronic illnesses (Bury, 2012; Dalley, 1996). My findings suggest that people and families need both their own EIK of fibromyalgia, practical support from healthcare professionals, secure employment, and financial support from welfare services to manage life with fibromyalgia. Those who did not have this often struggled to cope when managing daily life.

Fourth, participants implied that employers who adjusted participants' working schedules and offered part-time work helped some of them retain employment. Employers should be made aware of what fibromyalgia is, how it can impact their employees, and be told how they can support their employees who have fibromyalgia, such as offering secure part-time contracts and/or work from home options. Doctors could play a part in using their authority to communicate how employers could support their patient within the workplace.

Throughout this thesis I have highlighted the benefits of multi-disciplinary research through drawing on the theories of ableism, relationality, and family practices to highlight how particular biomedical aetiological forms of illness knowledges are valued over that of experiential knowledges, and how this can impact the lives of families experiencing fibromyalgia. I argue that my findings, and contributions (theoretical, and practical) cannot be understood as separate from wider systematic valuations of knowledge, UK policy trends of austerity and its assumptions of informal family support, nor from the history of welfare deservingness within the UK. I suggest that we only present a partial picture of families' experiences of chronic illness when we do not acknowledge the wider

systematic processes which can marginalise families, and the emotionally interlinked and normatively informed lives that families may live.



## 8 References

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## 9 Appendices

### 9.1 Appendix 1: Draft of Interview 2 Guide Interviews on Participant-led Narratives

Ask if they consent to being recorded.

- 1) What did you write about?

#### **About the Positive Event:**

- 2) Why did you pick this event?

*(General probe questions, are these events important to you/your family? Was the place significant? How it made you feel?)*

- 2a) What do you think are the most important parts of this event? Why?

*(Probe: was illness significant? The person's reaction? Where it happened?)*

- 2b) What do you think are the least important parts of this event? Why?

*If appropriate ask 4 and 5. If not, continue to 11.*

- 3) Do you feel your (or your family member's) illness impacted that day?

*(Ask if not already explicitly discussed)*

- 4) Would a diagnosis have changed anything about that day?

- 5) **Ask you own questions about the event. (Account specific questions).**

#### **About the Negative Event:**

- 6) Why did you pick this event?

*(General probe questions, why are these events important to you/your family? Was the place significant? How it made you feel?)*

6b) What do you think are the most important parts of this event? Why?

*(Probe: was illness significant? The person's reaction? Where it happened?)*

6c) What do you think are the least important parts of this event? Why?

*If appropriate ask 8 and 9. If not, continue to 10*

7) Do you feel your (or your family member's) illness impacted that day?

*(Ask if not already explicitly discussed)*

8) Would a diagnosis have changed anything about that day?

**9) Ask you own questions about the event. (Account specific questions).**

*Only ask 10) if they have previously disclosed and been happy to speak about their own illness*

10) Do you feel your own illness (not fibromyalgia) impacted your relationships that day?

11) Is there anything else you would like to mention, that you think is important?

12) Are you happy for me to use the information you have given me so far in this research?

## 9.2 Appendix 2: Children Draft of Interview 2 Guide

Ask if they consent to being recorded.

- 1) What did you write about?

### **About the Positive Event:**

- 2) Why did you pick this day?

*(Probe: was it fun? Boring? Exciting?)*

- 3) What are the most important parts to you? Why?

*(For example, where it took place? Who was there? Family member feeling ill?  
How things made you feel? Why are these the most important?)*

- 3b) What were the least important/boring parts to you?

*(For example, where it took place? Who was there? Family member feeling ill?  
How things made you feel? Why are these the least important?)*

- 4) Was your family member unwell that day? Would it/did it change your day?

*(Ask if not already explicitly discussed: Probe if they knew, how they knew, would knowing change the day)*

- 5) Ask questions about the event. (Account specific questions).**

### **About the Negative Event:**

- 6) Why did you pick this day?

*(Probe: was it fun? Boring? Exciting?)*

- 7) What are the most important parts to you? Why?

*(For example, where it took place? Who was there? Family member feeling ill?  
How things made you feel? Why are these the most important?)*

7b) What were the least important/boring parts to you?

*(For example, where it took place? Who was there? Family member feeling ill?  
How things made you feel? Why are these the least important?)*

8) Was your family member unwell that day? Would it/did it change your day?

(Ask if not already explicitly discussed)

9) [Ask questions about the event. (*Account specific questions*)].

**Only as 10) if they have previously disclosed and been happy to speak about their own illness**

10) Did you feel unwell on the good/bad day? You do not have to answer this if you do not want to.

11) Did feeling unwell change your day? For example how you spoke to people.

12) Is there anything else you would like to mention, that you think is important?

## **Adult and Young People Interview**

### **Introduction**

**Introduce myself.**

**Ask again if they consent to the interview, and for it to be recorded.**

**Start off with something about them, rapport building...**

- 1) How would you describe yourself?

*(Probe: age, gender, relationship status, parental status, class, education, employment, hobbies, illness other than fibromyalgia – for person with fibromyalgia and family members).*

- 2) Which of these are most important to you, and why?
- 3) What are your favourite things about spending time with family, and why?
- 4) What are your least favourite things about spending time with family, and why?

### **Typical Day**

- 5) Can you take me through an average weekday?

*(Probe: what is done in morning, afternoon, evening? Who do you speak to? Who do you interact with? Do participants work? Go to school? Volunteer? Do domestic labour? Does illness feature?)*

- 6) Can you take me through an average weekend?

*(Probe: what is done in morning, afternoon, evening? Who do you speak to? Who do you interact with? Do you have days out? Spend time at home? Visit family, friends? Does illness feature?)*

### **Relationships**

7) Can you map out the people who are important/meaningful to you?

*(Probe: these can be friends, family, colleagues, neighbours. Can also include people you don't like).*

7a) Who are these people? How often do you see them?

*(Probe: do they live near you? Is there a strong emotional tie? How long have you known these people? What makes it easy to maintain relationship, if not, what makes it hard (e.g. distance, other commitments – child care, work, illness etc.)*

## **Places**

8) Where are your favourite places you like to go?

*(Probe: places you like to go, could be nostalgia, could be comforting etc.)*

9) Where are they? Why are they your favourite places?

*(Probe: how often do you go? Are the people important to you connected to favourite/least favourite places?)*

9a) What are you least favourite places to go?

10) Where are they? Why are they your least favourite places?

*(Probe: how often do you go? Are the people important to you connected to favourite/least favourite places?)*

## **Support**

11) In your opinion, what makes someone/a place supportive?

*(Probe: could be financial, emotional, physically supportive etc. Let them define it).*

12) Are there certain people and places you feel comfortable asking for support?

*(Probe: work, government, friends, family etc. Do you have any real life examples of this?)*



13) Why is this? Is it context specific?

14) Are there certain people and places you don't feel comfortable asking for support?

*(Probe: work, government, friends, family etc. Do you have any real life examples of this?)*

15) Why is this? Is it context specific?

### **Illness**

16) Do you think your fibromyalgia/the fibromyalgia of your family member impacts your relationships with others and access to places? You don't have to answer this.

*(Probe: why is this? Feeling unwell? Lack of understanding from others? Lack of accessible places?)*

### **ONLY ASK PERSON WITHOUT FIBROMYALGIA**

17) Do you have your own illness that may impact your relationships with others and access to places? You do not have to answer this.

17b) How do you think your illness does/does not impact your relationships with others and access to places?

*(Probe: feeling unwell, other's understanding of your illness)*

### **Conclusions**

18) Is there anything else you would like to mention you think is important?

19) Are you happy for me to contact you again to conduct a written diary and diary based interview?

20) Are you happy for me to use the information you have given me so far in this research?



9.4 Appendix 4 Draft of Interview Guide Semi-Structured Interviews Younger People  
**Children's Interview Schedule 1**

**Introduction**

**Introduce myself.**

**Ask again if they consent to the interview, and for it to be recorded.**

- 1) How would you describe yourself?

*(Probe: age, gender, parental status, class, education, hobbies, illness other than fibromyalgia – for person with fibromyalgia and family members)*

- 2) Which of these are most important to you, and why?

**Typical Day**

- 3) Can you take me through an average weekday?

*(Probe: what is done in morning, afternoon, evening? Who do you speak to? Who do you interact with? Do participants work? Go to school? Volunteer? Do domestic labour? Does illness feature?)*

- 4) Can you take me through an average weekend?

*(Probe: what is done in morning, afternoon, evening? Who do you speak to? Who do you interact with? Do you have days out? Spend time at home? Visit family, friends? Does illness feature?)*

**Relationships**

- 5) Can you write/draw out the people who are most important to you?

*(Probe: these can be friends, family, classmates, neighbours).*

- 5a) Who are these people? Do you see them a lot?

*(Probe: do they live near you? Is there a strong emotional tie? How long have you known these people? What makes it easy to maintain relationship, if not, what makes it hard (e.g. distance, other commitments – live far away, school, illness etc.)*

## **Places**

6) Where are your favourite places you like to go?

*(Probe: places you like to go, could be a good memory, could be comforting etc.)*

7) Where are they? Why are they your favourite places?

*(Probe: how often do you go? Would you find the people on your map here?)*

7a) What are you least favourite places to go?

8) Where are they? Why are they your least favourite places?

*(Probe: how often do you go? Would you find the people on your map here?)*

## **Support**

9) In your opinion, what makes someone/a place supportive?

*(Probe: could be financial, emotional, physically supportive etc. Let them define it).*

10) Are there certain people and places you feel like asking for support?

*(Probe: school, friends, family etc. Do you have any real life examples of this?)*

11) Why is this? Is the place important? *(school, home etc.)*

12) Are there certain people and places you don't asking for support?

*(Probe: school, friends, family etc. Do you have any real life examples of this?)*

13) Why is this? Is the place important? *(school, home etc.)*

### **Illness**

14) Do you know when you're family member is unwell?

*(Probe: How do you know? What happens when they are unwell? Do you think it changes the way you speak to them, or they speak to you?)*

15) Do you have an illness yourself? You do not have to answer this.

*(Mention this is different from a cold).*

15b) What happens when you are unwell?

*(Probe what happens when both they and their parent are unwell).*

### **Conclusions**

16) Is there anything else you would like to mention you think is important?

17) Are you happy to take part in the diary and second interview of the research?

18) Are you happy for me to use the information you have given me so far in this research?



## **Do you know someone who has been diagnosed with fibromyalgia?**

My name is Catriona, and I am a PhD student at the University of Stirling. I am interested in the support available to you and your family, and relationships and places you find supportive/unsupportive when having fibromyalgia/ a family member with fibromyalgia.

To take part you must have been/or know a family member who has been diagnosed with fibromyalgia, and have other family members willing to take part who are aged 10 or older.

The research involves an interview, a written account based on a family event agreed by you and your family members, and another interview about the written account. Your participation is voluntary, and you and/or your family members can leave at any point.

If you would like more information please do not hesitate to contact me at:

Tel:

Email:

If you would like to contact someone else regarding this poster, please contact my supervisor Professor Kirstein Rummery at:

Tel:

Email:





## **Information Sheet: Families, Relationships, and Fibromyalgia**

Hello, my name is Catriona, and I am a PhD researcher at the University of Stirling. My PhD is on the relationships of family members where a member has fibromyalgia. It is funded by the Economic Social Research Council (ESRC).

### **The Study**

I am interested in family members' relationships and lives where one member has fibromyalgia. I want to know how you and your family members interact around each other, and what makes someone supportive/unsupportive of a family member's fibromyalgia. I also want to know the places you find supportive/unsupportive of your own/a family member's fibromyalgia, and whether/how you think you/your family member's fibromyalgia does or doesn't impact your life.

### **Why am I doing this?**

I am interested in finding out what relationships and places inside and outside your home – for example home, school, work - are supportive and unsupportive when a family member has fibromyalgia. This is because relationships and places are important and can offer a lot of support and comfort to us in our daily lives.

### **Who takes part?**

You and family members interested in taking part. In order to do this research one of you taking part must have fibromyalgia. The other members taking part must know of you/your family member's fibromyalgia. Participants must be at least 10 years old.

### **What does the research involve?**

This research involves an interview with you alone on:

- Who is important to you and why?

- People and places who can and can't help you in regards to you/your family member's fibromyalgia.
- What fibromyalgia means to you.

This interview gives the option to map out people and places that are supportive/unsupportive to you in relation to you/your family member's fibromyalgia.

### **Where will this take place?**

The place of interview will be negotiated between me (Catriona) and yourself. We can re-arrange interviews if you are busy.

### **How long will this take?**

This depends on you, and can be negotiated at the start of the research. The following times are *estimates only*.

1. Before doing interviews, we can meet to discuss the research. This could take approximately an hour.
2. Before conducting any interviews a meeting with the family to go over the information sheets and sign consent forms/ or provide audio consent in person is also required. We can discuss the location of the interviews and the times that suit us here. This will take approximately an hour.
3. The individual interview will last approximately an hour.

### **What if I do not want to take part?**

Taking part is voluntary. You do not have to take part if you do not want to. If you do not want to take part please let me know.

### **What if I consent but change my mind?**

You can leave at any point without explaining why.

You only need to inform me that you are leaving, and whether you would like any previous interviews/maps to be used within this study/published works.

If the person with fibromyalgia withdraws from the study then the research with all family members will stop. If this happens, you must inform me if I can use any information you have given me so far.

**What if I want to leave, what happens to my information?**

I will store your information (interviews, maps etc.) for 2 months after you inform me you wish to leave. This is in case you change your mind and wish to re-join the study. After two months your data will be destroyed, unless you have given consent for me to use it within the research and future publications, or want to continue taking part.

**Will my information be confidential?**

With your permission interviews will be audio recorded and notes will be taken. Only I will listen to them and read these notes. I will show you how to work the audio recorder so you may switch it off at any point if you do not want something to be recorded. In ordinary circumstances I won't discuss your interviews or maps with your family members, even if you have spoken about it amongst yourselves.

In rare cases your information will not be confidential as if you tell me you are likely to be harmed/are engaging in illegal activities I will have to report this. I will always tell you if I need to tell someone of something you have said/done, and why, and if you have a preferred person to tell.

If you want to be interviewed in a semi-public place – like a café – it may be overheard. Please bear this in mind when choosing where you would like to be interviewed.

**Will my information be anonymous?**

I will never tell anyone your name, or where you live. This is to protect you and your information. However there is a risk that people who know you well may be able to recognise you despite anonymising your name and location.

**What will happen to the results of this study?**

The results will be published in journal articles, presentations, and book chapters. You will also be given a summary sheet of the findings when the research is finished.

**Will taking part benefit me/my family?**

While taking part may not benefit you directly, I hope that the information you say may help to improve the awareness and support available to families with fibromyalgia, and so improve the lives of families with fibromyalgia. It is hoped that the findings of this project will improve services and support available to people with fibromyalgia and their families. Understanding your experiences of this illness is the only way to change what is currently offered.

Your access to support groups/services will not be affected by participating in the research. These groups/services will not know you have chosen to take part.

### **Are there risks to taking part?**

This research may cover sensitive topics – such as illness - that could upset you. If you become upset the interview can stop and you can leave the research, or begin the interview at another time.

### **What happens if I/my family want to take part?**

If you haven't already, please give my contact details to your family members so that they can express an interest in taking part. Once everyone who is interested has contacted me, we can arrange a time to meet.

### **What happens if a family member does not want to take part?**

You do not need your whole family to participate to take part yourself. However, your family member with fibromyalgia must also consent to take part in the research for the research to take place.

### **Who can I speak to if I want to take part?**

You can contact me (Catriona) through:

Email:

Phone:

Mail:

### **Who can I speak to if I have a complaint/worry about the research, and do not want to tell the researcher?**

If you would like to speak to someone who is not the researcher, you can contact: Professor Kirstein Rummery.

Email:

Phone:

Mail:





## **Information Sheet**

### **Information Sheet: Families, Relationships, and Fibromyalgia**

Hello, my name is Catriona, and I am a PhD researcher at the University of Stirling. I am looking at relationships in families where a family member has fibromyalgia. My project is funded by the Economic and Social Research Council (ESRC).

#### **The Study**

I am interested in family members' relationships and lives where one member has fibromyalgia. I want to know how family members interact around each other. What makes you able/unable to confide in someone (this could be neighbours, friends, classmates) about a family member's fibromyalgia? What makes someone supportive/unsupportive of a family member's fibromyalgia? I want to know the places you find supportive/unsupportive of a family member's fibromyalgia. I also want to know whether you think your family member's illness impacts your life.

#### **Why am I doing this?**

I am interested in finding out what relationships are like inside and outside of the family when a member has fibromyalgia. This is because relationships are important and can offer a lot of support and comfort to us and those we care about. They are a big part of our daily lives and can be an influence on what we do or how we feel no matter where we are.

#### **Who takes part?**

You and any of your family members that are interested in taking part. In order to do this research someone taking part must have fibromyalgia (such as a parent/guardian). The other members taking part must know of your family member's fibromyalgia.

As a person under 16, your parent/guardian must give their permission to your taking part before you are able to do so. You must also be 10 years old or older to take part.

## **What does the research involve?**

This research involves an interview with you alone on:

- Your daily life.
- Who is important to you and why?
- People who can and can't help you in regards to your family member's fibromyalgia.
- What fibromyalgia means to you.

This interview allows you to draw – like a spider diagram - people and places that are supportive/unsupportive to you in relation to you/your family member's fibromyalgia.

## **Where will this take place?**

The place of interview will be agreed with me (Catriona), yourself, and your parent/guardian. These can be re-arranged/cancelled if your plans change.

## **How long will this take?**

This depends on how much we talk about, and can be agreed at the start of the research. The following times are *estimates only*.

- 1) Before doing interviews, we can meet to discuss the research. This could take approximately an hour.
- 2) Before the interviews a meeting with your family to go over the information sheets and give me your permission is needed. We (myself, you and your parent/guardian) can agree where the interview takes place and the times that suit us. This will take about an hour.
- 3) The interview with you will last about an hour.

## **What if I do not want to take part?**

Taking part is your choice. You do not have to take part if you do not want to. If you do not want to take part please let me know. You can choose to stop taking part at any time without penalty.



### **What if I give my permission but change my mind?**

You do not have to give me a reason for leaving. You only need to tell me that you are leaving. If you decide to stop taking part, we can discuss what to do with your interview/maps.

If the person with fibromyalgia leaves the research then the research with all family members will stop. If this happens, you must tell me if I can use any information you have given me so far.

### **What if I want to leave, what happens to my information?**

I will keep your information (interviews, maps etc.) for 2 months after you tell me you want to leave. This is in case you change your mind and want to come back to the study. After two months your data will be destroyed unless you have given me permission to use it within the research and future publications, or want to continue taking part.

### **Will anyone know about what I have told you?**

With you and your parent/guardian's permission interviews will be recorded and notes will be taken. Only I will listen to them and read these notes. I will show you how to work the audio recorder so you may switch it off at any point if you do not want something to be recorded. In ordinary circumstances I won't discuss your interviews or maps with your family members, even if you have spoken about it amongst yourselves.

In rare cases, you may say something that makes me concerned for the safety of you or someone else. For instance, you may tell me you are likely to be harmed/are breaking the law. I may have to report anything that is said that causes me concern. I will always tell you first if I need to tell someone of something you have said/done, and why, and ask if there is someone you would prefer I talk to.

### **Will my information be anonymous (will anyone know my name)?**

I will never tell anyone your name, or where you live. This is to protect you and your information. However there is a risk that people who know you well may be able to recognise you despite anonymising your name and location.

### **What will happen to the results of this study?**

The results will be published in journal articles, presentations, and book chapters. You will also be given a summary sheet of the findings when the research is finished.

### **Will taking part benefit (be good for) me/my family?**

While taking part may not benefit you directly, I hope that the information you say may help to improve the awareness and support available to families with fibromyalgia, and so improve the lives of families with fibromyalgia. It is hoped that the findings of this project will improve services and support available to people with fibromyalgia and their families. Understanding your experiences of this illness is the only way to change what is currently offered.

Your access to support groups/services will not be affected by participating in the research. These groups/services will not know you have chosen to take part.

### **Are there risks to taking part?**

This research may cover sensitive topics – such as illness - that could upset you. If you become upset the interview can stop and you can leave the research, or begin the interview at another time.

### **What happens if I/my family want to take part?**

If you haven't already, please give my contact details to your family members so that they can tell me they are interested in taking part. Once everyone who is interested has told me they are interested, we can arrange a time to meet.

### **What happens if a family member does not want to take part?**

You do not need your whole family to participate to take part yourself. However, your family member with fibromyalgia must also give their permission and take part to allow the research to take place.

### **Who can I speak to if I want to take part?**

You can contact me (Catriona) through:

Email:

Phone:

Mail:

### **Who can I speak to if I have a complaint/worry?**

If you would like to speak to someone who is not the researcher, you can contact: Professor Kirstein Rummery.

Email:

Phone:

Mail:



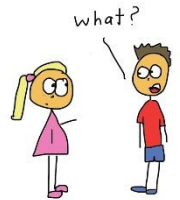


Hello my name is Catriona, I am a researcher at the University of Stirling.

I would like to ask you about your family, friends, your day to day life, and what happens when a family member you know is unwell with fibromyalgia. It involves one step.

**Step 1:**

If you want, we can talk about your family, the people who are important to you, your day to day life, your favourite places, and your family member's illness.



**What will I do?**

I would like to record and write notes about what you have said. We can discuss this, and this will not happen if you are not okay with it.



**Will my parents know what I have said/written?**

No, I will only tell someone what we have talked about if I am worried you might be hurt. But, I will always tell you this before I tell other people.



**Where will this happen?**

I will sit down with you and your mum, dad, or guardian and we will talk about where you want to have these conversations.

### **Do I have to take part?**

You do not have to take part. The choice is yours. No one should tell you that you must take part.



### **What do I need to remember for now?**

You do not have to take part.

You can change your mind, and ask your parents or me about this.

### **What do I do next?**

If you do want to take part, please tell one of your parents or me (Catriona).

If you do not want to take part, please tell one of your parents or me (Catriona).



To take part, your family member who is unwell must also agree to the take part.

### **Who can I speak to if I want to take part?**

You can speak to me (Catriona) through:

Email:

Phone:

Mail:

### **I have a worry/am upset about the research, and do not want to tell Catriona?**

If you are worried/upset about anything written here and don't want to speak to Catriona, you can speak to Professor Kirstein Rummery:

Email:

Phone:

Mail:







## **Families, Relationships and Fibromyalgia**

### **Over 16s Consent Forum**

I \_\_\_\_\_ agree to take part in this research study which is exploring the relationships of families where a member has fibromyalgia.

I have read and understood the information sheet given to me by Catriona. I have been able to ask Catriona questions about the research, and she has answered them.

I understand that:

- I understand what this research is about. If I have any more questions about the research I can speak to Catriona.
- If Catriona is worried that I am likely to be harmed or if I am engaging in illegal activities, she may have to tell the relevant authorities. I understand that she will not do this without telling me first, and she will ask me if I have a preferred person to tell.
- With my agreement, Catriona will record my interviews and take notes. I understand that Catriona will not write down, or record, anything I do not want to be written/recorded.

- I consent to any maps/drawings of people or places I draw within the research to be used within future publications by Catriona. I understand that Catriona will anonymise the maps of people or places I draw to the best of her ability, and will ask me beforehand if I am comfortable with her using them in publications. I understand that I can withdraw this consent at any point by contacting Catriona.
- I understand that I legally own any drawings I do in this research, however Catriona needs to hold the copyright of these so that she can use them. I understand that I can withdraw this consent at any point by speaking to Catriona.
- My participation in this study is voluntary and I can leave at any point.
- I do not have to take part because my family is taking part.
- If I do not want to answer a question, I do not have to.
- Catriona will give me an alias and anonymise identifying information about myself to the best of her ability
- My information (interviews and written accounts) will be used by Catriona in her PhD thesis, and may be used in future publications, and presentations, and I agree to this. I understand that I can withdraw this consent at any point by contacting Catriona.
- If there is information I do not want used or published, I will let Catriona know and we can discuss this.
- I can ask for my information (interviews, written account etc.) to be destroyed or returned to me. I can keep them and ask for them not to be used in the research.
- Catriona is storing my information on a password protected computer and hard drive, and in a locked drawer in her office at the University of Stirling
- If I have any worries about this research I can speak to Catriona.

**Signed:** \_\_\_\_\_

**Date:**

\_\_\_\_\_

If you have questions about the research, or would prefer to give audio consent, please contact me in person, or by:

**Email:**                      **Tel:**

Mail:

If you want to speak to someone else about the research, you can contact Kirstein Rummery:

**Email:**                      **Tel:**

Mail:





## **Families, Relationships, and Fibromyalgia**

### **Under 16s Consent Form:**

I \_\_\_\_\_ agree to take part in this research study which is exploring the relationships of families where a member has fibromyalgia.

I have read and understood the information sheet given to me by Catriona. I have been able to ask Catriona questions about the research, and she has answered them.

I understand that:

- I understand what this research is about. If I have any more questions about the research I can speak to Catriona.
- If Catriona is worried that I am likely to be hurt or if I am breaking the law, she may have to tell my parent/guardian and/or the relevant authorities. I understand that she will not do this without telling me first, and she will ask me if I have a preferred person to tell.

- With my agreement, Catriona will record my interviews and take notes. I understand that Catriona will not write down, or record, anything I do not want to be written/recorded.
- I understand that any drawings of people or places I do in this research could be used in future publications by Catriona. I understand that Catriona will anonymise the drawings of people or places I draw to the best of her ability to protect my information and privacy, and she will ask me beforehand if I am comfortable with her using them in publications. I understand that I can withdraw my permission whenever I want if I am not comfortable with this.
- I understand that I legally own the drawings, however Catriona needs to hold the copyright of these so that she can use them. I understand that I can withdraw this permission at any point by speaking to Catriona.
- My participation in this study is voluntary and I can leave at any point.
- I do not have to take part because my family is taking part.
- If I do not want to answer a question, I do not have to.
- Catriona wants to give me a false name to protect me and my privacy to the best of her ability. I agree to this.
- My information (interviews and written piece) will be used by Catriona in her PhD thesis, and may be used in future publications, and presentations, and I agree to this. I understand that I can withdraw this permission at any point by speaking to Catriona.
- If there is information I do not want used or published, I will let Catriona know and we can discuss this.
- I can ask for my information (interview, written piece etc.) to be destroyed or returned to me. I can keep them and ask for them not to be used in the research.
- Catriona is storing my information on a password protected computer and hard drive, and in a locked drawer in her office at the University of Stirling

If I have any worries about this research I can speak to Catriona.

**Signed:**

**Date:**

**FOR THE PARENT/GUARDIAN**

My child and I \_\_\_\_\_ have understood the terms above,  
and I agree for my child to take part in the research.

**Signed:**

**Date:**

If you have questions about the research, or would prefer to give audio  
consent, please contact me in person, or by:

**Email:**

**Tel:**

Mail:

If you want to speak to someone else about the research, you can contact  
Kirstein Rummery:

**Email:**

**Tel:**

Mail:





**Families, Relationships, and Fibromyalgia – Harm Protocol**

This study is looking at family relationships of families where a member has fibromyalgia. It is looking at what people and places are supportive/unsupportive to families. It is looking at whether fibromyalgia impacts the lives of families.

Those recruited will be 10 years old and over. Participants will be informed of the research from the information sheet. Participants will be re-assured that their information is confidential and will be anonymised to the best of the researcher's ability.

Participants' disclosure of abuse or the threat of immediate and serious harm to themselves or others is not expected, however in the case that it arises the following protocol has been established to guide the researcher on how to proceed during recruitment, data collection, and any subsequent meetings with participants.

- 1) When gaining the consent of participants, the research has a duty to ensure they understand what is involved in the project, and that they are not being coerced by another person.
- 2) She will tell them during the consent form signing that any disclosure of abuse/immediate serious harm may result in confidentiality being broken for her to alert the relevant authorities. However, she will always discuss this with them, and ask what their favoured option is for dealing with the risk of abuse/serious immediate harm. She will speak to her supervisors if it is appropriate, and inform the participant of her decision to do so. If appropriate, the researcher will provide a list of support services to the participant. The same process applies to under 16s, except, where appropriate, their parents may also be informed.
- 3) Unless abuse or immediate serious harm to themselves or another is disclosed within an interview or diary, the participants' information will remain as confidential and anonymous to the best of the researcher's abilities.
- 4) If past abuse (either victim or perpetrator) to a participant or someone they know is disclosed within the interview, the researcher will provide a list of places the person can contact for support if it is appropriate.

- 5) A participant may not view their experiences as abuse or that they may be at risk to immediate, serious harm. It is not the researchers' job to define these experiences, and if appropriate she can provide a list of support organisations. However, if an immediate, and serious risk of harm is found the procedure in 2) will be followed.
- 6) It is the choice of the participant to engage with support services in the case of abuse, the researcher has done her duty of providing information of such support.
- 7) Participants can leave the research at any point. Likewise if the researcher feels unsafe/in danger in a research environment – for example someone's home – she can end the interview and leave.

9.12 Appendix 12: Support Services in Event of Participant Distress

**\*\*note this is an example copy and was not used within the research\*\***

<b>Place</b>	<b>Address</b>
<b>Samaritans</b>	<p><b>Address: XXXX</b></p> <p><b>Phone: XXXX</b></p> <p><b>Email: XXXX</b></p>
<b>Breathing Space</b>	<p><b>Address: XXXX</b></p> <p><b>Phone: XXXX</b></p> <p><b>Email: XXXX</b></p>
<b>Fibromyalgia Support Group</b>	<p><b>Address: XXXX</b></p> <p><b>Phone: XXXX</b></p> <p><b>Email: XXXX</b></p>
<b>Carers Support Group</b>	<p><b>Address: XXXX</b></p> <p><b>Phone: XXXX</b></p>

	<b>Email: XXXX</b>
<b>Pain Association</b>	<b>Address: XXXX</b>  <b>Phone: XXXX</b>  <b>Email: XXXX</b>
<b>Women's Aid</b>	<b>Address: XXXX</b>  <b>Phone: XXXX</b>  <b>Email: XXXX</b>
<b>Abused Men in Scotland</b>	<b>Address: XXXX</b>  <b>Phone: XXXX</b>  <b>Email: XXXX</b>
<b>Childline</b>	<b>Phone: XXXX</b>
<b>NSPCC</b>	<b>Address: XXXX</b>

	<p><b>Phone: XXXX</b></p> <p><b>Email: XXXX</b></p>
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## 9.13 Appendix 13: Researcher Safety Procedure

### **Researcher Safety Procedure**

The researcher will inform her supervisors via e-mail/face to face when and where she is conducting research, and that she will check in with a fellow PhD student. If she is not in contact at her agreed upon time with a fellow PhD student, the student will contact her supervisors. In the event the researcher does not contact her designated colleague when field work is finished the following procedure will occur:

- 1) The colleague will try to contact the researcher
- 2) If the colleague cannot contact the researcher and the interview is occurring in a support group/place with a telephone (such as a café) the colleague will contact these places.
- 3) In the event the location has no knowledge of the participants' whereabouts, the colleague will contact the researcher's supervisors.
  - If it is out of hours the colleague will move to stage 4.
- 4) In the event the researcher's supervisors have no knowledge of her whereabouts, the colleague will get in touch with the pre-arranged and agreed emergency contacts.
- 5) If the emergency contacts do not know the researcher's location, the emergency services will be contacted.