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Portfolio Title Page:

The Construction of Pain: A Counselling Psychology perspective

Thesis title: How Do Patients with Fibromyalgia Talk about their Experience Of Fibromyalgia?

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Table of Contents

Acknowledgements	6
Declaration.....	7
Preface.....	8
Part A: Research Thesis	8
Part B: Publishable Paper	9
Part C: The Client Study/Process Report	9
The Link.....	10
Personal Reflection	13
References.....	14
Thesis.....	16
Thesis Abstract	16
Title: How Do Patients with Fibromyalgia Talk about their Experience Of Fibromyalgia?..	16
Chapter 1: Literature Review.....	17
Introduction	17
Genealogy	20
Genealogy of Fibromyalgia	20
Diagnostic Criteria	23
Characteristics of Patients with Fibromyalgia	29
Treatment for Fibromyalgia	29
Construction of Fibromyalgia.....	31
Medical Construction of Fibromyalgia	33
Psychological Construction of Fibromyalgia.....	42
Social Construction of Fibromyalgia	57
Introduction Summary	68
Chapter 2: Methodology	70
Chapter Overview	70
Research Question and Aims	70
Research Design.....	70
Theoretical Position of the Research.....	71
Social Constructionism	71
Critical Realist Approach.....	72
Summary of Epistemology and Ontology.....	73
Choosing a Methodological Approach to Research	74
Discourse Analysis	74
Foucauldian Discourse Analysis.....	74
Alternative Approaches to Research.....	76
Procedural Aspects	77
Recruitment and Sampling	77
Participants	77
Interview Setting	79
Semi-Structured Interviews vs Focus Groups.....	79

Semi-Structured Interviews	80
Interviews	81
Pilot Interview	82
Interview Schedule	83
Analytic Steps	84
Analytic Process	86
Validity and Reliability	89
Ethics.....	89
Reflexivity	90
Chapter 3: Analysis	94
Research Aim Reminder	94
Chapter Overview	94
Biomedical Discourse	96
Referral	98
Medical Professional's Opinions	100
Power Paradox.....	103
Power Transition.....	105
Diagnosis.....	107
Treatment.....	109
Overall Experience.....	112
Psychological Discourse.....	116
Symptom Experience.....	116
Treatment.....	118
Pain Clinics	125
Self-help	127
Social Discourse	129
Overall Experience.....	130
Social Life	133
Work	137
Support	139
Analysis Reflection.....	141
Positioning Theory.....	143
Chapter 4: Discussion.....	148
Chapter Overview	148
Summary of Discourses	149
Biomedical Discourse.....	149
Counselling Psychologist perspective.....	155
Psychological Discourse.....	158
Counselling Psychologist perspective.....	161
Social Discourse	164
Counselling Psychology perspective.....	167
Discourse Dynamics.....	169
Agency and Power	172
Research Evaluation.....	175
Applicability.....	177
Methodological Limitations and Further Research	178

Discussion and Analysis Reflexivity	179
Personal Reflexivity	181
References.....	183
Appendix A: Participant Recruitment Poster	210
Appendix B: Participant Information Sheet	211
Appendix C: Consent Form	216
Appendix D: Debrief Form	218
Appendix E: Interview schedule.....	219
Appendix F: Transcript with colour coded six-stage analysis (By Hand)	220
Appendix G: Transcript with colour coded six-stage analysis (By Adobe).....	221
Publishable Paper	222
<i>Title: How Do Patients with Fibromyalgia Talk about Fibromyalgia; A Discourse Analysis</i>	223
Abstract	223
Introduction	225
Genealogy of Fibromyalgia	225
Diagnostic Criteria	226
Doctor-Patient Relationship	228
Rationale for the Current Research.....	230
Method	231
Theoretical Stance	231
Methodological Procedure	231
Results.....	233
Biomedical Discourse.....	233
Medical Professional's Opinions	236
Power Transition.....	237
Diagnosis.....	239
Treatment.....	241
Overall Experience.....	243
Discussion.....	246
Implications.....	248
Limitations and Future Research	249
References.....	250
Appendix 1: Journal of Social Science & Medicine Author's Instructions	255
<i>Client Study/ Process Report</i>	225
<i>Title: Reaching Insight Through Empathy: A Person-Centred Case Study.</i>	225
Case Study.....	259
Introduction	259
Setting and Referral	259
Theoretical Framework	260

Assessment.....	262
Case Formulation	265
Development of Therapy.....	267
Supervision.....	269
Evaluation of Therapy	270
<i>Process Report.....</i>	273
Rationale for Work.....	273
Lead into Session	273
Transcript	274
Discussion.....	290
References.....	292

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Part B: Publishable paper.....	222-258
Part C: Case study.....	259-292

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Declaration

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Preface

This portfolio consists of three pieces of academic work: a research thesis, a publishable paper (based on the thesis), and a client study/process report. These three constituent parts of the portfolio will be given a brief overview, followed by a discussion of how they are linked in theory and in practice. This portfolio will also offer the reader evidence of the research and clinical practice skills I have developed over the course of my training as a Counselling Psychologist.

Part A: Research Thesis

The thesis constitutes a piece of original qualitative research concerned with how patients with Fibromyalgia talk about their experience of Fibromyalgia. Seven semi-structured interviews were conducted with Fibromyalgia patients. These interviews were analysed using Foucauldian Discourse Analysis (FDA) as a means to identify and highlight the discourses and consequences of their constructions. The analysis revealed that the participants constructed Fibromyalgia within three discourses; biomedical, psychological and social. Depending on whom the participants were referring to, they talked about Fibromyalgia within different contexts and sometimes similar positionings, practices and subjective experiences were made available to them.

A discussion grounded in the analytic findings and relevant literature is then presented, followed by an evaluation of the study. In addition, a Counselling Psychologist perspective is given as a guide to how in practice psychologists can be used to improve services for Fibromyalgia patients. Given the findings, I conclude how further research could be conducted to widen the knowledge of other researchers working with Fibromyalgia patients.

Part B: Publishable Paper

The journal to which I wish to submit my publishable paper is *Social Science and Medicine*.

The paper summarises most of what is described above, but rather than focus on each discursive theme, it focuses on the biomedical construction of Fibromyalgia. This is due to the dominance of the biomedical discourse in Fibromyalgia. When genealogy is understood in the Foucauldian sense (history of the present) seeks out the emergence of Fibromyalgia, it is talked about within a medical discourse with increasing literature regarding the aetiology including genetic, neurological, immunological and hormonal factors to name a few (Atzeni et al., 2019). Therefore, diagnosis is made by a medical professional and such clinicians are more likely to encounter patients with suspected Fibromyalgia first, in their clinical practice, before any other professionals. Therefore, these encounters and the language used in these interactions have an impact that needs to be brought to the attention of practitioners to possibly improve the doctor-patient relationship, as my research demonstrates.

I chose *Social Science and Medicine* journal as it publishes material relevant to any aspect of health concerned with mental health, health care, clinical practice, health policy and organisation. The concept of Fibromyalgia deals with these many aspects of health and I therefore feel that as a social scientist interested in health, illness, and health care professionals, my study would be a good fit for this journal.

Part C: The Client Study/Process Report

The client study is a piece of work that I undertook as part of my Counselling Psychology training. It describes the therapeutic process for an Asian man with whom I worked in Brief person-centred therapy. This piece of work highlights the challenges and successes of working

in a new modality and my journey with my client. It centres round the importance of empathy whilst discussing substance abuse, difficult emotions and lifestyle changes with the aim of co-creating change so that the client could live more authentically. The case study is a summary of our work together whilst the process report details a transcript of a session and what took place, with my thoughts on the process explained.

The Link

There are epistemological and ontological differences between the research thesis/publishable paper and the client study. Throughout my training I have come to understand that as a Counselling Psychologist I have been in the position of grappling with these tensions both as a researcher and a therapist. Developing a reflexive awareness of what it means to be a person, and how therapists understand their clients through the questions and responses attained in session, whereby the client is constructing a version of themselves, all depend on the epistemological and ontological assumptions of the model therapists work from (Willig, 2019). As a result, I must be mindful of the assumptions I make to construct my clients, their distress, and my position as a therapist which may impact how I relate to my clients.

My thesis is grounded within a social constructionist position whereby individuals socially construct their experiences of the world which is shaped by historical, cultural and social systems. Therefore, I argue that Fibromyalgia is socially negotiated through language by different discourses that inform practices. From this position, knowledge is restricted to what an individual can construct and limits what an individual can do within a particular context

(Willig, 2012). As a practitioner in my case study, I used a person-centred model which constructs the person as striving to be loved and valued with a need to self-actualise. From this perspective a client needs to be given the right conditions (core conditions) provided by the therapist which facilitate the expression of a client's true self with the aim of reducing the client's psychological distress (Willig, 2019). Thus, in my case study I change my position as a psychologist to view the person as an individual capable of changing the meaning they ascribe to their psychological distress rather than them being restricted to the discourses they draw upon in their talk about their emotional pain.

A Foucauldian Discourse Analysis was the chosen method for the research as it is not concerned with truth but with how individuals' subjective experiences become constructed through language and the effects that discourses have on an individual's subjectivity. Despite the lack of agency perceived in FDA, Oksala (2005) argued that participants are capable of self-reflexivity and critical reflection of their own positioning and thus are able to use their agency to negotiate satisfactory identities through language in order to act differently as a way to reinterpret their reality within the prevailing discourse. McNamee and Shawver (2004), noted that for therapy as a process of social construction language is the focus of concern which pays attention to the discourses clients use and how certain discourses constrain different forms of action which consequently lead to different realities. Thus, attention to language positions the therapist within a reflective relationship with their own actions as well as the actions of others. Hence, in therapy, therapists are not aiming to persuade a client to see their difficulties as they do from an expert position, but as a conversation whereby the focus is on dialogue and not on the client, their psyche, problems or relationships separated from the conversation that constructs them. Therefore, McNamee

and Shawver (2004), suggested that the discursive therapist can be positioned in an open manner to suit any method of therapy, through engaging in a relational process whereby reality, truth and values are co-constructed within the therapeutic space.

Hence, throughout the pieces of work presented in this portfolio, language was the focus of how individuals construct pain (the topic of conversation). Within a medical discourse chronic primary pain is defined as pain in one or more anatomical region that persisted for more than three months and is associated with significant emotional distress and/or functional disability, and where symptoms are not better accounted for by another diagnosis (WHO, 2020). From a postmodernist position, pain can be seen as a consequence of discourse, which suggests that pain as a sensation has no implicit meaning (Fox, 1993). Fox argues that discourses on health and illness within medical sciences, for example, provide the possibility that only once the concept of pain takes on a meaning can it contribute to subjectivity. Therefore, it could be argued that an individual does not experience pain or attribute meaning to it but instead the individual is an effect of a particular construction. In my research thesis, participants' construct Fibromyalgia mainly within a medical discourse as pain with other bodily symptom experiences, whilst my client from the client study talks about an emotional pain he experiences. From a critical realist position (the position of my research analysis), it could be argued that both types of pain (bodily and emotional) are experienced as real and both participants and client talked about pain as being associated with psychological distress and as impacting functioning. However, how these individuals make sense of their pain differs. Thus, the focus of the portfolio looks at how pain is constructed through the language used to talk about pain.

Personal Reflection

It may have been my experience working with clients with Functional Somatic Syndrome and long-term co-morbid mental and physical health issues that raised the question of understanding how a particular pain condition could be talked about by different people. As an Assistant Psychologist and before my work as a Trainee Psychologist, I worked in a clinic within a general hospital that provided psychological therapy for patients with functional symptoms. It was working here in this clinic that I became aware of the problems attached to the diagnostic label for those who had Fibromyalgia and the experiences of having a chronic pain condition that other people had difficulty understanding. As someone with a chronic pain condition myself, I found it perplexing that there was a group of people experiencing chronic pain and not being believed by those around them, and I tried to imagine what my life would be like if my chronic pain was not believed either. It was from this experience that I wanted to understand the topic of Fibromyalgia in depth. So, I began to research the topic and realised the controversy attached to the diagnostic label, due to the uncertainty of Fibromyalgia being a legitimate medical diagnosis for some medical professionals (Fitzcharles et al., 2013).

Furthermore, reflecting back on my clinical work as an assistant, I was hearing how differently Fibromyalgia was being talked about by different people; Consultants, Trainee Doctors, Psychiatrists, patients and patients' family members, and I noticed the power struggles within the doctor-patient relationship. As I began my doctoral training, I began to recognise that there was a role for psychologists within the doctor-patient relationship that could be utilised and I began to wonder how psychologists could help more with this client group. It was pondering such issues that led me to my research question, which permitted me to

investigate the topic in depth from the perspective of patients. I feel very passionate about making a difference to Pain Management Services (which Counselling Psychologists who work with this client group mainly work within) to help this clinical group through contributing to evidence-based research to support action for change.

In terms of my academic learning, throughout my training, the importance of language has increasingly become apparent to me. For example, when writing my case study, I noticed how cautious I had to be in expressing my ideas, in the wording used to talk about my client and in the theories to support my practice. A misplaced word or phrase could change the meaning of the entire sentence or paragraph, leading my reasoning to become invalid and possibly leaving me vulnerable to being misunderstood despite my best intentions. For me, this experience opened my eyes to the power of language in text and made me aware in my everyday life of how language is used and the impact words have. To this day, I am becoming increasingly aware of the impact of language and the implications this has for action and subjectivity.

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Thesis

Thesis Abstract

Title: How Do Patients with Fibromyalgia Talk about their Experience Of Fibromyalgia?

Objective: Fibromyalgia is classified as diffuse pain in 4 of 5 bodily regions associated with emotional distress or functional disability (WHO, 2020). The diagnosis can be problematized as the syndrome has an unknown aetiology due to its associated with multiple factors and no diagnostic testing. The purpose of this research was to uncover the ways in which patients diagnosed with Fibromyalgia talked about their experience of Fibromyalgia.

Design: A discourse analytic methodology was used to identify how patients who have the diagnosis in the UK construct their experience of Fibromyalgia and explored what subject positions, practices and possibilities for subjective experience are made available to them.

Method: Participants were recruited through social media using the snowballing method. Semi-structured interviews lasted one-hour (approx.) and the data was analysed using Foucauldian Discourse Analysis.

Results: Seven female participants aged between 25 and 57 identified three discourses which contributed to constructing Fibromyalgia within a biomedical, psychological and social discourse. Participants took up a medical discourse to construct themselves as an ill patient and were made to feel dismissed by their doctors who did not view them as having a medical condition which possibly left them feeling like an ill person stuck in a never-ending struggle for social recognition from others that they are ill. Drawing on a psychological discourse the participants seemed to have empowered themselves by taking up an active role in their treatment by focusing on self-management techniques to managing their symptom experiences.

Conclusion: In occupying different discourses, the participants found empowerment through being pro-active individuals which allowed them to gain access to further testing, the ability to self-manage their symptom experiences and preserve their sense of self from the negative opinions of those around them.

Chapter 1: Literature Review

Introduction

If you do a quick Google search on Fibromyalgia you will see many definitions referring to it as a medical condition characterised by widespread pain and accompanied by a variety of other symptom experiences. Yet, what you will not see at first glance is the confusion surrounding this diagnostic label, the controversies and the different ways in which the symptom experiences can be explained. With a little further investigation by looking into the sub-sections of these Google searches on the causes of Fibromyalgia a list of possible factors emerges and these sites suggest that the cause of the 'condition' is a combination of factors.

When genealogy (history of the present) seeks out the emergence of Fibromyalgia, it is talked about within a medical discourse as a diagnosis given to patients by experts on the syndrome. Diagnosis of a condition is typically based on patient history, a physical examination, and an exclusion of other illnesses (Pearce, 2011). But due to the unknown aetiology, comorbidity of symptoms, and connection with psychological factors, some researchers and doctors see the diagnosis, treatment and management of Fibromyalgia as complex, controversial and problematic (Kwiatkowska, 2018). The usefulness of the diagnosis is questioned by some medical professionals who argue that Fibromyalgia is not a valid diagnostic label due to the syndrome not being diagnosable through laboratory testing (Ehrlich, 2003). Thus, some doctors consider Fibromyalgia to be a 'fashionable' condition subject to over-diagnosis (Fitzcharles & Boulos, 2003). Yet, from a patient perspective, the diagnostic journey is long and marked by uncertainty with most patients typically having symptoms for an average of six years before the diagnosis is made (Rodham, Rance, & Blake, 2010). Some patients thus

respond with hostility to the proposed psychological aetiology of Fibromyalgia (Hadler, 1997). The confusion surrounding Fibromyalgia and its diagnostic label and the different ways it can be constructed will therefore form the backdrop for my literature review.

This literature review will examine how Fibromyalgia is constructed in expert texts and in the discourses used to talk about it. To aid the structure of this review, I began my research by inputting key words 'Fibromyalgia', 'history of Fibromyalgia', 'classification of Fibromyalgia', 'patient experiences of Fibromyalgia', 'treatment for Fibromyalgia' into search engines such as Google Scholar and City Library. To help assess the appropriateness of the studies available, the abstracts of the research papers were read to ascertain the different ways in which Fibromyalgia has been constructed in expert texts from its earliest conception to the present day. Once a paper was selected, the reference lists led me to other relevant articles to support the review. As Fibromyalgia was first talked about within a medical discourse, the first part of the literature review details how Fibromyalgia came into being in the 1970s as muscle pain and gained recognition by researchers who changed the diagnostic criteria over time (from the 1970s to the present day). This study was conducted between 2018 and 2021, therefore, 'present day' includes research papers published up until 2021. Next, to set out the different issues for consideration and implications for what can be done within this particular discourse, research papers also discussed the doctor-patient relationship, the effects of the power dynamics within this relationship, and the economic cost of having Fibromyalgia this will also be outlined. This information was used to highlight the consequences attached to the medical discourse in expert texts.

Fibromyalgia evolved from a solely medical discourse to include psychological and social factors, and these factors (from their experts' perspectives and institutions) form the other subheadings of this literature review. Within a psychological discourse Fibromyalgia can be constructed as Chronic Widespread Pain with the predisposition to trauma and maladaptive emotional regulation. Key words such as 'IASP concept of pain' and 'classification of chronic pain' led to an exploration of the evolution of the concept of pain from a multidimensional perspective. These papers as well as the expert texts that contained information regarding the treatment of Fibromyalgia and patient experiences also included a description of how psychologists conceptualise pain and Fibromyalgia, and the different therapeutic approaches used to manage pain. The practical application of some of these approaches is then discussed. Following this, an outline of the therapist-client relationship will then be reviewed. Lastly, I will examine how illness is socially constructed and how this impacts how Fibromyalgia is spoken about through a social discourse. Topics discussed in literature discovered in patient experiences of Fibromyalgia conceive of the syndrome in terms of a hidden illness, with social and medical doubts leading to negative effects and stigmatisation and the need for social acceptance. These have then been summarised.

Overall, this literature review aimed to explore how Fibromyalgia is talked about within expert texts and the consequences attached to its definitions. In doing so, this review aimed to map out the construction of Fibromyalgia from its earliest reference to the present. In addition to highlighting the relevance of such a study to the discipline of Counselling Psychology, gaps in the literature will be exposed in order to formulate the research question that will address the purpose of the study.

Genealogy

The Foucauldian concept of genealogy is concerned with revealing the procedures, practices and institutions involved in the production of discourse and knowledge and their power effects (Carabine, 2001). Thus, genealogy is concerned with writing a history of the present to find out how a particular present and its effects came to be (Foucault, 1967). Discourse can be considered as a system of knowledge, truth and power which constructs objects and subject positions (Willig, 2013). Through constructing a phenomenon in terms of how it is produced through ways of speaking, thinking and writing over time (Foucault, 1967) discourse can construct realities such as 'illness' and subjects such as 'patients' into being (Willig, 2013). This thesis will not present a full genealogy of Fibromyalgia as tracing the full history of the construct is beyond the scope of this thesis, however, I will be looking at how Fibromyalgia is currently constructed in society in general and by experts in particular.

Genealogy of Fibromyalgia

To understand the genealogy of Fibromyalgia, one must examine the history of how it came into being. This requires an examination of the medical research that took place to define and redefine the diagnostic criteria used by medical professionals to diagnose their patients. Looking at European literature dating back to the 16th century, descriptions of musculoskeletal aches and pains have been noted (Inanici & Yunus, 2004). In 1592, French physician Guillaume de Baillou first introduced the term 'rheumatism' to describe clinical presentations of muscular pain and acute rheumatic fever (Ruhman, 1940). By the 1800s literature on muscular rheumatism was being published around Europe, including in Britain where one surgeon, William Balfour, in 1815 used the expression 'tender points' to refer to inflammation in muscle connective tissue which caused pain (Balfour, 1815). This concept of

tender points, which referred to painful regions in various parts of the body, was used for many years amongst physicians (Valleix, 1841). Gowers (1904) was a British neurologist who introduced in an article the term 'fibrositis' to describe spontaneous pain and sensitivity to; compression, sleep disturbances, fatigue and the aggravation of symptoms due to exposure to acute and chronic cold and muscular overstrain. He suggested manipulation as treatment, which today could be considered as physiotherapy, and cocaine injections, which might today be considered as pharmacological therapy. Gower's theory was supported by pathological research provided by Stockman (1904) and thus the term 'fibrositis' was used for the next 72 years. However, due to a lack of laboratory tests and an uncertainty around the physical signs, the recognition of fibrositis in the wider world was hindered (Inanici & Yunus, 2004).

Around the 1950s more research was being conducted in the US and Canada that led to the recognition of regional fibrositis, now termed Myofascial Pain Syndrome, and generalised fibrositis now known as Fibromyalgia (Slocumb, 1940). At the time, Slocumb referred to fibrositis as the most common form of acute and chronic rheumatism. However, Kelly (1941) proposed a theory to explain the nature of tender points which caused referred pain, and this may have been the first mention of the Central Nervous System (CNS) being involved in muscle pain. Kelly's theory took an organic approach to the diagnosis. However, during and after the Second World War, the occurrence of fibrositis among soldiers increased, leading to greater attention from researchers (Hench & Boland, 1946). Boland and Corr (1943) used the term 'psychogenic rheumatism' to describe symptoms that included the absence of inflammation in the muscles or joints, pain and the association with depression and stress. However, Halliday (1937) suggested that the term fibrositis should be replaced by the term 'syndrome' to describe pain and stiffness experienced as muscular rheumatism as this term

was similar to the manifestation of chronic psychoneurotic states. Thus, the process of combining the mind and body instead of keeping them separate in the aetiology of a diagnosis began. To this day the debate around the syndrome being organic versus psychological still continues.

In the late 1970s Smythe and Moldofsky (1977) proposed the concept of Fibromyalgia and a working set of criteria for the diagnosis. The term Fibromyalgia is comprised of *fibro* meaning 'fibrous tissues' from New Latin, and the Greek words *myo* 'muscle' and *algos* 'pain'. This which literally translates to 'painful muscle and fibrous connective tissue' (Anwar & Fahim, 2013). Hence, Fibromyalgia is described as a condition characterised by painful tender points located around the body. Smythe and Moldofsky (1977) provided the first qualitative measure for Fibromyalgia and identified the characteristics of the syndrome as non-refreshing sleep, tender points and widespread aches of more than three months' duration. Tender points required patients to have 12 of 14 pre-specified points in their body that were pressure sensitive. In practice, however, this high measure of tender sensitivity was uncommon. Wolfe et al. (1985) stated that different clinicians were at the time using different amounts of physical force in the examination, which highlighted that the originally proposed number was too high. This led to different clinicians reducing the number of tender points by up to 50%, thus amending the criteria.

Yunus et al.'s, (1981) study using this clinical population introduced a new formal set of diagnostic criteria with pain, stiffness or aching in three anatomical areas for at least three months, with the addition of at least five tender points. Yunus et al.'s study outlined that patients would also have three of the following previously undescribed symptoms: anxiety,

stress, fatigue, Irritable Bowel Syndrome (IBS), subjective swelling, numbness or chronic headaches. This study also showed Fibromyalgia to clinically overlap with several other conditions therefore, the new criteria focused more on symptoms associated with psychiatric illnesses than a reduced pain threshold. Thus, Fibromyalgia began to be constructed in terms of both a psychological and a biomedical condition, with the terms Psychosomatic, Somatic Symptoms or Functional Somatic Syndrome implying the psychological/psychiatric mechanisms (Yunus et al., 1981). Subsequently, Hudson and Pope (1989) published a paper suggesting an overlap between medical-psychiatric conditions in which Fibromyalgia related conditions such as IBS and Chronic Fatigue Syndrome (CFS), and several psychiatric disorders such as depression, panic disorder and obsessive compulsive disorder, are inter-connected. Therefore, it could be argued that the biomedical discourse used to construct Fibromyalgia began to incorporate a psychological discourse in the early 1980s by inferring that psychological factors such as anxiety, depression and stress contributed to the symptom experience for those with Fibromyalgia.

Diagnostic Criteria

Towards the end of the 1980s, there were many different diagnostic criteria for Fibromyalgia in both research and clinical settings, as most cases did not align with standardised diagnostic criteria, leading to a reduced validity and reliability of the diagnosis (Inanici & Yunus, 2004). As a result, Wolfe et al. (1990) published the American College of Rheumatology (ACR) classification criteria for Fibromyalgia following a meta-analysis of these independent criteria available. They classified Fibromyalgia as a reduced pain threshold for at least three months, which established the concept of Chronic Widespread Pain (CWP) and the presence of 11 or more tender points. This meta-analysis has been described as significant because the ACR brought about the first official recognition of Fibromyalgia. The legitimised syndrome resulted

in an upsurge in patient support groups and an increase in scientific studies into the mechanism of Fibromyalgia, leading to improved treatment strategies and convincing sceptical doctors who did not believe Fibromyalgia existed due to the unknown aetiology (McBeth & Mulvey, 2012).

Although the ACR produced homogenised classification criteria for Fibromyalgia, criticisms were raised. Berenguer et al. (2009) conducted a systematic review of the literature about the classification of Fibromyalgia, which revealed that the 1990 ACR criteria were flawed in differentiating CWP and Fibromyalgia. Their systematic review claimed that the way in which patients expressed their pain made it difficult for clinicians to discriminate the type of pain experienced and thus diagnose the underlying disease. Therefore, the use of tender points was the only way to differentiate between the two disorders. Despite this, research found the use of tender points was too subjective as a criterion and thus created a great degree of variation between doctors due to the way it could be interpreted (Wolfe & Michaud, 2009).

To address the critics, Wolfe et al. (2010) updated the ACR criteria to eliminate the tender point exam and instead developed the Polysymptomatic Distress Scale. This severity scale included the Widespread Pain Index, which was used to differentiate Fibromyalgia patients from those with other disorders, and the Symptom Severity Score as a measure of cognitive symptoms, sleep, fatigue and other somatic symptoms. Despite the measures being used in a clinical setting, there were still a possible 41 somatic symptoms listed which did not help clinicians differentiate between mild to severe symptoms, and this possibly led to ambiguity into the clinical diagnosis (Wolfe et al., 2011). As a result, clinicians produced self-reported questionnaires for their patients to use as a subjective examination to guide them.

Consequently, a modified version of the 2010 criteria eliminated doctors' subjective estimates of the patients reports of the extent of their somatic symptoms and replaced the 41 symptoms with just three specific self-reported symptoms. This made it easier for clinicians to use the tool in clinical practice and allowed for a large-scale epidemiological investigation into the prevalence of Fibromyalgia (Toda, 2011).

However, the changes instigated by the ACR were met by more criticism from researchers and doctors who did not support Fibromyalgia being a distinct entity. These critics debated that Fibromyalgia should be considered as part of the CWP continuum instead of being its own disorder. Henningsen, Zipfel and Herzog (2007), claimed that there is an overlap in the diagnostic criteria between Fibromyalgia, IBS, chronic headaches and chronic fatigue. They proposed the term Functional Somatic Syndrome (FSS) to define these patterns of persistent bodily complaints with no sufficient explanation of an organic pathology. They stated that these symptoms are part of one single syndrome and therefore should not be treated separately. This perspective was supported by epidemiological and clinical studies such as Aggarwal et al. (2005) who revealed that 50% of the Fibromyalgia clinical population report an overlap of FSS symptoms. Fitzcharles et al. (2013) argued that numerous authors shared their view that Fibromyalgia was not a single diagnostic disease criterion but rather part of a syndrome due to the identified commonalities in symptomology. Hence, Fibromyalgia should not be referred to as a disease but rather a syndrome (Fitzcharles et al., 2013). As a result, Turk (2005) argued that clinicians should take a lumping rather than splitting view when diagnosing this heterogeneous group of patients, which would allow for a more individualised approach to treatment according to the specific characteristics of each patient. Accordingly, with the change in the understanding of Fibromyalgia, the ACR classification was further

developed in 2016 in order to focus on widespread pain rather than regional pain whilst the other essential components remained (Littlejohn & Guymer, 2019). Moreover, FSS is also known as an umbrella term linked by different specialists to different names such as Medically Unexplained Symptoms (MUS), (Wessely, Nimnuan & Sharpe, 1999), which suggests that the language used to describe Fibromyalgia are interchangeable.

Although Fibromyalgia was recognised by the World Health Organisation in 1992 (WHO, 1992), it seemed that outside of the US, the guidelines set out by the ACR may not have been widely disseminated to other medical professionals who encountered Fibromyalgia syndrome in their everyday practice, which may have led to delays in diagnosis and treatment (Arnold, Clauw & McCarberg, 2011). Moreover, despite progress in understanding and treating Fibromyalgia, due to the lack of specific laboratory testing, biomarkers and similarities to other conditions, the diagnostic process can be considered complex by doctors as there is no clear organic pathology (Marchi et al., 2019). Consequently, in practice, it has been suggested that in practice most medical professionals take an individualised approach to the treatment of their patients, depending on their stance towards the diagnostic criteria and classification of Fibromyalgia as a medical or a psychological condition (Ehrlich, 2003). Moreover, for those sceptical doctors, it has been argued that the diagnosis could cause patients to search for medical help for a problem that does not exist and may medicalise a problem that is psychosocial in nature (Hadler & Greenhalgh, 2005).

On the other hand, although the ACR was originally developed for both classification and diagnostic purposes, for Fibromyalgia, under the DSM V (APA, 2015) and ICD-10 (WHO, 2016) Fibromyalgia was classified under Somatic Symptom Disorders and was characterised as

severe widespread pain, fatigue, cognitive disturbances, somatic symptoms, irritable bowel symptoms, anxiety and depressive symptoms. Symptoms typically include chronic musculoskeletal pain, tender point aches and stiffness in the absence of any joint inflammation or tissue damage (Mease, 2005). Thus, Fibromyalgia was seen as a syndrome with the absence of an organic pathology or a confirmatory diagnostic test and is associated with psychopathological issues and social consequences (Bellato et al., 2012). However, from this point of view, Fibromyalgia was considered as part of the CWP continuum and the concept of pain was considered to be associated with an underlying pathophysiological mechanism or, in other words, related to a physiological process associated with disease or injury which contributed to the pain problem (Schmidt-Wilcke & Diers, 2017). Furthermore, Nicholas et al. (2019) argued that terms such as 'functional' and 'somatoform' were vague and ambiguous ones which some took to mean 'all in the mind' or 'disorder of function'. This caused confusion between the physical versus psychological aspects of the syndrome and had implications for treatment.

To overcome the limitations of not having a clear definition associated with psychiatric disorders, the term Chronic Primary Pain (CPP) was developed by the International Association for the Study of Pain (IASP) taskforce to acknowledge the multiple interacting contributions to pain presentations underlined by advances in the understanding of pain from psychological, social and CNS mechanisms (Raja et al., 2020). To support the recent developments in conceptualisation of pain processing, the aetiology of Fibromyalgia has been related to the dysfunction of the central and autonomic nervous system, neurotransmitters, hormones, immune system, external factors and psychiatric factors to name a few (Bellato et al., 2012). This highlights that Fibromyalgia is still not fully understood and shows that many

aspects could be involved in its aetiology. For example, the CNS has been described as the main mechanism involved due to the increased response to stimuli mediated by CNS signalling (Yunus, 1992). Another mechanism said to be involved is the descending inhibitory pain pathway which has been shown to impair patients by exacerbating the central sensitisation (Staud & Smitherman, 2002). Various neurotransmitters have been reported to be involved in the central sensitisation, such as serotonin, which has been described as modulating pain and is also involved in the regulation of mood and sleep, and this may account for the association between Fibromyalgia, sleep and psychological disorders (Juhl, 1998). Moreover, family studies have suggested that genetic factors associated with neurotransmitters may be a predisposition to Fibromyalgia (Buskila et al., 1996). Furthermore, Fibromyalgia has been considered a stress related condition involving the Hypothalamic-Pituitary-Adrenal (HPA) axis (Crofford, 2002). Research has shown that in Fibromyalgia the sympathetic nervous system could possibly explain the symptoms of anxiety, stress, fatigue and bowel irritability (Stisi et al., 2008). In addition, in relation to the underlying neural mechanism three types of pain nociceptors, neuropathic, nociplastic have been suggested to occur at the same time and therefore pain management requires an individualised and multimodal treatment programme (Popkirov, et al., 2020). Not only has the aetiology of Fibromyalgia evolved as a result of medical researchers providing evidence to show how psychological and social factors can be associated with it, but also the conceptualised of pain from a biopsychosocial approach has had implications for practice due to these associated factors.

Characteristics of Patients with Fibromyalgia

The prevalence of Fibromyalgia has been suggested to be around 2% of the world's population (Fitzcharles et al., 2013), 5.4% in the UK (Fayaz et al., 2016) and in the general population between 0.5 and 5% with the prevalence predominantly diagnosed in late middle-aged women (Branco et al., 2010). Despite increasing literature and knowledge about Fibromyalgia the aetiology is still unclear and includes many factors such as genetic, neurological immunological, hormonal, psychological and environmental and overlaps with other conditions (Atzeni et al., 2019).

Treatment for Fibromyalgia

Fibromyalgia is considered a chronic and incurable condition; therefore, the focus of treatment is on alleviating pain, improving sleep and increasing physical activity to restore associated functioning (Brecher & Cymet, 2001). As Fibromyalgia is linked to pain, depression, environmental and genetic factors, the medical recommendation is a multimodal stepwise approach including pharmacological and non-pharmacological components (Hauser et al., 2009). Due to the severity of patients' illness, presence of comorbidities and functional disability, medication selection is individualised and requires frequent monitoring by their doctors (Skaer, 2014). Pharmacological treatments are targeted at improving sleep, reducing pain and include antidepressants which have been shown to be useful in treating some cases of MUS (Edwards et al., 2010). Antidepressants, muscle relaxants and some opioids have shown to have the best efficacy in treating Fibromyalgia (Smith & Barkin, 2010). However, due to the multiple symptoms involved in Fibromyalgia, patients have reportedly been taking multiple medications for their different symptoms, yet half of participants sampled in one study reported non-compliance (Sewitch et al., 2004). Moreover, a three-year prospective study with Fibromyalgia patients found that most patients preferred non-pharmacological

treatments (Pöyhiä, Da Costa, & Fitzcharles, 2001). Studies have shown that Fibromyalgia patients take a variety of medication including analgesic medication to relieve their pain but with limited therapeutic benefit (Hooten et al., 2007). However, Mease et al. (2009) pointed out that the efficacy of treatments cannot be evaluated comparatively due to Fibromyalgia not having a definitive definition for responses, which means that the inclusion criteria for assessments in studies are inconsistent as researchers have used different instrument domains to describe Fibromyalgia. As a result, only key domains were used to determine clinical improvements.

The European League Against Rheumatism (EULAR) revised their original approach which included a focus on medication in favour of a multidisciplinary approach with a non-pharmacological focus for clinicians (Macfarlane, 2017). Although pain is the dominant symptom in Fibromyalgia, other systems such as poor sleep, cognitive impairment and mood disturbances all have an influence on an individual's quality of life; therefore, the EULAR non-medical intervention also included rest, heat, exercise, and distraction techniques. Thus, the EULAR guidelines emphasised that treatment by Counselling Psychologists should be comprised of a multidisciplinary approach rooted in CBT, exercise and patient education. They recommend that patients who find medication ineffective should have an individualised holistic biopsychosocial treatment plan and those who still struggle to maintain progress should receive long-term self-managed coping skills guidance provided by a specialist referral to psychology, psychiatry or the pain clinic (Macfarlane, 2017). Similarly, NICE (2021) guidelines suggest that management of CPP should include non-pharmacological approaches (exercise programmes, psychological therapy ACT or CBT, acupuncture and electrical physical modalities, and TENS machines) and the consideration of pharmacological treatments.

Bernardy et al, (2010) argued that for an effective treatment of Fibromyalgia a multidisciplinary pain management approach rather than patients or clinicians seeking a cure is needed. Thus, treatment focuses on combining the medical, psychological and social aspects of the syndrome and finding ways to manage these factors.

Construction of Fibromyalgia

A review of the literature of meta-analysis studies, opinion pieces, medical texts and journals reveals that Fibromyalgia is constructed as a medical diagnosis characterised as severe widespread pain, fatigue, cognitive disturbances, somatic symptoms, irritable bowel symptoms, anxiety and depressive symptoms (Nimnuan, Hotopf, & Wessely, 2001). Symptoms typically include chronic musculoskeletal pain, tender point aches and stiffness in the absence of any joint inflammation or tissue damage (Mease, 2005). According to the ICD-11 Fibromyalgia is a form of CWP characterised by diffuse pain in 4 of 5 bodily regions associated with emotional distress or functional disability (WHO, 2020). Patients with Fibromyalgia are described by medical professionals as being heterogeneous but share some characteristics as this multifactorial syndrome contains physiological and psychological factors with symptoms which vary in severity and negatively impact a patient's quality of life (Wolfe et al., 1995).

Psychological studies have consistently shown Fibromyalgia to be associated with psychiatric symptoms such as depression, anxiety, obsessive compulsive disorder and post-traumatic stress disorder (Dell'Osso et al., 2011; Henningsen, Zimmermann, & Sattel 2003). The most common comorbidities are mood disorders which have the highest prevalence in

Fibromyalgia (Løge-Hagen et al., 2019). Recent studies have disputed the direction and nature of these associations (Van Houdenhove, 2003); however, some studies have suggested that psychological distress plays a causal role in the syndrome (Goldenberg & Sandhu, 2002). Several studies also highlight other vulnerabilities such as low self-esteem, neuroticism, victimisation, irritability and maladaptive responses to loss (Bucourt et al., 2017; Hassett et al., 2000). These studies suggest that Fibromyalgia may negatively affect mood and daily life, possibly leading to feelings of hopelessness, sadness, anger, anxiety and stress (Marchi et al., 2019). Not all Fibromyalgia patients report traumatic histories or psychiatric disorders, which suggests this factor may be a variable aetiology (Bennett, 1995). However, from a psychological perspective, emotional trauma is constructed as a possible predisposing factor in Fibromyalgia as depression has frequently been shown to be a comorbid factor (Aaron et al., 1997), with psychological stress reportedly influencing the expression of pain (Goldenberg, 1999).

According to a social constructionist approach, the way chronic illness is constructed not only affects the individual in question but also how they manage their relationships with others in their social circles and those who professionally treat them (Armentor, 2017). Qualitative studies have found Fibromyalgia to be associated with multiple symptom domains which negatively impact functioning and quality of life (Olle et al., 1999). These subjective experiences have consistently described pain, fatigue, depression, and cognitive disturbances ('brain fog') as the most common symptoms experienced that interfere with daily functioning. It has been suggested that these symptoms can interfere with work performance, interpersonal relationships, and could generate secondary reactions of anxiety and depression (White, Lemkau, & Clasen, 2001). Those diagnosed with Fibromyalgia have been

described as struggling with the meaning of their diagnostic label, and to have had issues with stigmatisation and experienced negative reactions towards their diagnosis due to the unknown aetiology of the syndrome (Armentor, 2017).

Medical Construction of Fibromyalgia

Doctor-Patient Relationship

People with Fibromyalgia typically present to their General Practitioners (GP) in primary care when they feel unwell and exhibit physical symptoms that upon investigation do not appear to have an organic pathology (Edwards et al., 2010). It has been reported that Fibromyalgia can be diagnosed without excluding visible diseases but for doctors' security and moral obligation to exclude all diseases before giving a diagnosis, examinations must be made and have shown negative investigation results and normal examination findings (Goldenburg, 1998). From this perspective, Sim and Madden (2008) debated that Fibromyalgia is a diagnosis of exclusion. For some medical specialists such as rheumatologists who diagnose and rehabilitate musculoskeletal diseases and autoimmune conditions, Fibromyalgia is understood to coexist with several other conditions such as inflammatory arthritis, generalised osteoarthritis, lupus erythematosus and hypothyroidism (Choy, 2015). Although a referral to a specialist is not always necessary for a diagnosis of Fibromyalgia, these can be used if GPs are uncertain of a patient's presentation (Ferrari & Russell, 2013). However, critics of Fibromyalgia being referred to as a diagnosis of exclusion argue that some patients may be at risk of over-treatment of one condition and under-treatment of another (Cohen, 2017). Cohen (2017) summarised that in practice, it can be challenging for both the consultant and patient to figure out which aspect of the patient's pain is due to which condition. She suggested that the main challenge for consultants in treating Fibromyalgia is to avoid over-

investigation and multiple referrals, which in turn could reinforce health anxiety and potential iatrogenic harm in patients. Therefore, a balance between appropriate investigations and referrals should be maintained. This might be difficult for clinicians who report having demanding patients.

When Fibromyalgia is referred in the context of the absence of an organic pathology, in other words, as somatic or unexplained pain, such labels bring the legitimacy of patients' symptoms as a medical issue into question and they are then typically regarded by medical professionals as psychological or emotional problems (White & Moorey, 1997). Although, primary care physicians (GPs) and secondary care specialist (rheumatologists), accept the concept of somatisation in which patients express their distress through physical symptoms (Ross, 1999), studies have shown that such labels are problematic within the doctor-patient relationship (Wileman, May, & Chew-Graham 2002). For patients, the term 'somatisation' could possibly be considered a stigmatising label as it suggests that their symptoms are not real, but rather made up or feigned for secondary gain (Hazemeijer & Rasker, 2003).

For example, Wileman et al.'s (2002) Interpretative Phenomenological Analysis (IPA) study of GPs' attitudes to the management of patients that present with MUS in primary care revealed that GPs reported their patients lacked insight into psychological illnesses and consequently focus on and intensify their somatic symptoms to legitimise their help-seeking behaviour. This may be due to many Fibromyalgia patients opting for a biomedical explanation of pain rather than accepting a clinical view that their symptoms are solely psychological (Cunningham & Jillings, 2006). When patients sought a medical explanation for their symptoms, Wileman, et al. (2002) noted that GPs constructed their patients as controlling and authoritative in the

consultation leading to difficulties in managing the appointment, as GPs felt they had limited influence on changing their patients' understanding of the illness (Olde Hartman *et al.*, 2009). Consequently, research has shown that doctors have been found to feel frustrated by their patients with Fibromyalgia (Briones-Vozmediano, 2017).

On the other hand, from the patients' perspective, Sim and Madden's (2008) IPA study comprised a meta-synthesis of qualitative studies that summarised the illness experience of Fibromyalgia patients. They found that Fibromyalgia patients explained their experience within the biomedical model, whereby their Fibromyalgia was viewed as an organic pathology that could be identified through biomedical tests. Thus, their pre-diagnostic stage consisted of making sense of their pain and fatigue symptoms by seeking assistance from a medical doctor (Colmenares-Roa *et al.*, 2016) as they reported that they thought they were suffering from an undetected malignant condition (Sim & Madden, 2008). However, normal test results resulted in patients being referred for further examination to explore the possibility that they might be suffering from other diseases such as neurological or rheumatological disorders. This led to patients being referred to and seeing multiple specialists without receiving a diagnosis or receiving a diagnosis that was not Fibromyalgia (Madden & Sim, 2016). In the process, patients mentioned that these new referrals raised their expectations of finding answers to what was wrong with them and was a way for them to dismiss any claims of malingering by previous doctors (Sim & Madden, 2008).

Furthermore, Paulson, Danielson and Söderberg, (2002) found that these continuous investigations led to negative test results and patients often being told by consultants that there was nothing wrong with them. Furthermore, some patients reported having been told

by their doctors that their illness was psychological or had been imagined (Arnold et al., 2008). Despite patients suggesting that the onset of their symptoms was caused by psychological or social factors such as trauma or work overload, they nevertheless expected that something would be revealed through a medical investigation (Madden & Sim, 2016). Salmon, Peters and Stanley's (1999) study revealed that when GPs suggested that negative test results meant nothing was wrong and normalised and reassured their patients, with an explanation of somatisation, their patients in turn claimed that their symptoms were being rejected. Therefore, it could be claimed that patients' initial sense of hope in finding a medical explanation was replaced by disappointment. Furthermore, Edwards et al. (2010) argued that when doctors were unable to provide a clear diagnosis for their presenting problem this could lead to patients reporting that they felt misunderstood and their symptoms discounted.

Economic Cost of Fibromyalgia

Despite the availability of recommended treatments, diagnostic tests and management of Fibromyalgia being available to doctors, a diagnosis of exclusion can in practice lead to increased testing (Hiller, Fichter & Reif, 2003) and high health-care costs (Rao & Clauw, 2004). Empirical research has consistently shown that Fibromyalgia is associated with high rates of health-care resources (Spaeth, 2009). Hughes et al.'s (2006) quantitative study on the impact of a diagnosis of Fibromyalgia on health-care use in the UK found that Fibromyalgia patients had 25 visits per year to primary care services compared to 12 visits in control groups. They concluded that primary care patients with Fibromyalgia reported higher rates of illness and use of health-care resources 10 years prior to their diagnosis. The authors suggested that illness behaviour may have contributed to this increase in attendance. However, post-diagnosis they noted that possibly due to the lack of effective treatment diagnosis had a only

a marginal reduction in the use of health-care resources. This study shows that patients with Fibromyalgia visit their GPs more often than those who do not have this diagnostic label. This study reaffirms patients' beliefs that their symptoms stem from a medical condition and therefore should be dealt with from a medical perspective. This consequently has a social impact due to the high economic cost of their beliefs. Furthermore, Bermingham et al. (2010) estimated that nearly £18 billion per year is spent on health-care use and disability for somatisation amongst working adults in England. Overall, these studies reveal the high economic consequences of having Fibromyalgia.

Power Play within the Doctor-Patient Relationship

Colmenares-Roa et al. (2016) described the health system as an institutional social framework in which the behaviour and positions of those within the system become legitimised. In regards to the doctor-patient relationship, this relationship could be considered as an extension of society in which one actor has more power. For example, the doctor has access to medical knowledge and technological resources that make them more autonomous whilst the patient can be seen to be dependent on those resources (Giddens, 1979). Consequently, this power relation has been reported to affect illness trajectory, regulate treatment behaviour, and possibly shape ideas for both patient and doctor (May et al., 2004). In practice, this can lead to different explanatory models, as well as different therapeutic assessments, expectations and goals (Kleinman & Seeman, 2000).

However, the power balance can be shifted when patients reportedly employ strategies such as using their status as an experienced patient who knows the system and their illness to gain an advantage during the treatment process, and so influence their doctors (Colmenares-Roa

et al., 2016). Thus, patients take an active role in the process of research and treatment through a medical discourse by acquiring knowledge about their illness. Other strategies such as exiting, non-compliance, confrontation, persuasion and making demands are just some of the ways patients have evidently used their power to take command of their situation (Åsbring & Närvänen, 2002). Some patients, alternatively, enter into a collaborative relationship with their doctors whereby both use their experience and knowledge from their respective positions to understand, explain and map the patient's illness (Durif-Bruckert, Roux, & Roussett, 2015). From this perspective, it could be argued that patients are looking to be counted within the diagnostic and treatment process and consequently, both the doctor and patient use their competencies and abilities to create meaning to deal with the illness from a set of symptoms to a diagnostic label (Glattacket, Opitz, & Jäckel, 20102010).

Evidence-based practice has been criticised, as those reading these qualitative papers on patient experiences may have confirmed doctors' uncertainties and complexities experienced in clinical practice. Despite this, Mengshoel et al. (2021) argued that resulted in unifying teams and prompted further collaboration with doctors which developed into enhanced competency and practical skills to develop models of care programmes for chronic pain patients. Gluyas (2015) summarises three types of relationship between a health-care provider and a patient; a paternalist relationship in which the doctor is the expert on deciding the best treatment on behalf of their patients; an informative relationship where the professional informs the patient about their illness and offer treatment options for the patient to make a choice; and lastly an interpretative relationship in which the professions work with the patient to find out what is important to them to attain their desired outcome. Reflecting on the previous studies, it seems that most doctor-patient relationships described

have been based on the paternalist relationship in which the doctors use their expert knowledge to dictate to their patients what is medically best for them. However, the IPA studies mentioned above focus on how patients make sense of their experiences and possibly allude to the ineffectiveness of a paternalist relationship with their doctors.

According to Foucault (2000), discourses are a form of power/knowledge, thus what constitutes certain behaviours or actions is to produce knowledge and exercise power over others. Thus, it could be argued that when experts updated the definition of Fibromyalgia within CPP they also changed the nature of the interaction with patients in order to produce a collaborative rather than paternalistic approach to assessment and management. Hence, the possibility for agency, to act differently, could be seen as a form of discursive resistance, whereby the possibility of multiple subject positions emerges within the discourse (Caldwell, 2007). Foucault might have argued through discursive resistance that patients (those who are subjects of power) are allowed to act differently or reject their confinement within pre-determined discourses of power/knowledge. Therefore, within the biomedical discourse, whereby patients seem to be positioned as powerless in the face of their doctor's expert knowledge and treatment suggestions, continuous research suggesting the ineffectiveness of such management has evolved to allow for patients to have more agency within the relationship.

Using patients' experiences has been commonplace in health-care services since the 1990s in order to improve the quality of clinical effectiveness and patient safety (Gerteis et al., 1993). For example, researchers have studied patient illness experiences with the aim of helping health-care professionals better understand and meet patients' needs (Mengshoel et al.,

2021). As a result, this co-production of knowledge brings about a new approach to knowledge development whereby doctors and patients together bring their various perspectives and knowledge to collaborate equally to solve clinical challenges (Filipe, Renedo & Marston, 2017). Therefore, in having an interpretative relationship, Doebl et al. (2020) argued that using a person-centred approach allows for doctors to build trustful and on-going relationships with their patients by allowing patients' perspectives to be accounted for within the co-ordination of investigations into self-management strategies. In doing so, the patient becomes pro-active within the relationship, which has shown to improve quality of care, as patients with the support of their doctor have the opportunity to decide what works best for them (Ziebland et al., 2013). Hence, NICE (2021) guidelines suggest that those presenting with chronic primary pain should have a person-centred assessment based on enabling them to actively participate in their care through communication, information and shared decision making in order to produce a collaborative and supportive relationship.

Yet, as initially highlighted by the EULAR (Macfarlane et al., 2017), Doebl et al. (2020) reported that to date (since 2020) research has mainly focused on diagnosis and treatment of Fibromyalgia instead of research into the delivery and organisation of care for Fibromyalgia patients. As a result, it could be implied that there are challenges for clinical practice and health care policy in organising and delivering a multidisciplinary approach to Fibromyalgia. Doebl et al.'s (2020) study reportedly did not find any evidence-based models of care for Fibromyalgia patients that covered aspects of health care throughout the patient's journey from diagnosis to treatment. Instead, many studies could only explore patients' difficulties within the health system in terms of inconsistent care, a lack of timely access to services, or health-care professionals' struggles to provide the best care for patients due to limited

knowledge and not feeling equipped to deal with the psychological factors. Thus, these scholars revealed a gap in the literature in terms of a lack of research focusing on clinical practice compared to a large number of qualitative studies exploring patients' illness experiences.

Consequently, to attend to the problem of limited evidence currently available regarding the best way to organise health services for Fibromyalgia, Doebl's study notes that their research is part of a wider programme aimed at developing a model of care for people with Fibromyalgia in the UK. Through collecting information from patients about their current health-care status and by working with health-care professions, the lead researchers aim to understand how services are organised with the hope of ensuring a cost-effective model of care for Fibromyalgia patients and thus ensure better outcomes and higher patient satisfaction across the country (MacFarlane et al., 2019).

However, it could be argued that despite not having a model of care programme for the whole of the patients' journey, there have been emerging trials aimed at developing a model of care within individual NHS hospitals within that provides patient-centred education, advise on exercise, and guidance to support the development of self-management strategies for Fibromyalgia patients (Pearson et al., 2021). Pearson et al.'s (2021) model of care programme is delivered within a community setting as per government recommendations for treating long-term conditions. Such settings (as opposed to acute hospital settings) can provide specialist care closer to patients' homes in a cost-effective manner and in which patients are able to be involved and consulted on all aspects of the specialised programme. Thus, a change is observable in how services are providing care for patients with Fibromyalgia, moving from

a paternalistic towards an interpretative relationship in which patients are seen to be valuable in developing self-management strategies tailored towards improving their functioning (Du et al., 2017). As a result, with a shift to focus treatment for long-term conditions on self-management strategies, evidence has shown an improvement in physical function, patient engagement, improvements in mood and a reduction in health-care costs (Pearson et al., 2021).

Psychological Construction of Fibromyalgia

Definition of Pain

The IASP initially defined pain as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage’ (Merskey, 1979). This definition provided an anchor for healthcare professionals to facilitate the nature of acute or chronic pain (Williams & Craig, 2016). Chronic pain, in contrast to acute pain which is short-term, can be defined as pain that persists for more than three months, and which has been found to be unresponsive to medical treatment such as medication or procedures, leading to limited improvement to physical or emotional functioning which overall negatively affects an individual’s daily life (Turk, Swanson, & Tunks, 2008). Merskey’s definition of pain was widely accepted globally by clinicians, researchers and governmental organisations, as it provided a common understanding of pain using a multidimensional conceptualisation of pain in simple terminology (Raja *et al.*, 2020). Thus, the definition has remained unchanged for the last 40 years. This is problematic, as over the years there have been advances in the understanding of pain in terms of assessment and treatment with a move towards a biopsychosocial perspective.

Changes in our understanding of pain from a psychological viewpoint stemmed from the Gate-control theory of pain (Melzack & Wall, 1965) and subsequently the Neuromatrix theory of pain (Melzack, 1999), which argue that psychosocial and physiological processes interact to affect perception, transmission and evaluation of pain. These theories revealed to psychologists and doctors the complexity of pain processing and maintenance involved in chronic pain, which may have led to the conceptualisation of a multidimensional approach to pain being established; that is, the biopsychosocial model of pain (Roditi & Robinson, 2011). This perspective focused on viewing chronic pain as an illness rather than a disease, as well as recognising the subjective experience of different treatment approaches aimed at management rather than cure of chronic pain (Gatchel, 2005). The experience of chronic pain can affect an individual in multiple domains such as emotional distress, increased pain-related disability, altered cognitions and an overall reduced quality of life. As a result, the biopsychosocial perspective is an approach that views chronic pain from its complex, multifaceted experience resulting from the interplay of the patient's physiological states, thoughts, emotions, behaviours and sociocultural influences (Roditi & Robinson, 2011).

Consequently, the IASP definition has been criticised for various reasons, one of them being its Cartesian approach, which ignores the mind-body interaction, as the description of 'actual or potential tissue damage' suggests that biological mechanisms govern a pain experience despite the definition recognising the sensory and emotional factors involved in the nature of pain (Merskey et al., 2008). Likewise, Anand et al. (1999) argued that the IASP definition is essentially a verbal self-report that ignores non-verbal behaviours which those with language or cognitive impairments may use to communicate information. Thus the 'unpleasant

experience' may disempower and neglect certain patient groups that may not be able to verbally describe and thus authenticate their subjective experience of pain.

Similar criticisms have been raised regarding the IASP definition over the years, with some scholars offering alternative definitions for pain (Tabor et al, 2017; Williams & Craig, 2016). Williams and Craig are two psychologists who defined pain as 'a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components (2016, 2). This alternative definition provided social and cognitive perspectives and thus a more comprehensive dimension which recognised pain as functional and adaptive through non-verbal behaviours. Tabor et al. (2017) argued that the experience of pain is an estimate of potential bodily threat whereby pain is triggered by a somatosensory barrage that includes, but is not limited to, activity in high threshold primary receptors (nociceptors) and their projections. However, Cohen, Quintner and van Rysewyk (2018) disagreed with Tabor et al.'s suggestion of nociceptors as this defines pain within an observable activity in the nervous system, which contradicts the concept of pain being a subjective experience. Instead, they offered the following revised definition: 'Pain is a mutually recognizable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity' (Cohen et al., 2018, 6). This definition pointed to the first-person perspective of pain which allows for non-verbal communication such as behavioural cues to aid in the assessment of pain.

Despite these proposed changes to the IASP definition, these suggested alternative Despite these proposed changes to the IASP definition, these suggested alternative definitions of pain have been criticised for being redundant and outdated (Treede, 2018). It has been noted that

these scholars' suggestions reiterate concepts of pain that are already in the IASP definition, such as 'distressing or mutually recognised' being similar to the IASP wording of 'unpleasant', and also use words such as 'somatic' or 'actual or potential tissue damage', which have already been stated to be problematic (Cohen et al., 2018). Thus, Treede (2018, 2) reported that the reason the original IASP definition remained for so long was that it clearly defined pain as a subjective experience. It links pain to both physiology and emotional factors associated with an adequate stimulus such as tissue damage or an unpleasant experience; and the issue of verbal communication is alleviated by the following footnote to the definition: 'The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment'.

Nevertheless, in 2013 a taskforce was formed by the IASP to produce an updated version of the classification of pain for international use. With the help of public consultation to evaluate the new definition of pain, a new edition of the ICD (ICD-11) which the WHO adopted in 2019 includes a chronic pain classification for the first time (Raja, 2020). The new diagnostic entry for Chronic Primary Pain (CPP) was based on current scientific evidence and the biopsychosocial model in the ICD-11 provided a framework to aid in bridging obscure aetiologies characterised by a complex interplay of biopsychosocial factors (McCrystal et al., 2011). The ICD-11 classifies CPP as pain in one or more anatomical region that persists for more than three months and is associated with significant emotional distress and/or functional disability, and where the symptoms are not better accounted for by another diagnosis (Nicholas et al., 2019). Under the classification code of pain, chronic pain is divided into primary CPP and six subtypes of secondary syndromes. All secondary syndromes share characteristics of CPP with CWP being a secondary syndrome. Fibromyalgia is a form of CWP

and is currently defined as diffuse pain in 4 of 5 bodily regions associated with emotional distress or functional disability (WHO, 2020). With this classification system for chronic pain the ICD-11 provides a code for pain severity, intensity, distress and disability that could be used in clinical settings for specialised pain management and in primary care, and which could therefore provide in practice uniform criteria for health-care statistics, clinical trials and publications to support pain research and those with pain (Raja et al., 2020).

Trauma and Emotional Regulation

Biopsychosocial accounts of Fibromyalgia also suggest trauma as a predisposing factor. Research has shown that vulnerability factors such as emotional trauma (sexual and physical abuse and neglect), accidents (work injuries, traffic, fractures), and medical complications (post-op, infections) predispose an individual to Fibromyalgia (Low & Schweinhardt, 2012; Raphael et al., 2006). Moreover, psychosocial studies report that early adversities (insecure attachments, disturbed interpersonal interactions, trauma) may be associated with attachment difficulties, increased susceptibility to stress, disturbed affect regulation and dysfunctional health-seeking behaviours in adulthood (Ciechanowski et al., 2003). Additionally, changes in the endocrine, immune and pain-regulating systems have been associated with social-emotional factors (Waller & Scheidt, 2006). Therefore, from the biopsychosocial perspective, psychologists construct Fibromyalgia as involving a history of early adversities or trauma which may be risk factors for the development of maladaptive emotional regulation (Okur Güney et al., 2019). Consequently, psychologists incorporate aspects of emotional regulation training and interpersonal aspects into their therapy plans (Kleinstäuber et al., 2016).

Furthermore, psychological theories about Fibromyalgia and other somatic symptoms acknowledge that difficulties processing emotions can contribute to the development, progression and treatment of symptoms (Luyten et al., 2013). These associations have been supported by empirical and clinical reports that confirm this relationship as well as reporting that maladaptive emotional regulation is associated with pain and psychological comorbidities (Koechlin et al., 2018). From this perspective, Fibromyalgia may be associated with a lack of emotional regulation. Alexithymia is a psychological construct that describes a difficulty to cognitively process emotional experiences and a deficit in emotional processing (Taylor, Bagby & Parker, 1997). It is characterised by a difficulty to distinguish feelings from bodily sensations of emotional arousal, difficulty identifying and describing subjective emotions, limited imaginative capacity and an externally oriented cognitive style (Taylor, 2000). Therefore, Fibromyalgia patients are unable to accurately identify somatic manifestations of emotions, as alexithymic individuals are susceptible to incorrectly attribute physical symptoms to physical disease (Tuzer et al., 2011) and may also struggle to communicate their emotions (Torrado et al., 2018). Trauma and emotional regulation are some of the ways psychologists construct Fibromyalgia and consequently they include these factors in their therapeutic techniques. Furthermore, in terms of coping, Sim and Madden (2008) found that individuals with Fibromyalgia described using psychological techniques to manage their symptoms, thus a psychological construct was used when individuals spoke of how they use emotion-based strategies (either problem-solving techniques or dealing with thoughts and feelings) as an effective way to manage their symptoms.

Psychological Therapy

In the absence of a cure, success is defined by psychologists as adaptation to symptoms and self-management. Psychologists construct pain through psychosocial and behavioural factors that significantly contribute to the experience, persistence and exacerbation of pain, with self-management complementing the biomedical constructions of pain (Turk, Swanson & Tunks, 2008). There are various psychological therapies that inform adaptation and self-management of client's symptoms. These include Psychodynamic approaches, Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT), Behavioural approaches; Motivational Interviewing, Relaxation, and Guided Imagery, Operant approaches; Fear-avoidance and Psychophysiological techniques; and Biofeedback (Roditi & Robinson, 2011; Waller & Scheidt, 2006). As the term 'patient' invokes a medical construct which positions an individual within a sick role, psychologists prefer to use the term 'client' to refer to their clinical population, as this positions the individual within a collaborative relationship (Shevell, 2009).

Psychodynamic approaches are based on the assumption that unconscious factors influence the onset and maintenance of symptoms and thus chronic physical pain may be a somatic presentation of emotional distress (Engel & Schmale Jr, 1967). A systematic review of meta-analysis studies of abuse in Fibromyalgia patients showed that compared to the general population and control groups childhood trauma was reported to be significantly higher in Fibromyalgia patients (Häuser et al., 2011). Such large-scale studies have shown a history of physical and sexual abuse being related to the diagnosis of Fibromyalgia, which suggests that childhood trauma may be a developmental tendency in Fibromyalgia patients (Haviland et al., 2010). As evidence of childhood physical and sexual abuse supports their assumptions,

psychodynamic therapists focus on early relationship experiences reconstructed within the therapeutic relationship with the aim of improving emotional regulation by reintegrating emotions into symbolic and available mental processes (Frischenschlager & Pucher, 2002). As a result, a psychodynamic therapist may require clients to have a level of psychological insight in which they accept the possibility of emotional factors playing a role in their symptom presentation before therapy begins. Scheidt et al.'s (2013) randomised control trial in brief psychodynamic psychotherapy in Fibromyalgia found treatment was effective in improving health behaviour, medication and Fibromyalgia-related symptoms.

Other psychological approaches to Fibromyalgia focus on treating symptoms such as stress, anxiety, depression, sleep problems and unhelpful coping mechanisms which are related to the syndrome (Macfarlane et al., 2017). CBT has been the most researched psychological intervention for Fibromyalgia, with its efficacy being demonstrated through meta-analyses and systematic reviews (Bernardy et al., 2010; Morley, Eccleston, & Williams, 1999;). CBT is based on the principle that our thoughts, emotions and behaviours influence each other and thus dysfunctional thoughts shaped by an individual's belief system are responsible for negative emotions. As a result, cognitive, behavioural, affective, sensory and physical factors each play a role in how an individual experiences pain based on their underlying beliefs about a pain experience (Bennett & Nelson, 2006). Treatment using this approach focuses on providing psychoeducation about pain conducted within a supportive, encouraging and empathetic environment between therapist and client, and typically combines assertiveness skills, stress management, problem-solving techniques, sleep management and goal setting to enhance patients' sense of self-control (Roditi & Robinson, 2011). As a result, clients increase their perception of control over their pain, learn to better manage their pain-related

behaviours and thoughts, and overall re-evaluate the meaning they ascribe to their pain (Thieme & Gracely, 2009). Through this collaborative and constructive process, clients can become active participants in their treatment whilst identifying obstacles to success, developing relapse prevention plans and recognising the factors contributing to the maintenance of their chronic pain, so gaining mastery over their pain and improving their mood (British Pain Society, 2013).

ACT is a third wave CBT approach which emphasises the importance of facilitating the patient's progress towards attaining a more valued and fulfilling life by increasing psychological flexibility rather than strictly focusing on restructuring thoughts (Hayes, Strosahl & Wilson, 2009). The six core processes of ACT are acceptance; cognitive defusion; being present; self as context; values, and committed action. Through these processes, ACT takes a holistic approach to increasing psychological flexibility and decreasing distress by targeting ineffective control and avoidance strategies (Hayes et al., 2006). The theory suggests that through psychological flexibility a client can learn to experience both good and bad feelings and therefore control their behaviour in order to create a meaningful life (Blackledge & Hayes, 2001). In its application to chronic pain, ACT encourages clients to view their pain as inevitable and accept it in a non-judgemental manner so that they can continue to derive meaning from life despite the presence of pain (Roditi & Robinson, 2011). Research has shown ACT to significantly improve psychological flexibility and pain-related functioning in patients with Fibromyalgia (Wicksell et al., 2013).

Behavioural approaches focus on stress management as it is generally accepted by most psychologists that stress from environmental, physical and emotional factors is a key

contributor to the onset and maintenance of chronic pain (Turk & Monarch, 2002). Therefore, relaxation techniques aim to activate the parasympathetic nervous system to reduce physical and mental tension levels and thus allow clients to become more aware of their physiological and psychological states in order to increase control over pain (Roditi & Robinson, 2011). A systematic review and meta-analysis study of the effectiveness of mindfulness-based stress reduction found improvements in some symptom presentation and reduced subjective illness burden (Lauche et al., 2013). Guided Imagery, on the other hand, helps clients use all of their senses to create a safe, vivid and serene environment to achieve a sense of relaxation and distraction from their pain-related thoughts and sensations (Jamison, 1996). Zech et al.'s (2017) systematic review supported the efficacy and tolerability of GI in reducing the key symptoms in Fibromyalgia. Additionally, Motivational Interviewing is based on the stages of change and assumes that an individual can change through learning and accepting self-efficacy (Miller & Rollnick, 2002). Chronic pain clients who adhere to the biomedical model in that they believe their symptoms have an organic pathology, through MI become aware of how other factors such as emotional or environmental ones can impact their pain, and thus might start to entertain the possibility that they can learn self-management techniques to adapt to a life with chronic pain (Turk et al., 2008).

Based on Skinner's (1953) principles of Operant Conditioning and modified by Fordyce (1976), the Fear-Avoidance model proposes that clients can become trapped in a vicious cycle of distress whereby their myths about pain related to negative appraisal of pain and its consequences may in the short term provide relief but may in the long term exaggerate somatic perceptions of pain, leading to fear or avoidance of activities that may cause the pain (Vlaeyen et al., 1995). The model focuses on how clients interpret their pain as it proposes

that clients' avoidance or hypervigilance of physical sensations may create safety behaviours, making them more vulnerable to further pain and suffering, thus maintaining their pain cycle (Crombez et al., 2012). Research has reported that pain catastrophising has been associated with the maintenance of the pain cycle (Vlaeyen et al., 2002). Furthermore, fear of movement and avoidance behaviour towards physical activity has been shown to be highly prevalent in patients with Fibromyalgia (Nijs et al., 2013). Treatment is therefore aimed at breaking the fear-avoidance cycle through graded exposure to feared discomfort or engagement in physical activity. Through psychoeducation about pain and cognitive restructuring of maladaptive thoughts and expectations around pain and activity, psychologists support clients in developing self-management techniques and promote lifestyle changes to reduce flare-ups and prevent set-backs (Roditi & Robinson, 2011).

Biofeedback is a self-regulatory technique which assumes that the level of pain is maintained or exacerbated by autonomic nervous system dysregulation, believed to be associated with the production of nociceptive stimulation (Turk et al., 2008). The objective of biofeedback is to teach clients to interpret physiological data using equipment. This helps them to learn to recognise tension areas within their bodies and subsequently how to relax those areas to reduce muscle tension (Roditi & Robinson, 2011). This procedure monitors and reports clients' bodily responses such as brain electrical activity, blood pressure, blood flow, heart rate, skin temperature and other physiological functions through an auditory and visual modality. Thus, the client will use certain self-regulatory skills to reduce their pain or maladaptive physical response to an undesired event such a stress response (Turk et al., 2008). This treatment has been found to be helpful in managing Fibromyalgia (Mur et al., 1999), showing significant reduction in short-term pain intensity with effects mediated

through cognitive changes such as increased self-efficacy and coping strategies (Glombiewski, Bernardy, & Häuser, 2013).

In summary, from a psychological perspective Fibromyalgia can be treated using different types of therapeutic approach. Although CBT has been shown to be the most efficacious, a combination of treatments can be applied as each individual with Fibromyalgia is different and thus the symptoms they would like to manage may vary. As a consequence, different approaches may work for different individuals (Roditi & Robinson, 2011). However, despite the various different psychological therapies available to manage chronic pain, a recent systematic review by Williams et al. (2020) found that on average CBT reduced the experiences of pain and distress only by small amounts, and there was little evidence to support ACT or other therapies in managing these conditions. Therefore, it could be argued that psychological therapy on its own may not be an effective way to manage a chronic pain condition and this further supports combining psychological therapies with other treatment approaches as suggested by NICE guidelines.

Pain Management Programmes

In the UK, Pain Management Programmes (PMP) can be found within the National Health Service (NHS) as a comprehensive, integrative and interdisciplinary approach used to manage chronic pain and its associated problems (Grady *et al.*, 2015). This multidisciplinary treatment framework includes a combination of treatments incorporating analgesics, physical therapy, behavioural therapy and psychological therapy (British Pain Society, 2013). Based in outpatient, community or intensive care residential programmes that run as a group, sessions may include patients with different types of pain (Wilson, 2017). Psychological therapy provided is grounded in CBT and this approach has been used for Fibromyalgia patients as

evidence suggests that deregulated pain processing in Fibromyalgia patients is initiated and maintained by interactions of molecular, affective, cognitive and behavioural factors (Gracely et al., 2002). Furthermore, scientific evidence has shown long-term effectiveness for multidisciplinary treatment programmes, with lasting subjective and objective outcomes relating to an increase in daily functioning, mood and medication and work status, with the multimodal approach being cost effective (Patrick, Altmaier & Found, 2004).

Client-Therapist Relationship

It has been argued that public knowledge and beliefs about psychological disorders with regard to recognising specific disorders, risk factors, causes and professional help available is limited (Von Dem Knesebeck et al., 2018). Although some mental health conditions are well known, such as depression, anxiety and schizophrenia, people often do not know what they can do to prevent other psychological problems, which may lead to delays or avoidance in treatment or possibly suspicion towards recommendations for therapy (Jorm, 2012). Due to the lack of knowledge about the aetiology of Fibromyalgia and its multiple contributing factors, it has been reported that doctor-related barriers to diagnosis and treatment pose a risk to the doctor-patient relationship and may hinder access to other health-care resources (Löwe & Gerloff, 2018). Some patients with Fibromyalgia may not recognise the underlying emotional factors associated with their symptoms and consequently when referred for psychological treatment may be described as resentful of any psychological implications, which may possibly impact their attendance and motivation for therapy (Ford & Long, 1977). Furthermore, a psychological research study has highlighted that when patients' Fibromyalgia symptoms have been interpreted as psychological or imagined, these patients perceived their doctors or others in their social circle as seeing them as hypochondriacs or psychologically

unwell (Arnold et al., 2008). This may create self-stigmatisation, which can come across as a sense of shame and weakness at being seen as mentally ill rather than physically ill, with consequent social implications (Byrne, 2001).

Clients with psychiatric comorbidities have often been described by doctors as difficult patients, which may lead to a reduction in the level of quality of care. Arnold et al.'s (2008) study highlighted that patients often reported long and stressful roads to diagnosis before experiencing the relief of diagnosis. The study further indicated that during the diagnosis process patients' concerns included: not being taken seriously, suffering from the unpredictability of symptoms, experiencing loss of intimacy, social isolation and changes in self-perception. Thus, these authors found that a negative impact on daily life was a common theme in patients diagnosed with Fibromyalgia, which may have led to patients finding it difficult to access adequate support from doctors or friends and family. Due to the high prevalence of depression and anxiety found in chronic pain patients, psychologists have been described as the profession most suited to dealing with these psychiatric and mood disorders (Bair et al., 2003). As a result, psychological therapies aim to address these cognitive, behavioural and emotional factors to support clients' self-management strategies aimed towards attaining meaningful goals (Eccleston & Crombez, 2017).

Roditi and Robinson (2011) suggested that psychologists (Clinical or Counselling) can effectively help clients feel more in command of their pain control and enable them to live as normal a life as possible despite pain. Psychologists aim to help chronic pain clients process important role transitions they may undergo (e.g. job loss), interpersonal difficulties they may be encountering (e.g. sense of isolation brought about by pain), and emotional difficulties

(e.g. anxiety, anger, sadness, disappointment) implicated in their experience. Taking a Rogerian approach to psychotherapy, which can be viewed as a fundamental approach for therapeutic practice, psychologists focus on creating an environment in which clients feel comfortable to independently recognise their own thoughts and achieve insight with the therapist to facilitate change (Mahoney & Baker, 2002). From this perspective, psychologists take a client-centred approach to therapy in which they utilise Rogerian techniques such as expressing empathy, having an attitude of unconditional positive regard, and acceptance of the clients' cultural and personal experiences within the therapeutic space in order to normalise and understand client experiences with pain to foster motivation for change (Rogers, 1979). Once clients are able to understand their pain and the meanings they ascribe to it, through some forms of therapy, Counselling Psychologists aim to help clients reinterpret the meaning of their experience and focus on improving daily functioning. Thus, the skills learned through psychological interventions empower and enable clients to become active participants in the management of their illness and instil valuable skills that clients can employ throughout their lives (Eccleston & Crombez, 2017). Additional benefits of utilising the biopsychosocial approach are that, unlike the biomedical model that focuses mainly on treating the biological components of Fibromyalgia through medication, this multidimensional approach has been shown to lead to increased rates of return to work, reductions in health-care costs, and increased health-related quality of life (Hulla et al., 2019). Thus, it can be argued that the biopsychosocial approach has the potential to improve clinical outcomes for those with Fibromyalgia by enhancing patient self-management strategies (Kusnanto, Agustian & Hilmanto, 2018).

Social Construction of Fibromyalgia

Social Construction of Illness

From a social discourse, contemporary understanding of what it means to be ill derives from Talcott Parsons Sick Role Theory. Parsons's (1951) theory defines a sick individual as a non-productive member of society, whose pattern of behaviour deviates from the norm. Parsons argues that in accepting the sick role, the individual is expected to seek competent medical help from a doctor to aid recovery. It follows from the model that recovery can only be achieved once a diagnosis has been made, thus an effective range of treatments can hopefully be applied (Varul, 2010). From this perspective, in order to attain a diagnostic label this status is externally given on the basis of an individual's behaviour (Mengshoel et al., 2018).

In the 1960s, new theories emerged that focused on the role of diagnosis within symbolic interactionism which took into account the actors' perspective and their social world (Madden & Sim, 2006), such as Labelling theory which emerged as an approach to understand deviant behaviour, but in regards to illness applied when the individual could no longer perform their social roles (Gove, 1975). However, criticism arose for this theory as it positioned the ill individual as a passive product of social interaction in which the act of the individual rather than their symptoms was the reason why they were labelled ill (Meile, 1986). Consequently, the diagnosis was applied by society which caused negative changes to the individual's identity. Subsequently, the theory of Negotiated Order rejected the notion of a passive individual and instead suggested that the process of diagnosis is negotiable, requiring an open exchange between the patient and doctor, with both parties exerting influence, even though the power remains in favour of the medical professional (Stewart & Sullivan, 1982). Gerhardt's (1989) interpretation of the theory argued that the aim of the health-care system

is to provide a diagnostic label to legitimise a patient's sickness claim. Without this validation, such as where there is no evidence of organic pathology, patients could be seen as claiming to be ill but cannot be socially sanctioned as such. Consequently, this may lead to the status of their diagnosis being questioned and patients may be considered by their doctors or society to be malingering for secondary gain (Woodward, Broom, & Legge, 1995). For example, Rohling et al. (1995) noted that financial compensation was a factor influencing symptom presentation for patients with chronic pain. If validation is given, this can offer the patient recognition by society in being an ill person and therefore, the patient can enter into the sick role (Cooper, 1997). However, the diagnostic label must take into account the patient's beliefs as doctors can give a diagnosis but the patient is free to accept or reject the label (Strauss, 1978).

Research highlighting patients' perspectives indicates that the function of diagnosis is to give meaning to the illness experience. Broom and Woodward (1996) argued that this is achieved by providing an explanation for symptoms, which in turn allows individuals to impose order and regain control over their illness experience, for a sense of mastery to occur over the meaning of the illness. Adams, Pill and Jones (1997) proposed that reinterpretation needs to develop, whereby any diagnosis must reflect the illness experience. They stated that the fit between patient meaning and clinical opinion needs to be established before a diagnosis is accepted. If this reinterpretation does not happen, a diagnosis may not be considered compatible with the individual's identity and may be rejected. These scholars additionally explained that individuals need to search for information in order to develop and refine the meaning of a diagnosis and thereby reduce patient uncertainty. From this perspective,

receiving a diagnosis is not a one-off event but rather a process of discovery which evolves over time and is never complete.

From a medical construct, to distinguish the ill from the healthy, diagnostic labels are applied in medical practice to determine who needs treatment and support and who does not (Jutel, 2009). A diagnostic label comprises medical knowledge and understanding of a particular disease, illness or health condition which shapes clinical practice. When an individual becomes ill and seeks treatment, during the diagnostic process a biomedical diagnosis uses pre-specified criteria to determine the patient's pattern of objective organic pathology, whilst psychological diagnoses include issues such as anxiety, and social diagnoses focuses on behaviours issues such as gambling (Mengshoel et al., 2018). Although the distinction between these three types of diagnosis can be blurred at times, typically, unlike biomedical diagnoses, psychological and social diagnoses have a set of symptoms that usually do not have a defined cause (Horwitz, 2002).

Through the diagnostic process doctors try to understand the patient's illness in order to provide the appropriate method of treatment. This process helps to shape the patient's meaning of their illness experience (Hydén, 1997). As the patient's illness experience becomes labelled, it is validated by a medical expert, which as a consequence socially legitimises that patient's illness (Nettleton, 2006). Moreover, from a biomedical perspective the responsibility for a cure transfers from the patient to the doctor (Brown, 1995). Yet, when the patient's illness cannot be explained by organic pathology or cannot be seen, doctors may attribute the patient's symptoms to psychological or social problems (Wainwright et al., 2006). From this standpoint, patients may be expected to take responsibility for themselves to manage

their own problems despite their expectations that this role would fall to medical professionals. This may lead patients to become dissatisfied with the health-care system and consequently take up personal strategies to change the meaning of their diagnosis (Jutel, 2009).

These three different theories – Sick Role, Labelling, Negotiated Order – provide an insight into the role of diagnosis. However, it is the function of the patient to give meaning to their illness experience (Madden & Sim, 2006). This is achieved by providing patients with an explanation of their symptoms which will allow them to regain control over their illness experience (Broom & Woodward, 1996). When a diagnosis does not fit or reflect the illness experience of the patient, the diagnosis given may not reflect the patient's identity and may not be accepted. Reinterpretation is said to occur when the patient develops a degree of knowledge and meaning of a diagnosis which in turn becomes compatible with and reflects the patient's illness experience (Adams et al., 1997). It could be argued that creating meaning in Fibromyalgia could be facilitated through the collection of a range of information resources from doctors with their expert knowledge, and from support groups with their shared experiences and non-medical sources of information (Madden & Sim, 2006). Following a Fibromyalgia diagnosis, patients stated that little information was given to them by their doctors about their new diagnostic label so they sought information from other sources such as the internet, self-help groups or books (Lempp et al., 2009). With a diagnosis such as Fibromyalgia in which the aetiology is unclear, the lack of clarity may not have provided patients with a source of meaning, which in turn may have restricted them in eliciting increased support from health professionals or significant others (Madden & Sim, 2006).

Using the social discourse, Fibromyalgia has been constructed as a hidden illness that creates social doubts in its patients which can then lead to patients not being believed by others that they are ill. There have also been gender differences and stigmatisation associated with having the diagnostic label. Although these constructions highlight the negative social connotations associated with having Fibromyalgia, to some, social acceptance can be found when using the label. The following paragraphs will summarise the social constructions of Fibromyalgia found in qualitative research from psychological, sociological and medical research studies.

Hidden Illness

Sociological, psychological and medical research has focused on the problems individuals face with their families, and how they manage and make sense of their illness (Arnold et al., 2008; Bury, 2002; Lempp et al., 2009). As there is no clear aetiology or standard treatment for Fibromyalgia, it has been reported that individuals often describe feeling rejected, misunderstood and disbelieved (Henriksson, 1995). Consequently, Fibromyalgia has been described as an invisible illness due to the lack of outward bodily signs of a physical abnormality or any organic pathology to detect a disorder (Neumann & Buskila, 2003). This invisible illness can possibly lead to Fibromyalgia being contested by an individual's social circles – family, friends and work colleagues – as their credibility can be called into question, creating difficulties that impact the individual's relationships and social roles (Barker, 2011). Subsequently, this may lead to their social circles and their doctors being sceptical about the nature of the pain and other symptoms described by those who have Fibromyalgia (Conrad & Barker, 2010).

Hellström et al.'s (1999) phenomenological study found that Fibromyalgia participants reported that some doctors regularly questioned the moral and social legitimacy of Fibromyalgia, leading to their credibility being doubted due to the lack of a clear outward sign of illness. Having a chronic illness that is hidden may have led these participants to report feelings of being undermined and stereotyped by doctors for having an illness which stemmed from a diagnosis of exclusion. Furthermore, research has shown that speaking excessively about an illness could be interpreted by others as groundless suffering from unreal pain (Schaefer, 1995). Similarly, some patients reported that their family and social relationships became strained, due to a loss in various areas of their social lives (Lempp et al., 2009). Consequently, some patients described debilitating physical and emotional symptoms; feeling lonely, isolated, decreased enjoyment and a sense of grief about the loss of their previous identity (Raymond & Brown, 2000). Some individuals with Fibromyalgia described avoiding people who reacted negatively to their illness in order to avoid being exposed to enacted stigma. Other reasons why only women with Fibromyalgia withdrew from social activities were fatigue and difficulties planning ahead due to the unpredictability of their illness (Åsbring & Närvänen, 2002).

Social Doubts

Lempp et al.'s (2009) qualitative study on Fibromyalgia patients' experience of living with the syndrome and receiving treatment highlighted many consequences associated with Fibromyalgia. In terms of health identity (mental distress & impact on social life), patients reported a lack of self-confidence and sense of self whereby they experienced dissonance between how they felt on the inside and how they looked to others on the outside. Their study supported other research that highlighted patients' daily and frustrating struggles to

prove their illness to doctors, family, friends and work colleagues who could not objectively detect any physical illness (Barker, 2009). This lack of acceptance of a real illness was due in part to the lack of available knowledge patients could use in order to explain their illness to others. Some participants could not convey a clear understanding of Fibromyalgia to others or explain what was wrong with them in a way that others understood. This possibly led to others questioning the reality of their illness (Barker, 2009). Additionally, it has been suggested that patients became aware of the ambivalent attitudes towards Fibromyalgia and legitimacy claims surrounding it being a real condition, as well as the hesitancy of doctors to use the diagnostic label, only during the diagnostic process (Wuytack & Miller, 2011). Consequently, the doubts held by doctors may have led patients to doubt their own experiences as to whether or not their symptoms were imagined, 'all in their head', or an over-reaction to a normal event (Armentor, 2017).

As a result, individuals with Fibromyalgia reported experiencing negative comments from work colleagues who inferred that they were not trying hard enough to overcome their illness or were using their illness as an excuse to not work before receiving a diagnosis (McMahon et al., 2012). Similarly, for family and friends it has been stated that some family members can be supportive in sharing domestic responsibilities whilst the individuals were ill but others expressed doubts regarding their illness (Cooper & Gilbert, 2017). For some patients, using a wheelchair or walking stick as a visible marker to illustrate their symptoms was reportedly used to help them gain respect and legitimacy from others in their social surroundings (Lempp et al., 2009). It could be suggested that those with Fibromyalgia received varying degrees of social acceptance (Wuytack & Miller, 2011).

For some patients the diagnostic label justified giving themselves permission to spend time on self-care and partially released them from social demands and responsibility (Hallberg & Carlsson, 1998). It has been suggested that the diagnostic label can counteract scepticism and negative attitudes held by other people within the individual's social world to help legitimise their illness experience (Cooper & Gilbert, 2017). Armentor (2017) proposed that the way in which Fibromyalgia is explained to other people determines social acceptance or rejection. She argued that when Fibromyalgia is explained in specific terms by patients through an authoritative account of their illness this can lead to greater social understanding and sensitivity from others.

Gender Differences

Interestingly, most of the initial medical research on Fibromyalgia omits reference to sex (male/female); however, historical references to symptoms of hysteria and neurasthenia have been associated with the condition (Armentor, 2017). Therefore, it could be argued that as those who have Fibromyalgia are predominantly women, psychiatric explanations are being used for a medical condition that is poorly understood (White et al., 2001). Similarly, it could be argued that the DSM V classification of Fibromyalgia as a Somatoform Disorder, could be seen as a culturally shaped idiom of distress to describe concerns about a wider range of personal and social problems without indicating an organic pathology (Hadler & Greenhalgh, 2005). As a result, it could be suggested that doctors may have believed that as a diagnosis of Fibromyalgia is more common in women, this may have been due to women being more prone to expressing their emotions through physical symptoms, expressing negative affect, and thus paying more attention to physical sensations than men (van Wijk, Huisman & Kolk, 1999).

Furthermore, Briones-Vozmediano (2018) conducted a study in Spain on how health professionals constructed patients with Fibromyalgia. Their findings suggested that as Fibromyalgia affects more women than men, the health professionals interviewed perceived Fibromyalgia to be a women's disease. These stereotypes from the health professionals support previous research that has noted that the gender of the patient has an effect on doctors' decision-making processes in regards to the diagnosis and management of pain-related diseases (Borkhoff et al., 2009). Bösner et al. (2011) found that doctors tended to assume different causes of pain depending on a patient's gender, for example, symptom severity could be underestimated in women as psychosomatic symptoms were commonly used as an explanation for their symptoms. This may lead to women feeling ignored, dismissed and rejected by their doctors (Kool et al., 2009). Briones-Vozmediano (2018) implied that as a consequence a Fibromyalgia diagnosis in male patients may be difficult to some degree, due to doctors' harbouring the idea that Fibromyalgia is socially accepted as a women's disease in Spain and therefore male sufferers being unlikely to seek medical help. Furthermore, these researchers argue that as more women seek medical help this may account for the over-diagnosis of Fibromyalgia in women and the under-diagnosis in men.

Stigma

Goffman (1972) noted that a person with a stigma can be either discredited, which means they are visibly different to others or discreditable, which indicates that they have a deviancy that is not visible. For those with Fibromyalgia both cases could possibly apply as there is a lack of external signs and others may interpret patients as making up their illness, which may lead to stigma (Charmaz, 1983). Within the doctor-patient relationship, patients often described a struggle to prove their symptoms and to convince their doctors that their illness

was not psychological or made up in order to become a legitimate patient (Hellström et al., 1999). In turn this could lead to patients possibly being made to feel that if their symptoms are psychological they are to blame for their own suffering (Schaefer, 1995). Likewise, when work colleagues or family members infer that individuals are being lazy, these individuals may perceive their morality as being questioned and that others are doubting their motivation and attempts needed to recover (Mengshoel & Heggen, 2004). Thus, it could be argued that living with a chronic illness such as Fibromyalgia can lead to stigmatisation (Kool et al., 2009). However, in the psychological literature there has been an increased interest in stigma measures, with guidelines and suggestions examining how to measure mental illness stigma (Bos *et al.*, 2013). Yet, Fox et al. (2018) argued that these existing measures in the past may have lacked consistency in their definitions thus making it difficult for researchers to use them in clinical practice to evaluate their patients which in turn may have impacted efforts to develop interventions to reduce mental illness stigma.

Social Acceptance

Mengshoel et al.'s (2018) study on the diagnostic experience of patients with Fibromyalgia claimed that their participants mentioned that the onset of symptoms was attributed to an unexpected life event, physical or psychological trauma, or something dormant in the participants' body being triggered. The study participants reported that they initially ignored the growing number of symptoms until these became debilitating and their family and friends confirmed that something was wrong with them. This study highlighted that these participants ignored their symptom presentation until their surrounding social network could see the impact their symptoms were having on them, which confirmed that they were ill. Sim and Madden (2008) explained that most patients when given a diagnosis of Fibromyalgia are

relieved as this diagnostic label validates their illness beliefs by giving meaning and clarity to a previously ambiguous situation. A given diagnosis signified to patients that they were not suffering from an organic disease, would not end up wheelchair bound and were not psychologically unwell (Söderberg, Lundman, & Norberg, 1999). Furthermore, having a diagnostic label gave patients a name for their symptoms and allowed them to communicate this with other people (McMahon et al., 2012). As a result, the diagnostic label of Fibromyalgia contributed to the validation of patients' experiences as real by allowing patients to access sick notes, governmental funds, referrals to other health professionals, and brought about an awareness of a shared experience with other individuals with Fibromyalgia (Mengshoel et al., 2018). From this perspective, being given a diagnostic label allowed patients to give meaning to their illness.

It should be noted that these in-depth qualitative studies have limitations. The main limitation being that these studies focus mainly on women with Fibromyalgia and exclude men. However, this is due to the low proportion of men (10%) diagnosed with the condition (Collin et al., 2017). Nevertheless, Paulson et al.'s (2002) study on the lived experiences of men with Fibromyalgia found no noticeable differences in gender in terms of physical and psychosocial experiences. These researchers identified similarities in difficulties with identity and sufferers' inability to cope with pain. Moreover, a majority of studies involve small samples from primary or tertiary clinics, which cannot be generalised to the wider Fibromyalgia community (Mengshoel et al., 2018). On the other hand, it can be argued that these findings do represent direct insights from Fibromyalgia perspectives as the findings are consistently repeated, for example from studies that represent minority ethnic groups or were carried out in other countries (Colmenares-Roa et al., 2016; Homma et al., 2016; Schaefer, 2005).

Introduction Summary

This literature review highlights how the diagnosis of Fibromyalgia can be problematised by exploring how expert texts construct Fibromyalgia. Problematising a discursive construct allows for the scrutiny of a phenomenon that is taken-for granted in its daily uses so that what it does for individuals who use it within a given context can be examined. Research has shown that Fibromyalgia cannot be attributed to one single cause or a single disorder but rather appears to be related to biological, psychological and social factors that contribute to the development and perpetuation of the syndrome. As a result, the biopsychosocial model has been used to describe this syndrome as this incorporates all factors associated with the aetiology (Wolfe et al., 1990). Consequently, in deconstructing Fibromyalgia from expert texts, I have been able to show how Fibromyalgia can be talked about by institutional bodies and thus by those within positions of power. I have illustrated the discourses they use to construct the syndrome, and highlighted the consequences and limitations for action for each discourse.

However, there is a gap in the literature as most studies that examine Fibromyalgia discuss the experience of Fibromyalgia either from a patient or clinician perspective. These studies have looked into how individuals make sense of an experience and thus take an IPA approach in their research papers. These IPA studies have provided a clear understanding of what it is like to have Fibromyalgia and the difficulties in managing the syndrome both as a patient and as a clinician. So far, Briones-Vozmediano (2018) is the only discourse analytic study that has looked into how health professionals talk about Fibromyalgia, construct patients with Fibromyalgia and the consequences attached to referring to the syndrome as a women's

disease. However, these studies were conducted in Spain and talked about the implications within the Spanish health-care system.

Foucault (1979) argued that the way people think and talk about a topic such as illness and the way healthy or sick people are represented within society brings about implications for the way we treat people with these representations; in other words, discourses entail power relations. Hence, a Foucauldian Discourse Analysis focuses on issues of power by analysing various forms of social inequality such as disability or mental health and the way in which these are represented within society with a view to challenging such inequality through research (Burr, 2015). Limited research has been conducted on how patients with a diagnosis of Fibromyalgia construct their experience of Fibromyalgia and explored what subject positions, practices and possibilities for subjective experience are made available to them. This study, therefore, aims to explore these research questions and in doing so could provide guidance for social reform for Counselling Psychologists within the UK health system when working with people with Fibromyalgia.

Chapter 2: Methodology

Chapter Overview

This chapter will outline the aims and rationale for this research study. The theoretical positioning will be explained in terms of its epistemology and ontology. The methodology of the study will then be explained and how the chosen method was the best fit for the research aims. Next the research process will be described in terms of how the research was conducted, that is, recruitment, interviews, transcription and data analysis. Taking a reflective stance that shows my ownership of the research journey, I will be writing this chapter in the first person. As an ethical researcher, my conceptual, personal and emotional investments in this study will be noted to reflect my personal experiences in conducting this research.

Research Question and Aims

The aim of this study was to find out how patients diagnosed with Fibromyalgia construct their experience of Fibromyalgia and thus what subject positions, practices and possibilities for subjective experience of having Fibromyalgia are made available to them. This could provide guidance for social reform for Counselling Psychologists within the UK health system working with people with Fibromyalgia.

Research Design

Willig (2012) explained that qualitative research takes a bottom-up approach to data, by exploring in-depth and context-specific experiences in individuals. Unlike quantitative research which is about the relationship between variables, qualitative research takes a descriptive and interpretative approach that cannot be generalised to a wider population.

The aim of this study was to discover how individuals construct meaning for themselves in their talk of Fibromyalgia and how the discourses used influence subjectivity, positioning and practices. A quantitative approach was therefore inappropriate and I adopted a qualitative approach to my research question as it would allow me to access rich in-depth data to explore how individuals talk about Fibromyalgia and what it means to them.

Theoretical Position of the Research

Social Constructionism

Social constructionists challenge previous conventional views upheld by positivists and empiricists that knowledge is based on objective unbiased observations of the world (Burr, 2003). Social constructionism is a theory of knowledge that examines the development and construction of the social world. For example, in regards to illness, social constructionism focuses on how meaning is produced and how an individual's experience of an illness is shaped by historical, cultural and social systems. From this perspective, an individual's knowledge is created through daily interactions with others in their social life. It takes the approach that individuals socially construct their experiences of the world rather than starting with an individual's perspective (Young & Collin, 2004). From a constructionist perspective, feelings and experiences are socially constructed realities (Edleys, 2001). Consequently, what gets labelled as a disease or illness is socially negotiated (Conrad & Barker, 2010). Thus, an individual's internal experiences are considered to be influenced by external social constructs and institutions (Eatough & Smith, 2017).

According to a relativist ontology, language is the tool individuals use to give structure and meaning to their experiences, which have different consequences for one's actions (Burr,

2003). In other words, social constructionism sees language as a form of social action that constructs reality through discourse; therefore, multiple realities can exist. Within this philosophy Counselling Psychology research aims to understand how perceived social reality and knowledge is created by individuals (Schwandt, 2000). Therefore, research does not try to gain access to participants' inner experiences or how they make sense of their experience but instead focuses on how the participants construct their versions of reality depending on their social context.

Critical Realist Approach

Social constructionism is on a spectrum between extreme relativism and critical realism, with moderate social constructionism having an affinity to the latter. Relativists take a bottom-up approach to knowledge and view language as the creation of reality (Burr, 2003). Yet, critical realists take more of a top-down approach to knowledge by arguing that reality does not determine knowledge but restricts how we can construct the world and limits what can be done within these particular contexts (Willig, 2012).

Critical realists interpret text to gain access to an individual's underlying structures that produce meaning within a particular context and thus do not assume that the text directly reflects an individual's reality. Instead, moderate social constructionists focus on what can be said or done within a particular discourse within a particular context. Such researchers make references to the wider socio-cultural context by grounding discourse in social, cultural, economic and material structures to allow for reality that pre-exists and forms the way an individual constructs meaning within a particular context (Willig, 2012). In this way the

research can consider the possible consequences that emerge and have effects on that individual.

Ponterotto (2005) states that critical theorists argue that knowledge is mediated through power relations between social and historical contexts that are socially constructed through lived experiences. Hence, language is critical for the formation of subjectivity and how reality is constructed within these discourses. From this perspective, reality is socially constructed, leading to many different realities depending on context, time or individuals in any given situation. In this way, reality cannot be generalised (Mertens, 2009). Thus, critical realism combines constructionist and realist positions to argue that while meaning is made in interaction, non-discursive elements also impact meaning. Critical realists consider agency and subjectivity by understanding that an individual's actions will be influenced by personal and societal mechanisms independent of their thoughts or behaviours (Sims-Schouten, Riley & Willig, 2007).

Summary of Epistemology and Ontology

This study will therefore be taking up a critical realist position which informs its epistemology and ontology. The focus of this study is on how individuals construct their diagnosis of Fibromyalgia (context) and the consequences of the discourses they use (agency and subjectivity). I propose that there is a material world that is mediated through language being constructed and which has a reality to it independent of what is spoken about (ontology). As I am not assuming that data directly represents reality but instead that it needs to be interpreted to create meaning. In this way, reality is indirectly accessed through the discourses taken up (epistemology).

Choosing a Methodological Approach to Research

Discourse Analysis

Discourse analysis fits well with the theoretical positioning of this study. Discourses are a set of meanings or stories of institutionalised use of language which produce certain versions of events of the social world (Davies & Harré, 1997). Taking a critical view, discourse analysis examines meaning in texts to show how individuals account for and make sense of themselves and their social worlds (Shotter, 1993). This type of analysis proposes that individuals use language to construct versions of their social worlds and that their identity is established through discourses. Therefore, a discourse analysis seeks to identify the discourses individuals draw upon to make sense of their worlds and to examine the consequences and limitations of this (Burck, 2005).

Foucauldian Discourse Analysis

Underpinned by a constructionist ontology, discourse analysis operationalises Foucault's theories (Davies & Harré, 1990). Influenced by the post-structuralist ideas of Foucault, in the late 1970s, a Foucauldian version of discourse analysis was introduced to English-speaking psychologists. These psychologists investigated the implication for psychological research in the relationship between language and subjectivity (Henriques et al., 1988). Foucault (1982) regarded knowledge as form of power. He argued that expert knowledge about what is considered normal versus abnormal is a constructed through medical discourse, for example. As a result, he proposed that medical discourse has an influence on an individual's behaviour which subsequently impacts the individual's subjective experience of self, their identity and the medical interventions possibly made available to them. Therefore, individuals' perceptions of reality and thus how they perceive themselves are created by discourses.

Willig (2013) states that Foucauldian Discourse Analysis (FDA) is concerned not with truth but with how individuals' subjective experiences become constructed through language and the effects that discourses have on individuals' subjectivity. This type of discourse analysis explores how historically individuals got to be in a particular phenomenon and what the implications were for the individual's subjective experience and the consequences of their sense of self. In turn, these discourses give rise to certain views of the world being made available and certain ways of being within the world, which are constantly changing. These subject positions that are made available need to be negotiated and may offer contradictory experiences and practices for those who take up the position (Frost, 2011). This form of analysis suits my research aims as I am exploring the discourses made available to individuals with Fibromyalgia and their relationship to these discourses. However, Willig (2013) cautions that because FDA focuses on the use of language, FDA researchers cannot draw conclusions about the nature of a phenomenon in terms of what can be felt, thought or experienced.

There are several other limitations to FDA. Nightingale and Cromby's (1999) critical review of macro social constructionism highlights how if reality is socially constructed, an individual's agency, subjectivity and sense of self are secondary products of available discourses. For example, the process of constructing and negotiating one's social position is restricted by these available discourses. Willig (1999) revealed that individuals are constrained by their available discourses and those with the subject position of an illness are therefore left with limited potential to change their situation. Kitzinger (2015) demonstrated that individuals who tried to challenge their social institutions, could not break out of their discourses and thus maintained their sense of powerlessness. In this way, in terms of a medical discourse, patients' lack of medical knowledge positions them such that they have lesser rights in making

decisions about diagnoses or treatment options. Burr (2003) claimed that as a result social constructionism moves away from human embodiment (including agency) by neglecting individuals' experiences.

Alternative Approaches to Research

FDA does not allow for individual agency in how within the given context individuals negotiate their talk or operate language. Discursive Psychology overcomes this limitation by paying attention to the action orientation of language and how individuals use language to manage and negotiate social interactions within a given context (Brunton et al., 2018). However, despite these limitations of FDA, this study is suited to FDA as it seeks to explore language within a wider context by considering the effects of discourse and what could be said, by whom, where and when, as well as the constraints and limits these discourses facilitate and the subject positions that are taken up.

Research studies conducted on Fibromyalgia highlighted in this literature review examine the experiences of having the syndrome. These qualitative studies mainly use Interpretative Phenomenological Analysis (IPA) as a methodology to analyse the findings which tend to reveal how individuals make sense of an experience. However, there is a gap in the research in how Fibromyalgia can be understood using other types of methodology. For example, there is limited research on how Fibromyalgia is constructed, with just one Spanish scholar (Briones-Vozmediano) conducting recent research (2013, 2017, 2018) using discourse analysis to examine the construction of Fibromyalgia from different perspectives (policymakers, professionals, patients). However, there has not been a discourse analytic study on how UK patients construct Fibromyalgia, which this study seeks to discover.

Procedural Aspects

Recruitment and Sampling

Participants were recruited via social media through snowballing. Snowballing is widely used for qualitative research allows for the inclusion of geographically dispersed patients (Parker, Scott & Geddes, 2019), which fits with the aim of the study. The recruitment poster (**Appendix A**) was posted electronically on social media sites including Fibromyalgia support groups on Facebook and Twitter as well as on Helpfulpeeps. I also emailed six private Fibromyalgia clinics from across the country to advertise my poster on their notice boards for their patients to see. The poster invited volunteers to contact me directly via email if they were interested in taking part and I would then send them further information about the study (**Appendix B**). The inclusion criteria for the participants were that they had to be over 18 years old, diagnosed by an experienced clinician for more than three months (in accordance with the 2010 American College of Rheumatology classification criteria; Wolfe *et al.*, 2010) and be able to communicate effectively in English (so that they could communicate a range of experiences). The exclusion criteria included participants with severe mental health issues or severe physical issues. This was with a view to reducing talk of comorbidities which may have distracted from the main focus of the study. Adherence to the inclusion criteria was discussed during the pre-screening interview.

Participants

Due to difficulties initially recruiting, following weeks of poor response from social media posts and no engagement from the private clinics, seven participants would be chosen when volunteers eventually responded to take part in this study. These seven were deemed appropriate to address the research aims, and would be able to engage deeply with the

interview transcripts within the research timeframe. Research has shown that for discourse analysis it is not important to have a large sample size given that discourse analysis does not generalise its sample to a wider population (Frost, 2011). However, one day my study went viral on Twitter and a number of volunteers emailed me wanting to take part. A total of 24 volunteers emailed me for further information regarding the study and due to the high demand I took down all adverts on social media as I had reached my study capacity for participants. I emailed all 24 participants with the information sheet which contained further details about the study. Seven participants did not reply to my email. Of the remaining 17 participants who responded wanting to take part, the first seven participants were scheduled for a pre-screening interview to assess their eligibility, after which all seven were accepted. Dates and times were then arranged for interviews to take place, however, three of the participants (two males, one female) withdrew from the study before their interviews. Contact was then made with another three participants in order of who had responded to the further information email first. These three new participants passed the pre-screening interview and were scheduled for an interview date and time. As seven was already deemed to be a sufficient number to engage deeply with the transcripts in order to address the research aim and complete to research within the timeframe, the remaining 10 participants were informed the study had reached capacity.

In total, 7 UK-based women (4 of White backgrounds, 2 of Asian backgrounds and 1 of Middle-Eastern background) between the ages of 25 and 57 were recruited for this study. The pattern of more women than men volunteering for a study such as this one is a reflection of the high prevalence of females in those diagnosed with Fibromyalgia (Jones et al., 2015). Although homogeneity of data is not a concern for FDA (Taylor, 2001) and the participants could have

been recruited from anywhere in the world, this study only used UK-based participants as it was important in terms of the wider social context and discourses they might draw upon, with the aim of finding ways in which Counselling Psychology can contribute to improving the UK health system's provision for working with people with Fibromyalgia.

Interview Setting

Participants were originally only offered interviews at City University, as stated on the information sheet. However, during the pre-screening interview many participants voiced their objections to having to travel into Central London just for an hour, describing their struggles with mobility due to their chronic pain and their discomfort with large crowds on the tube making it difficult to travel. Therefore, the option of Skype was given as an alternative.

Lo Iacono, Symonds and Brown's (2016) study found that Skype interviews were as effective as a method of data collection in qualitative research as face-to-face interviews. They found that Skype interviews were time-efficient, financially manageable and thus increased the variety of participants studied. Moreover, as participants were in their own comfortable environment, they were more likely to feel open enough to talk in their own time. Six participants preferred to be interviewed via Skype as they felt more comfortable not having to travel to or within London. One participant met me at City University.

Semi-Structured Interviews vs Focus Groups

Conducting focus groups was considered as an alternative method of data collection. Focus groups deal with meaning making of a collective, social or shared activity using a more naturalistic approach (Hammersley & Atkinson, 2019). In addition, focus groups facilitate the

expression of individuals' ideas, beliefs and opinions through their collective sense of meaning. Willig (2012) suggested that rather than meaning being gathered on an individual basis as in an interview, focus groups allow the researcher to observe the process through which meaning is created and negotiated within the social context of the group setting. Participants of a focus group tend to have a shared experience and, in this case, all participants would have a diagnosis of Fibromyalgia. Although Willig explains the benefits of conducting a focus group as it is more in line with a discourse analysis, this data collection method is not always practical. For example, the participants I needed for this study suffer from chronic pain which could affect them at any time. So, it would not have been feasible to arrange a time where multiple individuals with a health condition could all get together on the same day, at the same time, in the same place.

Alternatively, instead of creating a group, I sought to access already established Fibromyalgia groups in the hope of using one of their sessions to conduct my research, as the participants would already be meeting at a particular time and place. However, I had difficulties accessing Fibromyalgia support groups. My struggles occurred when I reached out to the gatekeepers of these groups who failed to respond to my requests to advertise my recruitment poster on their social media pages. Therefore, although a focus group would have been preferable for a discourse analysis, it was impractical for my research and hence I opted for individual interviews.

[Semi-Structured Interviews](#)

It may not always be ethical or practical to collect naturally occurring data that fully represents an individual's experiences being studied, such as by sitting in on a medical

appointment; consequently, interviews are the most common method of data collection (Willig, 2008). This study used semi-structured interviews whereby set questions were administered to all participants with the option of adding supplementary questions to be added to probe the participants if they had difficulty elaborating (Marks & Yardley, 2003). This open-ended questioning style would allow me to compare all participants' responses about how they conceptualise and construct their experiences in response to the same questions (Frost, 2011). Although discourse analysis prefers a naturally occurring dialogue as its data source (Willig, 2008), I was aiming to recreate this element by providing a space of uninterrupted flow for the participants' narrative to be expressed however they saw fit, without imposing my assumptions by remaining open to all concepts that arose and thereby discover the participants' individual framework of meaning (Britten, 1995).

Interviews

Prior to the interviews, participants' consent was obtained. The consent form (**Appendix C**) outlined issues relating to data protection, confidentiality, their right to withdraw at any stage prior to the analysis process, and their chosen pseudonym to protect their identities. Each interview lasted around 60 minutes and was audio recorded. During the interviews, I tried to create a space where participants felt safe, comfortable and not judged so as to enable them to talk openly about a sensitive and personal topic. If any distress arose during the interviews, I used my therapist skills to express compassion and empathy; however, I tried to actively listen as much as possible so not to interrupt the participants' talk about their experiences as they saw fit. Participants were given time in the interview debrief, which detailed the aims of the study, to ask any questions they had. If any distress was experienced by the participants,

they could use the debrief form (**Appendix D**) which contained mental health helpline numbers and places to seek psychological support.

Pilot Interview

A pilot interview was conducted with a participant who met the inclusion criteria but lived in the US, where medical practices are different to those in the UK, and therefore could not be included as part of the data analysis. The aim of the pilot interview was to ensure the interview schedule was appropriate to answer the research question and was sufficiently sensitive. According to Majid et al. (2017), piloting interviews is a crucial stage in qualitative research. This preparation before the main study allowed me to try out the interview questions in order to address any practical issues that may have arisen, in addition to helping me gain practice in interviewing skills.

The pilot interview was helpful as it allowed me to ask different questions that focused specifically on my research question rather than having a general discussion about the topic. For example, I included questions relating to participants' feelings towards their clinicians and how Fibromyalgia changed their lives, which were then added to the interview schedule (**Appendix E**). The participant interviewed also made me reflect on the tension between the role of researcher and the role of therapist. There were aspects of the interview that were emotionally sensitive for the participant to talk about and I initially remained silent as not to influence their talk; however, this did not sit well with the therapist within me. After a while I realised that I would communicate my understanding of their experiences with an empathetic manner but not summarise their experiences for clarity, as this might hinder their expression of their experiences. This conflict I experienced was further discussed in

supervision. Overall, after the pilot interview, the interview questions I used were still kept broad to ensure that participants were able to talk about what it meant for them to have Fibromyalgia and what their experiences were like.

Interview Schedule

For the interview schedule, I initially had one question, 'tell me about having Fibromyalgia', as a way to introduce the participants to the topic of Fibromyalgia and to encourage them in a non-directive manner to construct their own meaning of the topic (Willig, 2013). However, as a novice to conducting interviews for qualitative data, I examined other doctoral research interview schedules and saw that they tended to include several questions to help prompt participants to offer the kind of data that would answer the research question. Thus, I added more questions, such as 'what does Fibromyalgia mean to you, how do you speak about Fibromyalgia to your friends..?', and 'have you been referred to any psychological services..?'. Such questions were used to help define the research aims and guide the participants on what to talk about if they needed a prompt. The questions that made up the interview schedule stemmed from the knowledge I had acquired during the literature review and my personal experiences working with this patient group. The pilot interview taught me to keep a better balance between maintaining control of the interview and allowing the participants space to talk as they wished about Fibromyalgia in order to generate novel insights whilst being mindful to not lose sight of the research question.

A challenge in the researcher being active in the interview process in discourse analysis studies was mentioned by Cruickshank (2012) who stated that the questions constructed by the researcher will not be the discourses in the purest form for the participants, as the

answers will partly be shaped by the discourses the researcher uses. Therefore, the responses of the participants in this study may have been shaped partly by my own discourses used to construct Fibromyalgia (biopsychosocial) and these may have influenced my participants to talk about the topic using the same discourse, and so limited the opportunity for new insights and discourses to arise. Moreover, when I revisited the interview schedule after the interviews had been carried out, I became aware that the question regarding challenging doctors' opinion was a directive and leading question influenced by previous research studies that have consistently commented on the imbalance of power in the doctor-patient relationship. However, the aim of the question, although poorly phrased, was to try to bring up the topic of power within the conversation.

Analytic Steps

The data was coded using FDA; whilst Foucault did not offer a specific approach to analysis (Foucault, 1982), other researchers have outlined various ways data can be analysed (Parker 1992; Potter & Wetherell, 1987). Willig's (2013) six-step FDA, although not a pure Foucauldian analysis as it does not include aspects of the historicity of knowledge (i.e. genealogy) that make up a discourse, was nevertheless employed as it addressed the study's aim and research questions. Willig's approach addresses how constructions of objects and subjects within discourse are explicitly or implicitly used in text and the implications of this for positioning, practice and subjectivity. The six-step procedure is as follows:

1. Discursive Constructions:

The first stage identifies the ways in which the discursive object (Fibromyalgia) is constructed in the text. All references to the discursive object, whether implicit, explicit or direct, will be highlighted.

2. Discourses:

The second stage classifies different discursive constructions of the object within wider discourses within the Foucauldian frames of power and the institutionalised discourses of medicine and psychology that regulate social practice.

3. Action orientation:

The third stage examines the intention and function of the different constructs that the discursive objects are capable of achieving within the text.

4. Positioning:

The fourth stage outlines the subject positions and objects that are made available within the meaning of the discourse noted in the previous stages.

5. Practice:

The fifth stage considers how discourses and the subject positions contained within them inform practice.

6. Subjectivity:

The sixth and final stage explores the relationship between discourses and subjectivity and summarises the social and psychological experiences of having Fibromyalgia made available by the discourses identified.

Analytic Process

Phase 1: Transcription

All interviews were transcribed verbatim by me to ensure anonymity and confidentiality. As I was using FDA as a research design and thus not analysing the micro details of my participants' talk, I decided not use the Jefferson's (2004) system of transcription notation. I felt that this omission was consistent with my methodology and research aims. Whilst laborious, transcribing allowed me to become familiar with the data. Goodman (2017) noted that early stages of analysis are conducted through the transcription process as this allows the researcher to familiarise themselves with the data whilst capturing the effect of the discourses in the participants' responses. Once all transcripts were completed, I read the data whilst taking notes of my initial impressions and to familiarise myself with the data as a whole. These notes were set aside when it came to analysing the text as the purpose of a bottom-up approach is to discover what the data is revealing and not what the researcher wants it to reveal.

Phase 2: Analytic Notes

I colour coded the data in order according to the six stages, transcript by transcript (**Appendix F**). When I started analysis on the first transcript I noticed that I could not analyse the transcripts line by line as others had demonstrated in their theses. In my participants' talk their meaning made sense within paragraphs rather than per sentence or transcript line. Therefore, I analysed my transcripts per paragraph. As there is no set way to conduct the six steps, I started to apply the steps in order as implied by the procedure's numbering. However, I had difficulty analysing in step order as I found myself noticing different steps at different times. So, when I noticed discursive objects, positioning or subjectivity appear in the text I would highlight them in their respective colours as I went along. I made detailed analytical

notes on action and practice as I felt these needed more elaboration for me to understand the intention of the participants' talk.

Phase 3: Modifying my Approach

As the process continued and I was on my third transcript, I realised two things. One, I was printing a lot of paper when I printed my transcripts to analyse, and two, there were too many pages to keep track of the work I was doing. I decided to find a more effective and environmentally friendly way to work before I continued with my analysis. I played around with Adobe and realised that with the sticker function my notes could still be colour coded and could be viewed quicker than on paper. For my next and subsequent transcripts, I analysed them on a PDF file in Adobe. I found this method to be more effective as I elaborated more on the other FDA steps, instead of highlighting words as I had previously done. This process also allowed me to engage more with the data (**Appendix G**).

Phase 4: Analytic Summary of Transcripts

Once the analyses of all the transcripts were complete I created separate document folders in Word according to the discourses used in my participants' talk to construct Fibromyalgia. These discourses were: Biomedical, Psychological and Social. These discourses arose as I went through each transcript, starting with the Adobe notes and copying every reference to the discourse under its respective folder, with the transcript number and line numbers, e.g. T7 L144-149. With the printed transcripts, instead of copying the full notes, I made reference to the actions discussed e.g. T1 L104-116: nervous system. At the end of this process, I found that I had a macro view of the data which helped me to develop the framework for presenting the findings.

Phase 5: Identifying the Main Themes

Within these separate documents of discourses, participants spoke about two or three themes of discursive objects. I went through each document and separated the data according to the themes discussed. I noticed early on that within each discourse the participants had spoken about similar topics, which made this grouping stage much quicker to sort out. It was from this grouping stage that I developed clarity on the way participants used discourse within their talk and the consequences this entailed. These grouping stages set out the basis for the sub-sections within my analysis chapter.

The three discourses – biomedical, psychological, social – arose as I felt the participants talked about Fibromyalgia in the same way as the expert texts constructed it. The biomedical discourse that the participants spoke about comprised their experiences within the medical institution whilst the psychological discourse arose from the participants' talk about emotional and functional difficulties with managing their Fibromyalgia without medical assistance. Lastly, the social discourse comprised the participants' talk about their experiences within society. I am aware that the biopsychosocial model used to construct Fibromyalgia in expert texts influenced how I summarised the discourses used in the participants' talk. At the time of analysing the data, other discourses may not have been considered due to my limited experience of carrying out discourse analysis, as I did not fully understand what a discourse was. However, I feel that other discourses that could have been used to construct how the participants talked about Fibromyalgia were not ignored, as the discursive themes that formed the sub-section within each discourse could have been considered as their own discourses, such as power transition, self-help or social life by another researcher.

Validity and Reliability

Qualitative research is concerned with specific individual experiences within a particular context, and the role of the researcher in this process is highly important in the attribution of meanings and interpretations of the data (Willig, 2013). Following Yardley's (2000) quality criteria, this research adhered to the following principles: *Sensitivity to Context*, which was shown through the literature review and methodology sections which incorporated social-cultural awareness and ethical considerations; *Commitment and Rigour*, which was demonstrated through my in-depth engagement with the process of data collection and analysis; *Transparency and Coherence*, which was shown through clear and detailed description of the methods and data, and the fit between the research question and the philosophical perspective adopted in addition to a reflexivity section; and lastly *Impact and Importance*, which will be demonstrated through this research enriching Counselling Psychologists' understanding of patients living with a diagnosis of Fibromyalgia and the social-cultural and practical implications for the wider community.

Ethics

This study received ethical clearance from the Psychology Department Research Ethics Committee, City, University of London (ETH1819-0084) and complies with the BPS (2014) and HCPC (2016) Code of Ethics for Human Research. This research adhered to the following principles: respect for autonomy, privacy and dignity of participants, scientific integrity, social responsibility and minimising harm. The nature of the study was explicitly outlined in the recruitment poster and informed consent form. All information given by participants was deleted if they withdraw from the study, did not respond to emails sent to them or could not take part due to capacity reached. Those participants who took part had their information

anonymised as confidentiality was paramount. Names and any identifiable details were changed. Printed consent forms from participants who conducted their interviews via Skype were securely stored separately from the printed transcripts to further protect the participants' identities. These printed consent forms were stored in a locked file. Before the interviews, participants were reminded of their right to withdraw from the study up until the point of transcription. Participants were fully debriefed after the interviews and were given the opportunity to ask any questions they had. The ethics application was considered low risk due to the limited psychological and emotional distress the interview may have provoked, as the focus of the study was mainly on the expression of meaning in participants' talk about a particular phenomenon. In the interviews privacy around sensitive topics was respected and the debrief form contained contact details for mental health helpline numbers and places to seek psychological support should participants need it. Recordings and transcriptions were encrypted and stored on a password protected laptop. Transcripts were not shared with participants for clarification on their comments; my aim was to examine how the participants constructed stories about their experiences and thus the data needed to be analysed as presented.

Reflexivity

As this research is grounded within a social constructionist perspective, critical attention needs to be focused on my knowledge-making process and practices within historical, professional and cultural writings about Fibromyalgia as suggested by Harper (2003). Harper argued that this process allows the researcher to become accountable to the analysis through an explanation of their interest and context. A criticism of discourse analysis is whether or not the themes and discourse emerge from the transcript instead of being constructed by the

analyst (Steady et al., 2016). Thus, reflectivity in discourse analytic studies is important to reveal the methodological process through which the analysis is produced (Figueroa & Lopez, 1991). Therefore, it is important that I highlight my position as a discourse analyst and outline the factors that influence me, both externally and personally.

As a scientist-practitioner in this process whereby all knowledge is constructed through discourse, I was aware of my own discourses made available to me from my research knowledge, and the problematic status of what my own knowledge as a psychologist provides, and what is used to construct this knowledge. As an Assistant Psychologist then as a first-year Trainee Counselling Psychologist, I have spent three years working in a clinic for clients with Fibromyalgia, and recognise that I am part of the expert position that previous clients of mine have resisted (along with any psychological perspectives) in the past. Therefore, with my interview schedule I was very mindful of this and tried not to come across as the expert in the room by allowing the participants to talk about their experiences as openly as possible. However, I believe that working with this clinical population has already helped me gain an understanding of their experiences and made me aware of the possible tensions held with medical and social discourses. This knowledge helped guide my process in choosing the questions for the interview. Furthermore, during the interviews, I did not wish to impose my own experience onto my participants in the form of exchange of stories, might have occurred as I did not want to influence their constructions.

Looking back at the interview questions once the interviews were completed, I noticed that I would construct my questions within a certain discourse and that the participants would then use it. For example, if I spoke about doctors they would talk about something medical.

Although the first question was open and asked: What does Fibromyalgia mean to you?, it was from the participants' answers that my constructions developed to form the next questions for them to elaborate on. Yet, I wonder how truly open I was due to my lack of experience conducting interviews for a discourse analysis. I recognise that I was positioning myself within a certain discourse by constructing my interview questions around the dominant discourses that I had discovered from my literature review. Therefore, the words and terms I used such as 'diagnosis' or 'therapy' in the interview question may have reflected the knowledge I had previously gathered rather than being as neutral as I had intended them to be. Being neutral in my interview questions by allowing the participants to elaborate on their talk would have allowed their own constructions and discourses of Fibromyalgia to emerge rather than, as I now see upon reflection, me asking possibly leading questions. I think I could have been less directive in my questioning to allow the participants to talk in the way they felt was necessary, by asking fewer questions and instead using prompts such as 'tell me more about that' when they became stuck. I feel this would have probably allowed for more discourses and discursive objects to arise.

After each interview was conducted, I noted down my overall impression of the interview, points of anxiety and any incidents that stood out for me. Through this process of reflection, I was able to get a better understanding of how I felt I did as a psychological researcher and how the participants may have experienced me in the interview. Moreover, there were aspects in my participants' talk that I could relate to when conducting the interviews and more so when analysing the function of their speech. I noticed that when my participants were describing their experiences, I could relate to their daily struggles, as I too have a hidden chronic pain disorder (Sickle Cell Disease). I utilised my personal therapist and research

supervisor to reflect on my own experiences or difficulties that arose. Being reflective within the research process, I became aware of my own judgements and the assumptions I was making in addition to the research knowledge I acquired on the topic and kept a diary to work through my own emotional responses, which were separate from the responses of my participants. Furthermore, to ensure that my analysis avoided being critical of my participants, which Harper (2003) noted could be a downfall for researchers in a position of power, I decided to refer to my participants using numbers to avoid revealing their identities or any behaviours I noticed in the interviews. As a result, I was able to focus writing my analysis on the effects of my participants' talk rather than engaging in any psychological interpretations of their verbal behaviour.

A challenge I had with analysing the text was truly getting to grips with a discourse analytic perspective and not making assumptions by claiming to understand how the participants felt from what they said, as this would be more of a phenomenological perspective. Since I have never carried out an IPA or any qualitative research in the past, as my previous work was quantitative, I had to learn that I could not make claims about a person's thoughts or feelings but only draw conclusions about the discourses they drew on in what they said. It took me a while to understand this philosophical concept and when I did come to terms with it, I noticed in my writing that I still made mistakes in my wording of a sentence. I found it really important in the early stages of analysing the text to read discourse analytic journal articles to become more comfortable and familiar with this style of writing.

Chapter 3: Analysis

Research Aim Reminder

The aim of this study was to find out how patients diagnosed with Fibromyalgia construct their experience of Fibromyalgia and thus what subject positions, practices and possibilities for subjective experience of having Fibromyalgia are made available to them.

Chapter Overview

Having considered different ways to present the analysis by reviewing previous FDA theses, I chose to structure this section by looking at the different aspects of the participants' experiences. The questions asked during the interview explored what the term Fibromyalgia meant to the participants and how they talked about Fibromyalgia to other people. In response, the participants seemed to be using different discourses to make sense of different aspects of their experiences. As part of their experiences, participants talked about their diagnostic journey, experience of symptoms and management of Fibromyalgia. Within these discursive themes, it became apparent whilst converting the micro data (analysis of the data per paragraph) into a macro view (separating out the discursive objects across all transcripts) that the participants were discussing their experiences within three main discourses. I therefore divided the analysis chapter into these three discourses that emerged from across the transcripts. In participants' talk, the three different discourses established were: biomedical, psychological and social.

The first discourse is biomedical. This sub-section contains an overview of how participants used the discursive themes of diagnostic journey, their experience with medical professionals,

power transitions, and their overall experience of having Fibromyalgia to construct their treatment of Fibromyalgia. The second discourse is psychological. This sub-section contains an exploration of how participants used the discursive themes of how their Fibromyalgia was managed by themselves and others around them to deal with the symptoms they struggled with. The third discourse is social. This sub-section highlights how participants used the discursive themes of their experiences within society and the perceptions of others within society to construct their management of Fibromyalgia.

Whilst analysing the data, I noticed that participants drew on different discourses to tell their story. They used certain discourses to talk about certain things. I noticed participants changed their discourse depending on whom or what they were talking about. For example, when participants were talking about their diagnostic journey or their treatment of Fibromyalgia they would draw upon a medical discourse to talk about their illness. When discussing the main symptoms they struggled with and their experiences with medical professionals such as GPs or Rheumatologists whose perceptions of Fibromyalgia were constructed within a psychological framework, participants drew on a psychological discourse. Additionally, when talking about their family and friends' perceptions of Fibromyalgia or their experience with other people, they would take up a social discourse. Throughout each of the interviews participants used language to negotiate their positions and detail the consequences attached.

Within the main body of text I have included direct quotations of participants' talk. I have referred to the participants by number to ensure confidentiality as the participants did not want to make up an anonymised name to be referred to. The following quotes will contain the participant number (Participant 1) followed by the transcript line number (e.g. L 155-157).

Biomedical Discourse

This sub-section contains an overview of how participants used the discursive themes of diagnostic journey, their experience with medical professionals, power transitions, and their overall experience of having Fibromyalgia to construct their treatment of Fibromyalgia.

All participants constructed their diagnostic journey within a biomedical discourse. Participants talked about their journey towards finding a medical explanation for their symptom experiences. Their journey started with bodily symptoms that led them to believe that there was something physically wrong with them:

‘When I define Fibromyalgia I just define how it is for me, just how it’s for me rather than everyone because I’m talking about myself and you know so when I describe Fibromyalgia I just kind of talk about the symptoms that I’m having so pain, fatigue, brain fog, sleep problems, things like that yeah.’ (Participant 4, L146-149).

In her opening point Participant 4 emphasises the word **‘define’**, which may be her attempt to find a definitive explanation for Fibromyalgia but it seems as if she has difficulty finding the words as she instead begins to **‘describe’** her personal experiences. This could suggest that for her there is not a comprehensive or definitive definition that she can draw upon to explain what Fibromyalgia is. As a result, she constructs Fibromyalgia based on her physical symptoms. In her talk, Participant 4 constructs Fibromyalgia as a set of symptoms; she mentions her own experiences as pain, fatigue, brain fog and sleep problems. Through her construction she speaks to a subjective experience within the biomedical discourse. This suggests that Fibromyalgia does not have a specific set of symptoms but that each person who has Fibromyalgia has a different symptom experience. It could be implied that

Fibromyalgia is experienced differently by different people. However, all participants described having the same symptoms. Furthermore, in using the term '**symptoms**', the participant infers that Fibromyalgia presents as a set of physical features that indicate an underlying condition or disease. In constructing Fibromyalgia as a set of symptoms, Participant 4 is positioning herself in a sick role. It could be implied that she wants to be seen as ill in order to receive medical assistance. Other participants used the same word, '**symptoms**', to describe their Fibromyalgia experience.

From describing these subjective bodily experiences, the participants went on to talk about visiting a medical professional to investigate the cause of their problems. The participants talked about seeking out a medical practitioner, in most cases their GP (General Practitioner) or doctor. In practice, their GPs conducted multiple medical investigations and medical tests, mainly blood tests during their diagnostic journey. In response to the first question 'Tell me about having Fibromyalgia' Participant 2 responded:

***'Before the diagnosis I was always in a lot of pain in different parts of my body but I didn't really know what that was all about. So I went to the GP and they told me to do all the tests etc then I was referred to the rheumatology department. They did tests, I had like a CT scan as well and then that's how they basically said that I've got Fibromyalgia because it's about different points in your body and the pain comes from that. But I think my experience was around other the things, so sometimes feeling low and getting, you know just having to stay up all night in pain.'* (Participant 2, L4-10).**

Participant 2 summarises the diagnostic experience of most of the participants. She explains that her diagnostic journey began when she experienced pain within different parts of her

body. From this participant's talk, she seems to construct her experience of Fibromyalgia as a bodily experience which leads to different areas of her body experiencing pain. In this extract, Participant 2 does not exclude the possibility of psychological or social influences, as it could be implied from her description of depression and poor sleep that these may have contributed to her pain experience. Thus, she may be suggesting that Fibromyalgia might not be a solely bodily experience but may also be associated with emotional disability. Moreover, it seems that the participant was told by her GP that the pain she was experiencing due to her Fibromyalgia may have resulted from **'different points in your body'** which could be a reference to the classification criteria which relates to the presence of more than one anatomical region being affected. Consequently, in practice, she seeks a medical doctor to medically investigate the cause of her pain. In seeking a medical professional, the participants are able to gain access to medical investigations and tests, in this case, blood tests and CT scans, to determine the medical cause of their pain. It could be argued that for Participant 2, receiving medical tests she may possibly make her feel validated that her pain could be of a biomedical nature due to her GPs pursuits of a medical explanation for her symptoms.

Referral

It was not clear why Participant 2 was referred to a rheumatologist; however, when Participant 7 was asked 'How were you diagnosed', she responded:

***'Basically first I went to my GP and I kept going kept going and I saw a different GP, she did a lot of different blood tests and one of my blood tests is a C-reactive blood test, its information marker was much higher, and then she referred me because I kept saying I feel very tired it's not normal to feel that tired you know.'* (Participant 7, L107-110).**

Participant 7 constructed her diagnostic journey as visiting a GP who conducted a medical test, again a blood test, to discover or investigate a medical reason for her subjective experience of Fibromyalgia which was fatigue. The participant talked about actively seeking out a medical explanation for her symptom experience by constructing herself as being persistent by visiting her GP practice multiple times and seeing more than one GP within her diagnostic process until one GP conducted the blood tests. In her talk, the participant implies that the blood test results indicated an abnormal marker but it was her insistence in stating her fatigue which led to a referral. This suggests that she visited her GP several times in order to get tests performed on her to confirm an abnormality within her blood. Thus for this participant it seems as if the blood tests were instrumental in her receiving a referral; however, the language she uses implies that this was not what happened. In practice, it seems as if blood tests are part of the medical investigations used by GPs to detect medical abnormalities. Participants whose blood tests indicated an abnormality went on to describe being referred to a rheumatologist for further medical investigations. The participants detailed how it was these medical professionals who then diagnosed them with Fibromyalgia.

Through their constructions the participants positioned themselves as patients within a doctor-patient relationship. The participants' constructions suggest that as patients they were not involved in the diagnostic journey as their medical tests were done to them by their doctors. For example, '**they told me to do all these tests**' and '**she did a lot of different blood tests**'. Their constructions suggest that the diagnostic process is a one-way system where the doctors have all the power within this relationship to decide what medical procedures are done to their patients. In practice, GPs use tests in order to determine their patients' medical fitness.

Medical Professional's Opinions

Participants invoked a psychological discourse when they described their experiences of other people's perceptions of Fibromyalgia being a non-medical condition, especially when talking about their experiences with their GPs. When asked about how medical staff talked to the participants about Fibromyalgia, Participant 6 replied:

'That particular GP, you know they have no time. Sympathy not there, empathy not there at all. Many of these doctors especially the specialists told me it's all in your head and just get up and don't pay attention' (Participant 6, L144-145).

Participant 6 constructed their GPs knowledge of Fibromyalgia through a psychological discourse. Many participants GPs or other health professionals constructed Fibromyalgia as a made-up condition that existed in their patients' minds and implied that it was not caused by any physical condition. As such symptoms could therefore be ignored. These constructions may leave participants possibly experiencing a lack of empathy and care from their doctors. In addition, the use of the term ***'all in your head'*** closes down the possibility of the participants' symptoms being a product of both mental and physical factors. It also suggests that the GP believes that Fibromyalgia is a psychological condition and not a medical one.

Other participants talked about similar experiences and constructed their doctors as taking a psychological perspective towards their symptom presentation during their diagnostic journey. Participant 5 responded to the same question with:

'a lot of the doctors, and I have experienced that from the way they've spoke to me believe that it is just psychosomatic and that's it. Didn't have this trust that you are actually in pain because you can't prove them with a blood test, there's nothing tangible to show them that

there is something wrong with you so you must be making it up or there must be something wrong with your brain and mental health rather than the actually physical body’.
(Participant 5, L68-73).

From her explanation, Participant 5 suggests that her doctors claim that Fibromyalgia is psychosomatic which implies that her diagnosis is not made up of a physical illness but possibly caused by psychological factors. This construction implies that her doctors took into account a psychological explanation for her symptom presentation rather solely relying on taking a medical construct. Yet in her talk, Participant 5 suggests that she was expecting more of an explanation from her doctor when she says ‘**just psychosomatic and that’s it**’. From her construction it could be argued she was possibly annoyed with her doctor that he only offered her a psychological reason for her symptoms with no other alternative explanation given. This may have left her feeling disappointed as a patient that her doctor could not find a medical explanation for her symptom experiences. Participant 5 goes on to construct an environment in which her doctors do not trust her pain to be real as she cannot prove her pain through scientific procedures such as a blood tests. She proposes that as these medical tests appear to show no tangible evidence of a something medically wrong with her, she is possibly left to think that her symptoms are not real and rather due to stress, hence the psychosomatic reference. Furthermore, in her talk she infers that since there is no medical evidence to prove she has a medical condition, her doctors construct her pain to be psychological and thus a problem with her brain an issue with her mental health rather than physical health. Moreover, in her talk the participant separates the ‘**brain and mental health**’, which possibly suggests that she may believe that psychological conditions are perhaps neurological deficits. Therefore, from her construction she may be implying that her doctors view Fibromyalgia as

a made-up or cognitive defect instead of a condition that affects the body. Thus, it could be seen that for this participant experiencing psychological difficulties is to do with the brain rather than the individual's body. This construction suggests that participants ignore the possibility of a psychological construct in favour of a biomedical construct to talk about Fibromyalgia whilst their doctors try to convince them of an alternative reason for their pain. Within this construction, participants are positioned as untrustworthy patients who potentially lie about their pain or make up what is wrong with them. It could be argued that within this position, participants may be left to experience a sense of powerlessness in changing the beliefs of their doctors who presume them to be well. This may lead participants to possibly feel as though they have no hope in proving to their doctors that their pain is real, that **'there is something wrong'**, and that there may be a medical cause for their pain. In practice, although medically the blood tests seem to some not to show evidence or be able to prove Fibromyalgia to be a medical condition, for other participants blood tests are constructed as a useful tool that helped them gain access to referrals to other specialists, which promoted the diagnosis of their condition. Therefore, it could be seen that a blood test as a diagnostic tool is beneficial to participants, depending on the outcome of the results.

During their diagnostic journey participants were seen by different medical professionals to figure out what was medically wrong with them. During that process participants described meeting with different health professionals who they constructed to have the same opinions, that is, that they were not ill but instead experiencing psychological difficulties. The participants talked about experiencing resistance towards their doctors and GPs and talked about trying to convince them that they were ill, hence the multiple visits, long diagnostic journeys and insistence on referrals to other medical specialists. For example, Participant 4

described visiting her Occupational Health professional who then referred her back to her GP, who then referred her to a rheumatologist before she was diagnosed. When Participant 4 was asked about how she felt being referred to different services to figure out what was wrong with her she replied:

‘Frustrating because I had always been told nothing is wrong but my body wasn’t behaving normally, like they say you are fine but my body wasn’t acting fine so then I just started to believe people when they say “it’s your mood, it’s depression” so yeah I just like maybe it is then because they keep saying there’s nothing wrong.’ (Participant 4, L241-242).

Through her construction, Participant 4 implies that there was something wrong with her body which may suggest that she thinks she is physically unwell. However, she goes on to construct other people, probably other medical professionals, who argued that on more than one occasion communicated to her that there was **‘nothing is wrong’**. She implies that others have suggested it was her mood, a depressive state, as possibly the reason as to why she was feeling different within herself. The participant is positioning herself as a powerless patient who has no choice but to accept and change her own beliefs about what she thinks is going on for her in her own body. It could be claimed that being told by different people that the reason her body was not behaving normally might be due to her mood may have convinced the participant to change the beliefs about her body from a biomedical to a psychological construct.

Power Paradox

In their talk the participants constructed how health professionals (mainly GPs) constructed Fibromyalgia within a psychological discourse. Participant 1 positions her health professionals

as doctors who did not take her symptoms seriously enough to warrant any medical attention. Thus, in practice when Participant 1 was told by her GP: ***'You have to educate yourself and you have to just heal yourself' (L41)***, this GP's advice could have been interpreted as doctors choosing to diminish their responsibility to provide further medical support by suggesting that it's the patient's own duty to make themselves better. From this position she could be seen as a powerless patient who cannot go against what her medical professionals say. This may leave her to possibly feel as if her doctors are dismissive and unsympathetic towards her as a patient. Yet, from a different perspective, this construction could also suggest that doctors are telling their patients that they have the freedom to do their own thing and thus positioning that patient as reclaiming their power by doing what they need in order to make themselves better. From this paradoxical position, on one level the patients are given the responsibility to do what they feel is necessary to make themselves feel better but on the other level, without the medical resources, this can also limit what patients can do medically to assist themselves in this process. From Participant 1's construction this might lead her to feel as though her symptoms are not being taken seriously and thus ignored, leaving her to possibly feel neglected as a patient and disbelieved that her symptoms are a medical problem that needs to be medically taken care of.

Yet Participant 1 goes on to challenge her GP's perspective: ***'no you have to understand it, this is a proper medical problem and although you can't help me with medication there are other ways you can help me' (L154-156)***.

Using this medical discourse, P1 is challenging her doctor's original psychological construction by positioning herself as a patient with the power to challenge her original positioning. In doing so she is regaining her power as a patient by dismissing the professional's claims that

she has to manage her symptoms on her own. Instead, in practice she is asking for alternative routes to medication that as doctors they can support her with. This may lead her to feel hopeful that there are other types of treatments available.

Power Transition

The power dynamic shifted when participants were able to reclaim their power by insisting which medical professional could investigate their symptoms: ***‘I went to the GP and I said “I want to go and see a rheumatologist”’ (Participant 5, L22)***. In this following comment, Participant 5 positioned herself as a powerful patient who could make decisions about her diagnostic journey by insisting on a referral to a specific medical professional. In her talk, the participant empowers herself by becoming involved within the diagnostic process by expressing her own demands about her diagnostic journey. Similarly, Participant 7 noted that it was her insistence that there was something wrong with her that led to a referral: ***‘she referred me because I kept saying I feel very tired it’s not normal to feel that tired you know’ (Participant 7, L109-110)***. Their constructions suggested that without being persistent towards their doctors and in doing so asserting their power, they would not have been referred. It could be argued that the participants may have been left to feel as if their symptoms were not taken seriously as they possibly felt that there was something still not normal about their symptom experiences even after their medical tests and visits to their GP. This suggests that the participants went looking for further medical investigations to prove their symptom experiences were of a biomedical nature.

Although the participants constructed transitioning from being a powerless to a powerful patient, throughout their diagnostic journeys they constructed their experiences as a patients

who were not believed to have a medical condition. The participants talked about how they had to be persistent to get more medical investigations performed in order to be believed that they were ill:

'I know it's quite common for people to be dismissed when they have chronic pain or Fibromyalgia in general because it's an illness that takes a long time to diagnose. There have been doctors that have dismissed me for a long time and it's taken a long time to have someone believe me and I've been diagnosed by that rheumatologist so quickly and I just cried because because it felt like somebody heard me for the first time, like it was that easy for him to diagnose me and like why did it take so long when I've been saying this for years and no one listened to me and it made me sad that it was that easy for him to just diagnose it and that I was right about it the whole time. (Participant 4, L202-210).

Participant 4's talk about the length of her diagnostic journey suggests that this is a common experience for people with chronic pain or Fibromyalgia. This extract highlights that Participant 4's experiences of chronic pain and Fibromyalgia are constructed to be different experiences but are both categorised as illnesses, and thus possibly conducive to the validation of her experience in having medical attention for years, which may re-emphasise participants' commitment to Fibromyalgia as a biomedical construct. It could be argued that the participant's mention of being seen by '**doctors**' in the plural may reflect the participant possibly manifesting herself as being ill in order to receive medical attention and eventually receive a diagnosis. From her construction of her experience of not being heard or listened to in the past, it could be argued that she may have felt her medical concerns were ignored by other doctors when she discussed them until she was seen by a rheumatologist. This experience may have left Participant 4 to feel dismissed by doctors and others in the past

whom she claims did not believe she was ill. Her subjective experience suggests that her diagnosis from the rheumatologist was quicker compared to her experience with other doctors. This possibly could have left her feeling sad and confused as to why one doctor could easily diagnose her when others did not know what was wrong, hence the descriptions of a long journey. In practice, she was diagnosed with Fibromyalgia by a rheumatologist. From her construction, Participant 4 originally positions herself as a powerless patient who was not being believed by her original doctors to one who eventually regains her power by being believed and proven that she has an illness. It could be inferred that her last phrase, '**I was right**', suggests that she was made to feel validated in her belief that she was ill from the start of her diagnostic journey.

Diagnosis

A majority of participants simply stated that they were diagnosed by their GP or rheumatologist but a few participants went on to describe the process by which they were diagnosed. Participant 4 describes it as follows:

***'So with the rheumatologist it was just like the diagnosis and like yeah he just said. He asked me about my history, what's been happening for me, I explained and then he prodded on my tension different parts of my body and he explained that if he thinks I have Fibromyalgia instead of CFS and he said it was kind of one and the same and he said Fibromyalgia is more about the pain and gave me like arthritis research leaflet on Fibromyalgia. And my GP, some of the GPs at my surgery don't really understand it very well so I think it's been like a learning curve for the both of us.'* (Participant 4, L165-171).**

In her response *'So with the rheumatologist it was just like the diagnosis'*, Participant 4 seems to be emphasising that the rheumatologist offered her no more than a diagnosis **'just like the diagnosis'** thus implying that he could, or even should, have offered more, for example, treatment. It could be argued that the participant was possibly left to feel as if she had to manage her diagnosis on her own. Furthermore, from this extract Participant 4 explains that she was diagnosed by a rheumatologist who took her history, possibly inferring a medical history here due to her seeing a medical professional, in addition to performing a medical examination on her. She implies that tension points around the body, the medical history and her pain experience led the rheumatologist to diagnose her with Fibromyalgia. Her quote indicates that in practice there is a medical procedure used by rheumatologists to diagnose Fibromyalgia. Prior to this extract, this participant talked about how she thought she had CFS as this was the label given to her by her Occupational Health Officer at work. Other participants talked about possibly having CFS due to the extreme fatigue they experienced as part of their symptoms. In her construction of the rheumatologist, Participant 4 suggests that he thinks that Fibromyalgia and Chronic Fatigue Syndrome (CFS) are similar conditions, but that the pain experience found in Fibromyalgia separates the two diagnoses. However, the casual phrase used to refer to CFS and Fibromyalgia as **'one and the same'** could possibly suggest that the participant constructed the rheumatologist as speaking in a casual way. She implies that the rheumatologist did not see the importance of distinguishing between the different diagnostic labels by giving the participant an explanation beyond stating **'Fibromyalgia is more about pain'**. The participant could have been left to feel as though she was not deserving of the rheumatologist's time or of being taken seriously enough, as **'he prodded'** her and then did not explain what Fibromyalgia was beyond giving her **'just like the diagnosis'**. She goes on to describe the rheumatologist referring to Fibromyalgia as part of

arthritis which could be implying that Fibromyalgia is related to inflammation of the joints. Moreover, in being given a leaflet, it could be argued that she may have been left to feel as though she had to manage her Fibromyalgia on her own without any further medical assistance. In her talk she explains that ***'some of the GPs at my surgery don't really understand it'***, which seems to point to a possible lack of understanding from some of her GPs knowledge in regard to her new diagnostic label and what it possibly entails. Nevertheless, it could also be argued that ***'it's been like a learning curve for the both of us'*** suggests that the leaflet may have helped the participant and the GP learn together about what could be the best treatment option for her. Thus, in practice, the participant may be left feeling that she is being supported on her journey of managing her diagnosis thanks to the doctor's signposting of the materials, which could possibly be beneficial for her.

Treatment

Participants talked about how they had not heard of the word Fibromyalgia before they were diagnosed and how post-diagnosis they had to conduct their own research to understand their new diagnostic label:

'He said "what you need to do is go away and do as much research on it as you can". He said "there is no cure, here's a tablet". He said "you need to learn how to manage it". And so yeah everything that I have learnt about it, I've learnt from the internet.' (Participant 3, L112-115).

In her construction of Fibromyalgia having no cure, Participant 3 implies that her doctor thinks there will be no relief from the symptoms caused by her condition. Her talk suggests that no medical relief can be provided by her doctor and thus treatment is limited to medication and

self-management. Most of the participants described being given medication to manage their Fibromyalgia. In their construction of being given medication, participants talked about being offered painkillers to manage their pain but some refused to take them due to the possible side effects such as dependency: *'I don't want to be on drugs, I don't want to be dependent on anything'* (Participant 2, L355). Other participants who took painkillers, meanwhile, mentioned how they stopped taking them as they did not find any benefit from them. Participants' constructions suggest that medication is a possible treatment for Fibromyalgia; however, they also suggest that there do not seem to be any medical benefit from taking them. It could be argued that the participants seem to be downplaying the benefits of the effectiveness of medication in constructing themselves as not receiving any significant help with their symptoms from their prescribing doctor. Consequently, the participants maybe putting themselves in a position whereby they possibly feel as though they are being let down by their doctors and perhaps left to their own devices. In practice, medication seems to be the only medical treatment available to the participants.

In their talk the participants position their doctors as giving them a choice in whether or not to take the medication, and by refusing to take the medication the participants are positioning themselves as powerful patients who can decide their treatment plan. However, initially in her talk Participant 3 constructs her doctor as absolving himself from responsibility as he tells her to *'go away'*, which seems to suggest that the only medical way he can help is by providing medication. This could possibly leave participants feeling as if they have no choice but to manage their treatment on their own. In addition, doctors may be giving the impression that their patients cannot seek any further medical help for their new diagnosis: *'I think the impression I get from GPs they just want people to get on with their life and sort themselves*

out' (Participant 7, L257-258). In possibly being left to manage their treatment on their own, participants seem to regain their power though educating themselves about their new condition. Participant 3 goes on to say that she learnt everything she knows about Fibromyalgia from the internet. This suggests that she learnt how to manage her Fibromyalgia on her own and without the help of medical interventions.

Participant 5 commented on how this learning on one's own could be done, constructing how treatment for Fibromyalgia should be conducted as follows:

'So I think health professionals are not really getting it right in terms of giving the right support, whilst yet again strategies are not properly developed for people who actually have this particular condition. They seem to be developed by the health professionals who always think they know better and it's just, it needs more involvement, you know, generally health and social care,...in terms of full productions with patient and experts by experience and families.' (Participant 5 L170-175)

From her construction, Participant 5 is suggesting that it is the health professionals' job to provide the support for people like her the patient. She is implying that health professionals are not providing the **'right support'** for their patients and therefore possibly inferring that they are not developing the right strategies for people with Fibromyalgia. The phrase **'yet again'** suggests that this is may not be the first time that incorrect strategies which may have not been suitable for people with Fibromyalgia could have been imposed not only on herself but also on other patients. This lack of development could possibly leave her feeling disappointed or that she is being ignored by health professionals for not doing, from her position as a patient, what she feels is needed to develop an effective form of support for

patients with her condition. Participant 5 seems to then go on to challenge health professionals' knowledge by stating **'who always think they know better'**. From her construction of health professionals, she seems to be criticising their knowledge about Fibromyalgia patients. Therefore, she is inferring that in practice, health care professionals may not know how best to help their patients.

From her talk the participant seems to be suggesting that support should encompass health and social care needs, which infers that both medical and societal support together may possibly be overlooked. In challenging her health professionals' knowledge, it could be argued that she is positioning herself as a powerful patient who has the required knowledge to give other patients the **'right support'**. Consequently, she is diminishing her health professionals' knowledge and experience as it is those authorities who should typically be positioned as experts on how best to manage and support their patients. Moreover, in proposing her own strategies to support patients with Fibromyalgia, with the phrase **'patient and experts by experience and families'**, Participant 5 seems to infer that those with Fibromyalgia and those whom it affects, i.e. their families, should be included in developing strategies to improve how health professionals provide support to patients. Thus, in practice, she is suggesting that patients and their families need to be more involved in the treatment process. This construction further supports the participants' earlier talk about the end of their diagnostic journey and possibly feeling abandoned and neglected by their doctors after diagnosis.

Overall Experience

Participants spoke about their overall experience of Fibromyalgia and about how other people did not believe them to be ill. They constructed Fibromyalgia as an invisible illness and

explained that their experiences of a subjective and hidden illness were not acknowledged or recognised by other people. In response to the question about the overall experience of having Fibromyalgia Participant 6 explained:

‘It can be very lonely I think because it’s so insular, it’s so you know it’s hidden, no one can see it and it’s only when you tell people that they are going to know... I have this illness.’
(Participant 6, L522-525).

Participant 6 is positioning herself as an ill person who is constantly involved in a never-ending struggle for recognition from others that she is sick. She talks about her experience of Fibromyalgia as a constant, silent and frustrating struggle of having an illness that no one else can see. The use of the phrase **‘when you tell people’** suggests that the participant has control of when and to whom she talks about her **‘illness’**. In doing so, it could be argued that the participant communicates her illness on her own terms to whomever she wants. However, from her construction of Fibromyalgia in practice it has been a lonely journey, one in which it took a long time to convince medical professionals, who told them they did not have a medical condition. In their talk, all participants described this long diagnostic journey and this battle to prove they were ill to their doctors who could not see anything medically wrong with them. This may have left participants feeling as though they had to hide their true experience of their illness **‘it’s so insular’**, which possibly left them feeling as if they had to deal with their experiences on their own. It could be implied that these experiences were common with a diagnosis of Fibromyalgia.

Throughout their diagnostic journey the participants described having initial expectations of being believed and given a diagnostic label from their symptom presentation by their GPs.

They talked about how they were not believed to be ill by their GPs and how within the process of being diagnosed had to convince their GPs that they had a medical condition. The participants talked about how this process was a negative experience for them:

***'It's very stressful because when you go to GP I think you expect them to know. You expect them to be able to pinpoint at what you're suffering from. So clearly if they, if they don't know. It think it's almost like they weren't, I wanna say the fact they won't take me seriously but I think they don't know.'* (Participant 7, L221-224).**

With the use of the word '**suffering**', Participant 7 implies that she has undergone hardship and pain or even distress because of her presenting symptoms, which may have left her feeling confusion and frustration towards her GP in not being able to tell her what exactly has gone wrong within her body. Thus, when she constructs having expectations in her GP's knowledge, she may be implying that her GP should have all the medical knowledge for all illnesses and thus should know how to treat them. Consequently, she is alluding to the GP not knowing about Fibromyalgia or understanding that she has it, which may possibly lead her to feel stressed that her expectations were not met. Other participants described similar experiences around how they expected their GPs to know what illness they had from the various medical tests conducted on them to deduce a medical condition. They went on to talk about how they were caught in a fight for recognition that they were actually ill despite their doctors' opinions that they did not have a medical condition, which resulted in the long journeys towards receiving a diagnostic label. In having such experiences, consequently, it could be argued that Participant 7 possibly felt that her concerns were not taken seriously.

So, when participants were eventually diagnosed with Fibromyalgia, this came as a relief to most participants as it seemed to have validated their illness experience that was previously being denied by their GPs:

‘when I was diagnosed, it was actually a relief because it helped me understand why I was struggling so much with life, you know. I had constant pain and I believed that there was something wrong with me and I’d been told “no, no, no” and ignored for so many years.’
(Participant 3, L 319-322).

Participant 3 constructed her experience of being diagnosed as a relief. This demonstrates that she may possibly feel as though she has been legitimised by a medical professional to be an ill person. She is positioning herself as an ill person who is now allowed to be seen as ill by others as she has been given a diagnostic label. In practice, this diagnosis could have helped her to understand the cause of her pain and the reason why she has been struggling with her life. Thus, it could be argued that the main impact of the diagnosis is social one in that the participants are being socially recognised as being an ill people. Furthermore, it seems as if the diagnostic label of Fibromyalgia in and of itself does not explain anything to other people, other than participants being able to attribute their symptoms to a condition with this name, as the condition itself seems to be poorly understood. Overall, it seems as if the benefits of having a diagnostic medical label are mainly social.

Psychological Discourse

This sub-section contains an exploration of how participants used the discursive themes of how their Fibromyalgia was managed by themselves and by others around them to deal with the symptoms they struggled with.

Symptom Experience

Following the participants' talk in suggesting that they could not be helped anymore from a medical perspective after diagnosis, and following a period of educating themselves, it could be argued that the focus of the participants' conversation changed towards an acceptance of psychological factors such as stress and anxiety in Fibromyalgia. When participants talked about their daily experiences of Fibromyalgia after describing having been referred to psychological services, they changed the way they constructed their understanding of Fibromyalgia by using both a medical and a psychological discourse. Through their constructions the participants would discuss the mind-body connection and thus would still use a biomedical discourse whilst trying to incorporate the possibility of a psychological connection as well for their condition. After talking about her diagnostic journey, Participant 5 mentioned that she was then referred to the Pain Clinic. When asked 'What did a psychology referral mean to you?', she said:

***'I think because I understand that, well I can see myself, that when I am more stressed, when I am more anxious, and the pain gets worse, so there is a definite connection there and it would be impractical and silly to think that brain has no part in most conditions to be honest with you.'* (Participant 5, L317-320).**

In this extract the participant states **‘I can see myself’**, which possibly suggests that following an period of education or learning about her pain **‘I understand’** she may be beginning to take a self-reflective perspective to examine the psychological experiences of her pain, which she possibly did not do before. Participant 5 implies that with Fibromyalgia there is a psychological connection. She constructs her understanding of Fibromyalgia as involving stress and anxiety, and implies that her pain is made worse the more anxious or stressed she becomes. Although she uses a psychological construct to understand Fibromyalgia; with her use of the word **‘brain’**, she is suggesting that there is a bodily organ involved in the connection between the physical and mental states that cause her condition. Therefore, it could be argued that she is highlighting the possibility that with Fibromyalgia there is a biomedical and psychological component and that the two constructs co-exist. This may lead her to position herself as an ill person with a condition of the mind and body, leading her to possibly feel that without considering the two constructs, she would be left feeling **‘silly’** and **‘impractical’**.

Similarly, Participant 1 described Fibromyalgia as ***‘like a vicious circle. It’s just your emotion***
Similarly, Participant 1 described Fibromyalgia as ***‘like a vicious circle. It’s just your emotion feeds your body and your body feeds your emotion’ (Participant 1, L258-259)***. From this extract, Participant 1 is highlighting that for her there is a connection between the body and the mind whereby these feed into each other and cause her symptom experience. She explains her comment in the context that ***‘it’s not you, it’s your hormones, it’s your you know neurotransmitters, it’s your serotonin, it’s your dopamine, it’s not you’ (Participant 1, L175-176)***, thus reinforcing her point that Fibromyalgia is a malfunction of the body and mind, which takes away her agency because the cause of her symptoms cannot be controlled.

Moreover, she proposes that ***'Fibromyalgia, it can be emotional driven' (Participant 1, L108).***

She is constructing Fibromyalgia as underpinned by an emotion that is manifested through hormones. This further highlights that although approached via a psychological discourse, participants still used a biomedical discourse to construct Fibromyalgia as a mind and body interaction. It could be argued that through their dual constructions participants were willing to consider how stress, anxiety and emotions played a role in their condition without giving up their investment in a biomedical discourse.

Treatment

In talking about the psychological approach to their Fibromyalgia the participants discussed being offered medication, psychological referrals, psychological therapy, referrals to Pain clinics and self-help strategies. The following section will examine the ways in which such treatment options were discussed within a psychological discourse.

Medication

One of the ways in which participants talked about how their GPs treated their diagnosis of Fibromyalgia was with reference to medication such as antidepressants and sometimes a referral to the Pain Clinic. Interestingly, when talking about how Fibromyalgia should be treated, participants focused on constructing Fibromyalgia from a psychological discourse by talking about treating their psychological symptoms. For example, Participant 5 proceeded to construct the treatment of Fibromyalgia within a psychological discourse by talking about anxiety causing tension, which to her was the cause of her Fibromyalgia. When she was asked how her treatment should be managed she said:

'Maybe not given antidepressants but something more like anti-anxiety because a lot of the tension and pain just comes more from stress and anxiety rather than depression,

depression comes as an effect of fibro rather than a source, a cause of it. I think the cause is more anxiety and pain so those two things should be better addressed' (Participant 5, L408-411).

From her construction, treatment of Fibromyalgia should be based on treating the psychological elements, which she implies are anxiety and stress and that these are what cause the pain rather than depression. She suggests that depression is not the cause of Fibromyalgia but may possibly be an effect of having it. Her construction '**depression comes as an effect**' possibly implies that people with Fibromyalgia develop low mood which to her suggests that low mood, may be a side effect of having Fibromyalgia rather than the main cause of symptoms. Furthermore, Participant 5 implies that she was offered medication as part of her treatment for Fibromyalgia. In talking about antidepressants, she is not saying that she refused to take medication as part of her treatment plan but instead implies that she would prefer the medication to be targeted at a different psychological construct, namely anxiety rather than depression. From her talk, it seems to her that depression is not the root cause for her Fibromyalgia but anxiety is. For her, therefore, in practice, the use of an anti-anxiety medication to dampen this anxiety response seems to be one of the ways in which Fibromyalgia should be treated, in addition to pain management. In her talk she also suggests that during her discussions with her GP about how to manage her Fibromyalgia once diagnosed, anxiety and pain were not adequately addressed. It could be argued that participants may feel as though their emotional as well as physical needs are not fully spoken about during their treatment talks with their GPs.

Referral

The participants constructed the Pain Clinic as a place that could help them learn to cope with or manage their Fibromyalgia. When asked what a referral to a psychological service meant to them, most participants described how they accepted the referral as it was a part of the treatment process, as their GP implied that they could do little to help them. Interestingly, those participants who were referred to the Pain Clinic described how the clinic consisted of psychologists and physiotherapists. One participant described how she accepted the referral as it came from a multidisciplinary team than included physiotherapists as well as psychologists rather than being a direct referral to a mental health service:

‘Because it wasn’t done individually to mental health unit to say, “oh you are with it as a mental health condition”, no, because it was a part of a package from the pain clinic, that was fine.’ (Participant 5, L323-325).

Participant 5 infers that Fibromyalgia and hence her referral is not and should not be considered a mental health condition. It seems as if she is trying to construct Fibromyalgia outside of a psychological discourse. It could be implied that to her, accepting the referral to the Pain Clinic, which in practice included a psychological service, was easier to tolerate than a separate referral direct to a psychological service. In her talk she uses the term ***‘mental health’***, which refers to psychological and emotional well-being. From her construction, it could be argued that a referral to a mental health unit might be associated with a feeling of stigma from which she might possibly be trying to disassociate. The use of the word ***‘no’*** may imply a strong rejection towards any implication or association she has of Fibromyalgia being linked to a purely psychological condition. Therefore, in practice she may have accepted a referral to psychological services as there were other services involved in her treatment at

the Pain Clinic. This construction shows a possible lack of acceptance towards psychology as a service and by extension its application involved in Fibromyalgia.

When referring to psychological services the participants used different terminologies to talk about the types of therapists they saw. A few participants talked about being referred to psychologists, counsellors, and some just said therapists. Whilst one participant discussed being referred to a psychiatrist, this participant, Participant 1 said:

***'My GP send me once to a psychiatrist. It was a weird experience because we sat there and this lady didn't even ask my name and I sat first time in my life, because in my culture we don't have this way this whereas just crazy people go to shrink or even a psychiatrist. No you go and talk to your cousin you don't go to you know. But here it's different and but I didn't know how to behave.'* (Participant 1, L398-402).**

In her talk, Participant 1 positions herself as a novice with regards to the experience of seeing a psychiatrist and this may have left her feeling as though the psychiatrist was possibly being distant and elusive for some reason unknown to her. By stating '**in my culture**' the participant is possibly inferring that there may be cultural differences for the possible reasons as to why some people may seek such a professional in their particular country. She explains that '**just crazy people**' see psychiatrists, which could indicate that in her culture psychiatrists are constructed as professionals who look after individuals perceived by others to be psychologically or physically unstable. In practice, she infers that it is culturally acceptable to turn to family members when individuals need to talk to someone about their problems. Furthermore, in using the term '**shrinks**' she is introducing alternative terminology for the

psychological profession, but one in which a negative stereotype could be implied. Thus, it could be argued that by saying '**you don't go**' in her culture, she highlights that psychiatrists may possibly be seen as professionals who see people who cannot be helped by their family members, and therefore she may be indicating that psychiatrists may be reserved for individuals who are beyond their families' capacity to help. Consequently, when she says '**but here it's different**' she may be suggesting that the culture around psychiatry is not the same as what she knows or is used to, which may possibly leave her feeling confused and unsure of how she is supposed to behave around a psychiatrist in the UK. In practice, it seems as if some participants may not have encountered such professionals before and therefore may have different expectations, which seem not to have been clarified at the first meeting. The other participants did not comment on cultural differences when engaging in psychological therapy in the UK, however, they did talk about what they wanted from psychological services.

Psychological Therapy

In talking about being referred to psychological therapy, the participants constructed how they perceived psychologists and psychological therapy. Participant 3 talked about how she felt more comfortable talking to a therapist than to her doctor. Prior to the following extract she stated that with doctors she only has 10 minutes to talk. She then goes on to say:

'Even at my last appointment I realised there were things that I'd left out that I really wanted to ask him. Whereas with the psychologist, you know they are there for 50 minutes and that feels like a comfortable amount of time to talk. You know by the end of it you are tired, you want to leave but yeah at least you leave feeling that you've been heard'.

(Participant 3 L453-426)

In this quote, Participant 3 constructs the psychologist as someone who is **'there for her'**, possibly suggesting that their focus is entirely on her and her needs in the allotted timeframe. This may leave her to possibly feel that **'50 minutes'** is a comfortable amount of time for her to talk about what she wants compared to the time she gets from her doctor. Thus she is positioning herself as an individual who may be more content to see a psychologist for her Fibromyalgia than she is to see her doctor who possibly makes her feel that they do not have time to thoroughly discuss her concerns. However, it could be argued that, despite the time being sufficient, she may possibly be left feeling exhausted by the experience of therapy; she states **'you want to leave'**, which may suggest that for her the process of therapy could be overwhelming. By saying **'you've been heard'**, she may be implying that she may not have been heard before and that the only time she feels heard is when she sees a psychologist. In practice, it could be said that psychologists may help participants to feel heard compared to their doctors.

In order to get a better understanding of participants' views about psychological input in their treatment for Fibromyalgia, they were asked to talk about what they wanted to learn from therapy. The main technique the participants wanted to learn from therapy was coping strategies. For example, when asked about how they thought therapy could help, one participant replied:

'I guess my response to pain like my thoughts around pain. My thoughts in general around what's happening with my body, how to like coping mechanisms or coping strategies. Like when I do have a flare and my mood gets low, I have lower mood because I'm in so much pain and like what strategies for what to do then and things like that.' (Participant 4, L403-406).

In this extract Participant 4 talks about pain within a psychological discourse by referring to **'my thoughts about pain'**, which could suggest that she is describing the cognitive concepts around understanding pain. This quote may imply that how she thinks about her pain may impact how she feels about her pain. From her construction of her pain, Participant 4 is positioning herself as a powerless person liable to lose control of her body and thoughts when she is in pain. Her loss of control may possibly lead her to feel depressed. In seeking therapy, she talks about wanting to learn to understand what is happening to her body in order to develop ways to better cope. Most participants spoke about wanting to learn coping strategies to help mainly with the stress they experience due to having Fibromyalgia. However, it could be seen that Participant 4's construction of pain stems from a bodily response which then incites a psychological reaction. Although the question reflects a psychological discourse, once again the participants draw from both a medical and psychological discourse when answering. This suggests that the participants understand Fibromyalgia from a dual construction and cannot separate the influence of the two discourses on their treatment.

A notable absence from the participants' construction of their psychological constructs of Fibromyalgia was childhood adverse effects. Interestingly, two participants did mention wanting to talk about childhood and current stressors to help them understand their Fibromyalgia and to indirectly help them cope with the pain: ***'I mean I do believe it could be linked to trauma in like your early childhood' (Participant 2, L169-170)***. They constructed Fibromyalgia as connected to childhood trauma and current stresses. However, these constructions followed on from how their doctors explained Fibromyalgia: ***'I don't really know but that's what the doctor said but he didn't explain. So I'm not really sure like what***

the link is' (Participant 2, L405-406). It could be argued that doctors have power over their patients by influencing their patients' constructions of Fibromyalgia within a psychological discourse after diagnosis. From this position the participants are seen to be taking up this psychological construct in order to add to their existing knowledge of Fibromyalgia.

Pain Clinics

In their talk about their experiences with psychological services within the pain management teams, the participants changed their constructions of Fibromyalgia from a medical discourse to a psychological one. One participant described her experience with a referral to a psychological service:

***'I was never referred to anything, but I did self-refer myself, just recently. But they said it was like an Acceptance and Therapy group run by NHS and they said "we're no longer running this course".'* (Participant 7, L552-553).**

Participant 7 talks about how she referred herself to a psychological service in her area which offered Acceptance and Commitment Therapy (ACT). Other participants mentioned how their pain clinics offered ACT as part of their pain management treatment programmes. In practice, ACT is a form of therapy used in Pain Clinics to help people with Fibromyalgia. In addition, the NHS receives self-referrals and referrals from health professionals for psychological therapy for Fibromyalgia. Furthermore, other participants mentioned a preference for having ACT over CBT by suggesting that CBT was associated with depression ***'I'd rather go for ACT than CBT for pain' (Participant 4, L423).*** For Participant 7, in making a self-referral she positions herself as taking personal responsibility in managing her treatment by seeking a way to cope with her Fibromyalgia through therapy.

Participant 7 says **'I did self-refer'**, which implies that she took a pro-active approach in accessing therapeutic services. However, despite her willingness to participate in psychological therapy she then refers to the unavailability of the service. Similar experiences were talked about by other participants who could not access therapy in their local area due to lack of availability. Other participants described not being able to attend appointments due to a lack of flexibility in slots offered as they were usually provided during work hours which meant that they either had to sacrifice their time by giving up work for the day or not attend the appointment at all: **'when I got the referral and I read about the clinical name, I was quite hopeful. It was just when I realised how inflexible everything is that my hopes crashed'** (Participant 5, L333-334). From the participants construction they imply in practice, they are making the effort to engage with psychological services but due to a lack of availability and flexibility in accessing the Pain Clinic. This seems to limit participants contact in receiving psychological therapy for their Fibromyalgia as the clinics are being perceived as remote and inaccessible. It also suggests across the country treatment for Fibromyalgia is not standardised as different participants construct having different experiences.

In constructing their experiences of having Fibromyalgia, participants described being possibly made to feel isolated as they did not have people around them who could understand their experiences. For example with their doctors they were possibly made to feel dismissed, ignored and not taken seriously when they initially raised their concerns about being unwell. Participants had similar experiences with other people who they spoke about also not believing them to be ill. When some of the participants were then referred and seen by a psychologist, one participant described her experience as:

'It's a relief, it's a relief to have somebody actually listen. You know I don't think even one

member of my family has ever said to me “how does this condition affect you, what does it do to you. How does it affect your day to day life”. Nobody, nobody has ever done that.’ (Participant 3, L413-415).

In her talk, Participant 3 constructs an environment of loneliness whereby the people closest to her do not ask her questions about how she manages her Fibromyalgia and how it affects her daily life. This may lead her to possibly feel neglected by her family members. It could be implied that when she meets a psychologist who asks her these questions that her family neglect to ask her she may feel relief, relief that she can talk about her personal subjective experiences of having this condition. Therefore, in practice, psychologists are seen to listen to participants’ experiences of their condition and may ask certain questions about their experience which no one has done before.

Self-help

Some participants were not able to access psychological therapies, either because they were never referred or because therapy was not available in their area. Those participants who were not offered a referral had either previously seen a counsellor or had turned to self-help books and practices to cope with their Fibromyalgia:

‘I do quite a lot of meditation, I’ve applied a lot of mindfulness meditation techniques so I’ve read a lot of that actually. And just looking at the areas where I can reduce stress and like maybe going out when the weather is nice I go sitting outside in the sun that makes me feel better and just spending some time alone with yourself and just trying to build yourself up.’ (Participant 7, L493-496).

This participant describes using mindfulness techniques to reduce her stress. From her talk, she has constructed her management of Fibromyalgia within a psychological discourse by focusing on herself and her internal process to enhance her quality of life. It could be argued that from this position she is taking responsibility for trying different methods, and through reading she is trying to accomplish building herself up by taking control over the management of her own treatment. Moreover, it could be implied that taking responsibility for the management of her Fibromyalgia has led her to possibly feel gratitude in other areas of her life. Similarly, other participants spoke about how through their journey of meditation they have developed self-growth. In practice, participants can develop their own coping mechanisms through meditation to help reduce their stress. Therefore, it could be argued that when the participants drew on a psychological discourse, this had an empowering effect on them as it gave them a sense of agency in managing their symptoms.

Another example that highlights the psychological discourse taken up by participants to empower themselves through managing their symptoms was when they described learning to cope with having Fibromyalgia on their own. Participant 7 describes how Fibromyalgia impacted her life by stating a list of things she learnt from her experience, commenting:

***'I think another thing that I learnt is how I can manage myself and how I can what's the right word. Because something like this has happened now so I have to learn to manage it. So I had to look at my coping skills really how can I cope with things and, so yes it was something that I had to learn, how to cope.'* (Participant 7, L485-487).**

In constructing Fibromyalgia as **'something like this has happened'**, it could be argued that Participant 7 may think that Fibromyalgia was imposed on her, which may possibly make her

feel like as though she had no control over her situation. However, she seems to be suggesting that in managing her Fibromyalgia by stating '**how I can manage myself**' she is implying that it is solely her responsibility to learn how to cope with her condition that she may possibly not have wanted to live with. From her construction, Participant 7 seems to be positioning herself as a powerful individual who has the agency to control and manage her Fibromyalgia on her own terms. By saying '**I learnt**' she is reinforcing her position as having done all the work to understand how to cope with her condition, possibly inferring that this was done without the influence of or help from other people. In her talk she implies that she used her own coping strategies that seem to be already in-built in her, and thus she may possibly be suggesting that she adapted them to cope with her Fibromyalgia. In this extract she uses words such as '**cope**' and '**manage**' when referring to her Fibromyalgia, which may suggest that this participant may think that she cannot be cured of her condition and thereby possibly feel as though she has a lifelong condition that she has to deal with forever. Thus, in learning how to cope and manage, it could be argued that she is learning how to cope with having Fibromyalgia indefinitely without considering possible alternative interventions. In practice, participants who did not seek or were not offered psychological therapy learnt how to manage their symptoms on their own using their own strategies.

Social Discourse

This sub-section contains the salient points of how participants used the discursive themes of their experiences within society and the perceptions of others within society to construct their management of Fibromyalgia.

Overall Experience

When approached from a social discourse Fibromyalgia participants talked about how they were viewed within society by their friends, family and work colleagues. All participants had experiences whereby they constructed talking about Fibromyalgia as a negative experience in which they described limiting their conversations about having Fibromyalgia with other people as these conversations led participants to possibly feel judged. Participant 7 talked about her experience with her manager at work whom she described as saying to her: ***'well you look fine to me, so I don't understand what's wrong with you'*** (Participant 7, L26). She describes how from other people's perspectives it is difficult to comprehend that something is wrong with her as she seems visibly well. She goes on to talk about her interactions with others about her Fibromyalgia by saying:

'there's a lack of awareness because this is an invisible illness. So really when you see me, you're gonna see me on my good day, you're not gonna see me on my bad day when I'm bed ridden are you, and people don't realise. I'm generally quite a smiley person so I have a smile on my face, I'm polite so "there's nothing wrong with her". But I wasn't always like that was I, you know. So I think there is a lot of prejudice against invisible conditions and people don't believe it.' (Participant 7, L37-41).

In her extract Participant 7 uses a biomedical discourse to construct Fibromyalgia as a **'condition'** and an **'illness'**. It could be implied that she views herself within a sick role in which she has a condition that no one else can see. Thus when she is ill she states that she confines herself to bed and avoids seeing other people. She then changes to a social discourse when she constructs other people's perceptions of her illness. From a social discourse it seems as if she is constructing her manager as denying that she is suffering from an illness, as they cannot

objectively see anything physically wrong with her. This may lead her to possibly feel as if other people have negative assumptions about her condition and therefore may possibly doubt her illness experience. The phrase '**a lot of prejudice**' suggests that the participant may feel that other people have a negative preconception about not only Fibromyalgia but other conditions which are not outwardly visible. From her construction of what other people believe '**this is an invisible illness**', she may be implicitly positioning herself as an ill person who has to defend herself when others question her illness. This may leave her to possibly feel defensive when her illness is questioned by others. Moreover, this could leave the participants feeling as though they have to hide their illness experience as they all position themselves as someone who has to constantly prove their illness to others who cannot see their condition. For Participant 7, this is a new experience.

Throughout the analysis each participant referred back to their experiences of other people's perceptions of them having Fibromyalgia, with most participants stating: '**I don't talk about it**' (Participant 6, L58). However, when asked to explain their statements, Participant 6 constructed her experience of Fibromyalgia by saying: '**It's challenging in terms of talking to other people about it, family members, it can be difficult at work, it's almost like a secret, because I feel embarrassed about it as well**' (Participant 6, L3-5). Participant 6 constructed Fibromyalgia as a challenging and difficult-to-define concept for other people, whilst constructing herself as having a hidden secret that she has difficulty sharing with others, possibly due to a fear of judgement based on past experiences.

By keeping her Fibromyalgia a secret from others, Participant 6 could be protecting herself from possible negative comments and opinions about her condition: '**I think there are still**

people out there that think it doesn't exist and that it's in your mind and you're being an attention-seeker or you're just being dramatic (L62-66). This may lead her to feel frustrated that others see her as physically well whilst to her she is suffering in silence as her pain is hidden. From her extracts describing how she is perceived within society, she constructs that people with Fibromyalgia are seen by others to possibly be attention-seeking or dramatic about their experiences. It seems as if their family, friends and work colleagues construct Fibromyalgia within a psychological discourse by claiming that their symptoms are all in the head and therefore possibly not real. From this construction, Participant 6 may be left to feel stigmatised and may be embarrassed that her Fibromyalgia experience might be viewed by others as a possible lie. It could be argued that in not talking about her Fibromyalgia within society she may be protecting herself by not being left in a position of possibly feeling powerless to convince others that she has Fibromyalgia, a real condition, and therefore she may be giving herself the chance to distance herself from other people's negative opinions.

Alternatively, some participants described how they did not tell people they had Fibromyalgia as they did not want their diagnosis to define them, or to be seen as someone with an illness. For example, Participant 2 explained:

'I don't want to be seen as a victim or someone who has got an illness or you know, I want to be seen as me. That's why I don't really tell people and I don't want anyone's sympathy and I don't want anyone's comments.' (Participant 2, L311-313).

In her talk, the participant seems to be differentiating between different parts of herself; she is suggesting that others see her as a victim or someone with an illness whilst she views herself as the opposite. From her construction, other people position her as a victim, which may

suggest that others possibly view someone with Fibromyalgia – and by association those with an illness – as helpless people possibly subjected to misfortune. It could be argued that from this position the participant may be left to feel as if others have sympathy for her. However, for this participant, she implies that these possible feelings of sympathy or comments about her illness are unwarranted. It also could be argued that the term ‘**illness**’ is used to construct other people’s perception of Fibromyalgia. With the biomedical discourse the participant is being positioned within the sick role – which she is rejecting. Thus from her talk, she infers that she resists this position placed upon her by others and instead reclaims her sense of self. It could be inferred that some participants are trying to not be seen by society as victims of their conditions. Thus by not telling people about their illness ‘**I don’t really tell people**’, it could be argued that the participants are in control of which versions of themselves they present within society.

Social Life

All participants talked about how Fibromyalgia impacted their daily lives, its impact on how they viewed themselves, and its impact on close relationships. Although the participants viewed themselves within a medical discourse by constructing themselves as having an illness or condition, they took up a social discourse to construct their experiences of having Fibromyalgia. For example, Participant 7 was talking about how she found having Fibromyalgia to be an isolating experience and when asked to elaborate she said:

‘It’s isolating because when you are ill, if you, it’s just the people around you and everything and you’re not feeling well so really even your family and friends won’t understand what you’re going through. Because initially no one really knows this condition and when you tell

them you've got it they don't really understand they go "oh we've heard of it but we don't know what I means". So if you're unwell then you're likely to do less, so you become socially isolated as well.' (Participant 7, L347-352).

In this quote, Participant 7 is constructing her experience of having Fibromyalgia as '**isolating**', which could suggest that she may possibly feel as if she is separated from other people and that she is all on her own with her illness. In using the term '**when you are ill**', Participant 7 is using a medical discourse to separate herself from the conversation in order to get the other person to imagine what it would be like to be ill, possibly like her. In this extract, Participant 7 does not explicitly refer to herself; however, it could be argued that she may be using her own experiences to get other people to understand her point of view. In her talk, she seems to construct a version of an ill person which consists of other people such as family and friends not having an understanding of what an ill person goes through. This may lead the ill person to possibly feel misunderstood or ignored by those closest to them. In talking about '**this condition**', it seems as if Participant 7 may possibly be referring to herself and having Fibromyalgia. Therefore, it could be implied that she may have been talking about her own personal experiences and constructing her experience of having Fibromyalgia, and possibly feeling as though her friends and family are not able to understand her experiences. With the use of the phrase '**oh we've heard of it**', Participant 7 is constructing her social circle's knowledge about Fibromyalgia. From her construction, it seems as though her family and friends have some knowledge about Fibromyalgia but possibly may not have enough information to fully understand '**what it means**' or how it impacts her. When she goes on to infer that being unwell leads the ill person to do less, it could be argued that from her experience of being the unwell person she may have experienced her functioning becoming

limited, which may have had an impact on her social life. This may possibly have led her feeling as though she is being isolated from her social circles and thus withdrawn from those around her. In practice, being ill may impact the ill person's ability to socialise.

In constructing their experiences within a social discourse, participants constructed themselves as being a burden to their families and other people. The participants implied that they had to rely on their family members for support but that doing so possibly hindered their independence. Participant 3 was constructing her overall experience in having Fibromyalgia as being a burden to other people. When asked to elaborate she said:

***'I am a burden. I'm not bringing in any money. Actually that's not true. I do have a business, I do see some clients, okay I bring in a little bit of money but it's not enough for us to live on. If I didn't have Fibromyalgia I would be earning big money, okay, I'm not even earning half of what the normal me is capable of bringing in.'* (Participant 3, L381-384).**

In her talk the participant uses the phrase '**I am a burden**' to describe herself. It could be argued that she views herself as a strain on or possibly a vulnerable member of her family. She goes on to imply that being considered an asset to the family entails contributing significantly to the family income. From her construction, she is implying that she is not working as much as she used to and is suggesting that having Fibromyalgia has caused her to earn less money, which to her has possibly left her feeling like a burden to her family. In her talk she is positioning herself as a different person by implying that she is not herself and possibly feels that Fibromyalgia has somehow changed her. It could be argued that she has been left to feel as though Fibromyalgia has changed her capacity to be an effective worker. Other participants spoke about similar experiences in which they constructed Fibromyalgia

as a condition that changed their identities, as they described how they were not the same person since having symptoms. This may lead the participants to possibly feel as though they cannot contribute towards their friends, family or work as they used to be able to do, which may possibly lead them to feel as though they weigh others down.

Furthermore, participants could feel powerless in their position to change their experiences. From their constructions of having Fibromyalgia, it seems as if these experiences were happening to them without their control. For example, Participant 3 described having Fibromyalgia as:

‘Overwhelming. Disabling. Life threatening, that’s not quite the word that I want to use but I mean, there have been times when I have absolutely wanted to end my life because I see absolutely no point in going on. Not because I’m depressed but because I don’t think I’ve got anything valuable to give back to society.’ (Participant 3, L341-344).

From her construction, Participant 3 implies that having Fibromyalgia is a threat to her life, as she sees no point existing if she cannot give back to society. From this position she seems to feel as if she is powerless or possibly restricted to change the value she can give to the wider community. She implies that not being able to contribute to society due to her supposed disability of having Fibromyalgia has left her to possibly feel overwhelmed or to some extent suicidal because she cannot change her position in life. It could be argued that some participants want to be in a position whereby they are active members of society and possibly may not like it when they are not seen as valuable to others. Thus in her talk the participant rejects the psychological implications that depression could be the reason why she wants to

end her life and instead stresses that not being a productive member of society may be the cause for her low mood.

Work

Subsequently, when talking about the implications of having Fibromyalgia, the participants spoke about their financial losses or problems at work which related to reduced hours or, for some, not working at all. One participant talked about not being employed and looking for work, and commented:

‘Yeah I think if there was a lot more recognition of the condition where people were willing to employ you, you know even if you could work from home on your bad days. But just acknowledging that I am a bright intelligent person, that maybe 60% or 70% of the time I can do really good quality work, the rest of the time I can’t and working with me you know then at least I’m contributing towards society in some way and plus earning some money.’
(Participant 3, L396-401).

In this extract Participant 3 is suggesting that due to a lack of recognition of Fibromyalgia, people may not be willing to employ her. She goes on to imply that she is not being recognised as the **‘bright intelligent person’** that she believes herself to be. However, she constructs potential employers as individuals who seem to be ignoring her intellect, possibly due to her **‘bad days’**. It could be argued that on her bad days this could potentially be due to her Fibromyalgia symptoms and she implies that when they happen, she needs time to rest and therefore cannot work. Participant 3 seems to be suggesting that potential employers are not willing to be flexible in their approach by letting her work from home when she needs to if she cannot function at her full capacity. As a consequence, it could be argued that she is being

positioned by these potential employers as a powerless citizen who cannot gain employment. This may leave her to become financially restricted by limiting her potential earnings and therefore possibly leave her feeling as though she is not contributing to society.

One of the areas that participants wanted to increase awareness of was the lack of available government funding for people with Fibromyalgia. Participant 7 noted that some people with Fibromyalgia whom she had spoken to through online support groups mentioned the lack of financial support available for people with this condition, as well as mentioning that Fibromyalgia is protected under the Equality Act and therefore that companies need to be taking Fibromyalgia seriously. In talking about a need for more awareness of Fibromyalgia, Participant 7 said:

‘And I think also people who had to give up work I know they are financially struggling to apply for Universal Credit because they don’t take this condition seriously enough so they are actually, they are being penalised for being ill and they don’t have any financial help.’
(Participant 7, L644-646).

In her talk the participant is suggesting that others with Fibromyalgia **‘had to give up work’**, which implies that they had no choice but to terminate their employment due to their **‘condition’**. In constructing Fibromyalgia within a biomedical discourse, it could be argued that Fibromyalgia is being viewed by those who have it as a medical condition. Thus the participants are trying to be positioned within society in the sick role by trying to access government funding to support their condition. Participant 7 seems to be suggesting that those who have Fibromyalgia have stopped working and thus may be in financial difficulty, and to her they should be able to apply for government funding. She is positioning those who

have Fibromyalgia as having an illness and with this illness position, they should be seen by others to be ill. However, from her construction, in practice they are not seen as ill people and therefore cannot claim to be ill or be entitled to the benefits that come with being ill, such as financial support. This may lead the participants to feel as if those with Fibromyalgia are being punished for having a condition which society is not taking seriously as an illness. Interestingly, Participant 7 in this construction separates herself from those seeking government support, which may suggest that not everyone with Fibromyalgia wants to be supported financially by the government. In practice, however, it seems as though people with Fibromyalgia who are not working have difficulties applying for Universal Credit and those who do work, do so on reduced incomes.

Support

Most participants mentioned that they had hidden their illness experiences or simply tried not to talk about Fibromyalgia to other people, possibly due to past experiences of a negative reaction. These experiences may have left the participants feeling that they are a burden on their close relations or on society. However, a few participants suggested that they had been supported by family members to whom they could talk openly about their Fibromyalgia:

‘So I have a lot of support from my friend and my children and everything, which is amazing and you know what it makes a huge difference when you have somebody who understands rather than. Because the more you think that okay it’s in my mind and I’m lazy or it’s my fault, the worse you get.’ (Participant 1, L256-260).

From this construction, Participant 1 may feel that being able to be open and having people around her who understand her symptom experience could lead her to feel that she can

manage her symptoms better than if she was having to cope on her own. In her talk, she constructs Fibromyalgia within a psychological discourse by suggesting that there is a possible problem in her mental state which may have led her to develop this condition and hence this is the reason why she may blame herself for causing it. In addition, she implies that her lack of movement or possibly her lack of involvement in activities could lead her to feel that all these negative evaluations of herself impact her symptom experience. Consequently, following all the participants' constructions of how others perceive their condition, in practice, it seems as if the perceptions of others could potentially impact how participants experience themselves and their attitudes towards having Fibromyalgia, which in turn could possibly affect how they manage their symptoms.

Using the social discourse from participants' social responses to Fibromyalgia and the dominant social construction of Fibromyalgia which they encounter in their day-to-day lives suggests that within this construction the participants cannot find a position of being a legitimate and valued member of society. It could be argued that this may be due to them neither being seen to be legitimately ill (and, therefore, able to occupy a legitimate sick role in society and receive benefits and sympathy) nor able to fulfil the functions of a productive citizen who contributes to society by working, supporting themselves and fulfilling their social roles (e.g. as parent, worker, partner, etc.). Therefore, viewing participants as not legitimately ill may be dependent upon the use of a particular construction of what a 'productive member of society' looks like, and furthermore, may be a product of discourse rather than an inevitable reality.

Analysis Reflection

After completing my analysis and to some degree whilst re-reading the transcripts, I noticed that when the participants were talking about Fibromyalgia they would also talk about how other people would construct Fibromyalgia. The participants would tend to switch between talking about their personal experiences of having Fibromyalgia which reflected their knowledge and what it meant to them to how other people perceived them having Fibromyalgia. Thus, the participants would talk about how other people such as their doctors (GPs and rheumatologists) and their social circles (family, friends and work colleagues) would construct Fibromyalgia. It was from these constructions that the participants talked about how they understood Fibromyalgia and how others perceived them. However, these constructions from other people seem to have had a negative impact on how the participants viewed themselves. When writing up my analysis chapter I became confused as to what the aim of my research was. Was it to identify the discourses that participants themselves used to construct Fibromyalgia which then informed their accounts of their experiences of Fibromyalgia, or was it to examine the discourses the participants identified in other people's talk about Fibromyalgia? Looking back at my analysis chapter I seem to have done both, although my focus was to do the former, as FDA seeks to identify the discourses in participants' talk.

When writing my medical discourse sub-section, I wrote about how medical professionals talk about Fibromyalgia. Although it is not the first time that I wrote about how doctors talk about Fibromyalgia, it is a good example of how I analyse other people's constructions instead of those of my participants. It is important to note that in that sub-section, I refer to the question that I asked the participants, which, when I reflect back, may have led the participants to

construct other people's perceptions of Fibromyalgia. I ask the participants how medical professionals talk to them about Fibromyalgia. At the time I did not realise the impact this would have in constructing other people's perceptions of Fibromyalgia, as it provided insight into how the experts understood Fibromyalgia compared to how my participants constructed Fibromyalgia using their own discourses. Consequently, the question led the participants to describe how doctors construct Fibromyalgia and thus provided insight into the discourses and consequences for actions in doctors' talk rather than the participants' talk which was the aim of my analysis. As a result, my analysis contains evidence as to how doctors construct Fibromyalgia, the discourses they draw upon and the limitations for their patients' subjectivity.

In summary, medical professionals constructed Fibromyalgia within a psychological discourse which positioned the participants as patients experiencing a non-medical condition. It could be argued that doctors tried to convince the participants that there was nothing medically wrong. Within this psychological discourse whereby the participants are positioned as frauds or liars in that they are described as 'nothing being wrong' with them or that their symptoms are 'all in their heads', participants may have been left to feel as though they have potentially made up their symptoms and that their pain is not real. This could also leave them feeling powerless or possibly that their symptom experiences are not taken seriously enough to convince their doctors that there is a medical reason to explain their pain.

Similarly, participants constructed how their social circles constructed Fibromyalgia within a social discourse. Without prompting, the participants talked about their experience with other people to construct their experience of having Fibromyalgia. This also meant that the

analysis had to examine how other people, not just doctors, constructed Fibromyalgia and the consequences this entailed for the participants' subjectivity. In their construction of other people's perception of Fibromyalgia, the participants talked about an existing social discourse that positioned them as attention-seekers or possibly being dramatic when explaining their symptom experiences. Their social circles would take up a psychological discourse much like their doctors by suggesting that the participants' symptoms were 'all in their heads' and therefore alluding to their pain not being real. From their constructions the participants were possibly made to feel stigmatised and embarrassed that their Fibromyalgia experience was possibly being viewed by others as a lie. This may have left the participants feeling as though they had to hide their illness experiences to protect themselves from feeling powerless within society against other people's negative perceptions of them and their positions an ill person not being accepted.

Positioning Theory

Influenced by Foucault's work, the concept of position and positioning was introduced by Davies and Harré (1990). Position is based on the concept that not all individuals involved in a social episode in a particular moment have equal rights and duties to perform meaningful actions (Harré, 2012), whilst positioning theory refers to the study of conflicts and how individuals use words and discourses to locate themselves and others (Moghaddam & Harré, 2010). Within this framework, language is historically and ideologically contextualised social action (Foucault, 1969). During a social episode like a conversation, people's talk helps to situate and define the 'other' and simultaneously define the speaker, thus, a system of speaking rights and responsibilities between the 'I' and the 'other' arises. Discourses define the conditions within which participants can act, orientate themselves, and the various

positions available to them (Tirado & Galvez, 2008). Discourses, therefore, are social practices as their rules are historical, localised events fixed in space and time, and for particular communities (Foucault, 1969). However, positioning theory overcomes these macro social limits by suggesting that the active participant is able to change subject positions within the construction of the social episode. In doing so, positioning can be seen as dynamic and fluctuating depending on the narrative through which they are constructed and thus negotiable, as it is possible for participants to resist the possible implications or consequences of an act, thus leading to the creation of social identities (Sabat & Harré, 1999). As a result, the analysis of discursive practice (positioning) could be seen as a diagnosis of the present rules and guidelines of social relationships (Tirado & Galvez, 2008).

In the analysis of the data, one could think of this change in positioning from the participants' talk towards their doctors or others as second-order positioning (Harre & Langenhove, 1991). This relates to the idea that individuals discover constructions that make concrete and possibly life-changing assumptions about who they are which leaves them to either engage with or reject these assumptions. Consequently, the discourse is described as being acutely 'felt' and demands interaction (Garden, 2019). Garden (2019) claimed that those in a minority or marginalised group naturally notice and analyse discourse, despite not using this terminology. He noted that minority group members are aware of the discourses within society that construct them negatively or causes them some form of discomfort. For example, those with a chronic illness may be viewed as 'other', which may lead them to be seen by the public as not abiding by social norms. Garden suggested that within the second-order positioning the 'ill person' is aware of how they are constructed externally and this creates a

division between how the ill person experiences themselves and how they are experienced by others.

Looking back at my earlier subheading in the medical discourse section entitled 'Medical Opinion', this could possibly be seen as an example of second-order positioning. Re-examining a quote under that subheading, I see that instead of talking about her own personal experience of Fibromyalgia, Participant 5 describes how she was spoken to about having Fibromyalgia, saying:

'So it being told that it's possibly psychosomatic and "are you not just a little depressed" or something like that, it just. I don't have time for people like this, I don't even try because if someone starts with that attitude, you can't really change someone's thinking in a 10-minute GP appointment.' (Participant 5, L89-92).

From her construction, she is implying that her doctor told her that Fibromyalgia is psychosomatic. From this construction, Fibromyalgia is being described from a psychological discourse through the implication that the participant's symptoms stem from her mood, hence the reference to her possibly experiencing depression. It could be argued that the participant could be made to feel trapped within this position as a psychological patient rather than a medical patient. It could similarly be argued that the participant engages with this construction by rejecting the psychological discourse being imposed on her – **'I don't have time for people like this'**. It could be suggested that the participant is dismissing not only the doctor but other people who have told her she is depressed or psychosomatic. The participant seems to be implying that the words **'psychosomatic'** and **'depressed'** have been used to describe her in the past. However, by dismissing the psychological construction imposed on

her the participant is reclaiming her power by ignoring and possibly not paying attention to the people who position her in this way. Moreover, the participant could be creating her social identity as an ill person by rejecting the original positioning placed upon her by her doctor who describes her as being depressed. Similarly, according to second-order positioning, the discourse is '**felt**' (Garden, 2019). Although Participant 5 does not make an explicit reference to her doctors she does imply that she is talking about not being able to change someone's '**attitude**' and '**thinking**' within the context of a GP appointment and therefore she may be referring to her doctor. This is also seen when Participant 5 goes on to say that she possibly felt that she had no choice but to accept the construction imposed on her – '**I don't even try**', '**you can't really change someone's thinking**'. The participant seems to be constructing herself as a powerless patient who cannot change how her doctor thinks about Fibromyalgia and by extension her symptom experience.

It could be argued that doctors construct Fibromyalgia within a psychological discourse which describes the participants as psychosomatic, depressed and that their symptoms are all in their heads. From this construction the participant seems to be positioned as possibly viewed as a fraudulent patient who might be making up their symptoms which to the doctor are seen as not medical but psychological in nature and thus do not require medical attention. This could possibly leave the participants feeling as though they are powerless to change the opinions of their doctors and are therefore stuck with these negative assumptions being imposed on them.

To conclude, my understanding of second-order positioning has helped me to integrate this distinction between how my participants construct Fibromyalgia and how others perceive and position the participants who talk about it.

Chapter 4: Discussion

Chapter Overview

The aim of this study was to find out how patients diagnosed with Fibromyalgia construct their experience of Fibromyalgia and thus what subject positions, practices and possibilities for subjective experience of having Fibromyalgia are made available to them. This was achieved by adopting a critical realist position to discourse analysis whereby how the participants make sense of Fibromyalgia needs to be interpreted through the language they use to construct their lived experience. Through the analysis of the interview transcripts constructions of the object 'Fibromyalgia' were identified. For this chapter, I will present a brief summary of the analysis focusing on the discourses the participants used to construct Fibromyalgia and the subsequent positions, practices and possible subjective experiences made available. The analysis demonstrates that the participants drew on three main discourses: biomedical, psychological and social, each leading the participants to experience different positions, practices and subjective experiences.

For each discourse utilised I will reflect on its implications for how Counselling Psychologists may help individuals with Fibromyalgia. The implications for Counselling Psychology are not a list of concrete recommendations that need to be implemented but suggestions that I propose as ideas, through which psychological therapy in practice can be utilised to empower a particular patient group within a UK health setting. Next, I will evaluate the research process in terms of quality, applicability and limitations and highlight areas for future research. I will conclude this chapter with a reflection on the analytic process and with personal reflections highlighting my research journey.

Summary of Discourses

Biomedical Discourse

A biomedical discourse was used by participants to describe their bodily symptoms and their medical journey towards diagnosis and treatment for their Fibromyalgia, which led to them being positioned as powerless patients who could prove they were ill through medical investigations, which led them to feel dismissed by their doctors and possibly feeling like an ill person stuck in a never-ending struggle for recognition from others that they are sick.

In terms of how Fibromyalgia was constructed, it was initially talked about by the participants as a set of bodily symptoms that echoed earlier versions of the diagnostic criteria such as in the DSM V (APA, 2015). The participants described Fibromyalgia as severe pain, fatigue, cognitive disturbances (which participants referred to as brain fog) and sleep difficulties. It could be argued that the participants were mobilising a dated biomedical construction of Fibromyalgia which differs from its contemporary biomedical construction. According to the DSM V classification criteria the syndrome was constructed as the absence of organic pathology characterised in the same way as the participants described. It could be suggested that the participants possibly viewed their bodily symptoms as a medical condition that needed to be investigated medically, as they may have had an illness not yet detected. However, the contemporary construction of Fibromyalgia defines the syndrome as diffuse pain in 4 of 5 bodily areas associated with emotional or functional disability (WHO, 2020). Thus, there current definition does not mention only a pathophysiological processing as suggested by previous construction, suggested and therefore, the concept of disease or injury contributing to the pain problem is no longer associated with the syndrome. This former understanding also seems to be the basis of the participants' construction of Fibromyalgia

thus their initial construction of Fibromyalgia is not supported by the current expert knowledge.

Over the years, expert literature on the construction of Fibromyalgia has evolved to include both psychological and social processes, with references to the syndrome as associated with psychiatric symptoms such as depression and anxiety being introduced in the 1980s (Yunus et al., 1981). However, the participants did not incorporate psychological symptoms in their talk as their presenting symptoms. Instead, these psychological symptoms were discussed almost as a by-product of their subjective experiences of living with the syndrome. For example, the participants described feeling stressed and anxious when their pain increased. Which possibly suggested to them that there was the possibility of a psychological and biomedical component in the condition. However, this connection arises only after their experiences of having the biomedical symptoms; hence their psychological symptoms maintain their bodily symptoms rather than trigger them. It could be argued, therefore, that the current findings do not support Okur Güney et al.'s (2019) findings which suggests that psychological symptoms trigger Fibromyalgia. It could be noted that the participants seem to disregard or may not know about the psychological processes that contribute to the changes in pain processing and thus the expression of pain that may explain their other symptoms such as anxiety and fatigue as suggested by Stisi et al. (2008). Thus, in their talk, participants refer to the psychological symptoms as secondary factors which for them may not be their primary concern when they visit their GP to investigate their bodily experiences. Consequently, the findings seem to imply that from the outset there is a disparity between the participants understanding of Fibromyalgia possibly being a pain condition associated with other bodily symptoms that need to be investigated medically, and compared to expert

text (medical or psychological) knowledge that constructs Fibromyalgia within a multidisciplinary approach (Doebl et al., 2020). These findings, therefore, highlight the difference in knowledge during the diagnostic process which may possibly be the behind the tension within the doctor-patient relationship, which participants talk about and other researchers discuss (Doebl et al., 2020). On the other hand, it could also be argued upon reflection that the participants' continued talk about Fibromyalgia as a chronic pain and their eventual description of an association between their pain, experiences of emotional (stress) and functional disability (difficulty working) is concurrent with expert constructions of Fibromyalgia (WHO, 2020).

From their construction of Fibromyalgia as a medical condition, the participants positioned themselves in a sick role which allowed them to seek medical advice and testing for their symptom experiences, which they described through the diagnostic journey and treatment process. Within a medical institution which positioned them as a patient within the doctor-patient relationship, initially the participants could be seen as powerless patients subjected to medical procedures being conducted on them to determine their illness. However, these medical procedures did not detect anything medically wrong with the participants which is concurrent with previous qualitative research (Paulson et al., 2002). Furthermore, from the participants' talk about their experiences with their medical professionals who constructed Fibromyalgia as 'psychosomatic', it seems that may have left the participants possibly feeling annoyed or as if their physical symptoms where 'all in their head'. Thus, the participants referred to other people and their doctors as people who suggested that their physical symptoms were made up and all in their heads, possibly implying that their symptoms were purely psychological and not a physical experience. The current findings support previous

research that has consistently shown that the use of the word 'somatic' by doctors when talking about patients' symptoms is problematic as it raises questions about patients' illness legitimacy. It suggests that symptoms are psychological or emotional problems instead of being a medical issue and thus leaves patients reporting that they feel misunderstood and their symptoms discounted (Edwards et al., 2010; Wileman et al., 2002).

Furthermore, from being constructed by others as having made up their psychological symptoms, participants may have been left to feel as if their bodily symptoms were being ignored, which may have left them to feel as if they could not be trusted as a patient as they could not prove their pain to be real. This may have left them in a position of powerlessness to change the opinions of their doctors and others around them who presume them to be well. Consequently, suggesting that participants have a psychosomatic condition means they are limited in their treatment outcomes. For example, the participants constructed their doctors after diagnosis as neglectful practitioners who possibly absolved their responsibility as medical professionals, as the participants seemed not to be able to be helped medically anymore. As a result, this could have left participants feeling as if the only option they had was to manage their treatment on their own, by taking medication or being referred to the Pain Clinic. Therefore, after diagnosis the participants may have been left to feel as if they were being abandoned by their doctors who possibly could not help them medically, although in practice participants talked about being offered treatment after diagnosis, which for some included medication and onward referrals to psychological services. In their construction of medication, the participants seem to downplay the effectiveness of the benefits that medication could offer and position themselves as being let down by their doctors. Research conducted by Hooten et al. (2007) concluded that medication had limited therapeutic

benefits to relieve pain for patients with Fibromyalgia. Therefore, it could be argued that the experience of medication being non-effective for the participants has been supported by empirical evidence. Consequently, for some participants, in being positioned as being psychosomatic, they may have felt disempowered to have their needs met in a medical manner which they initially wanted, despite having a medical diagnosis, and this possibly limited their access to taking up the sick role within society as other people viewed them to have a psychological and not a medical condition.

However, despite the initial sense of disempowerment as seen in the participants' talk, empowerment was a theme I found when reviewing how participants interacted with their doctors and others. From a biomedical discourse, if participants could convince their doctors to do further investigations or if they found some diagnostic test that revealed they had an illness, this resulted in them experiencing a sense of empowerment, as they possibly felt validated that what they were experiencing were medical issues despite their doctors saying otherwise. According to second-order positioning, individuals may be aware of their positioning within a discourse which makes certain assumptions about them that the individual can either accept or reject (Harre & Langenhove, 1991). Thus, in their talk, some participants talked about actively seeking a medical explanation for their symptoms by repeatedly visiting their GPs or requesting further investigations. As a result, it could be argued that some of the participants rejected the assumptions placed upon them by their GPs who constructed them as psychosomatic and therefore powerless patients appropriate for only limited medical treatment. Thus, in rejecting their original positioning the participants were therefore able to regain their power by insisting on referrals to other medical specialists to review their symptoms as they believed there was something medically wrong with them.

For some participants it was through these referrals that they were able to empower themselves as patients and were able to be diagnosed with Fibromyalgia, which could have possibly reaffirmed their belief that they were ill, despite their doctors and other people seeing no outward signs of illness.

In re-positioning themselves within the doctor-patient relationship, the participants seem to take a more active role within the relationship which previous research has been shown to be effective in practice for the co-production of knowledge in clinical challenges such as this diagnostic presentation (Filipe et al., 2017). Furthermore, from the participants talk, the need to be pro-active during the diagnostic process highlights previous research which has suggested a necessity for individuals to negotiate satisfactory identities as a patient through their ability to behave and take action as they would like (Burr, 2015) in addition to stating that patients are looking to be counted within the diagnostic and treatment process (Glattacket et al., 2010). Therefore, when the participants talked about opposing their doctors' medication suggestions or insisting on referrals, it could be argued that they were attempting to be a part of the diagnostic process by using their own knowledge as a patient to help gain a satisfactory diagnosis that suited their beliefs. As a result, the findings show that through rejecting their original positioning, placed upon them by their doctors, and thereby changing their positioning within the medical discourse, the participants were able to use their agency and empower themselves as patients. In doing so, the participants seemed to have asserted themselves and their beliefs that their problems were medical in order to gain access to further medical interventions, which some participants found to be beneficial as this enabled them to acquire a medical diagnosis. Subsequently, in having a diagnostic label, the participants seem to possibly feel validated in their symptom experiences which

may have been ignored for many years. It could be argued that having the diagnostic label of Fibromyalgia did not on its own provide an explanation for other people, but for the participants it allowed them to attribute their symptom experience to a medical name. Therefore, it seems as if the main impact in having a diagnostic label is to allow participants to become socially sanctioned as an ill person.

Counselling Psychologist perspective

Through an examination of how the participants constructed their diagnostic journeys, I noticed that the participants understood Fibromyalgia mainly from a biomedical discourse. It seems as if for the participants the main factors related to Fibromyalgia before diagnosis were of a biomedical nature whilst psychological factors that may contribute to their pre-diagnostic journey or towards the possible cause for their symptom experience were ignored. Likewise, all participants' first port of call was their GP, i.e a medical professional. This suggests that participants wanted a medical explanation for what they described as a medical illness. Moreover, as the participants did not seek out any alternative professions to explain or discover the cause of their symptom experience, it could be argued that a medical discourse heavily influenced the participants' understanding of Fibromyalgia from pre-diagnosis to how their condition should be treated.

This study has shown that the way in which the participants are possibly treated by their doctors within a medical discourse may be an ineffective approach in the diagnosis and management of Fibromyalgia patients. Therefore, as a guide to social reform, and in the context of this potential preference for a biomedical discourse, it could be argued that in the future Counselling Psychologists could be part of the conversation when patients present to

their GPs. From the participants' talk, it seems as if they were possibly made to feel ignored, dismissed and as a result may have been left to feel as though their symptoms were not taken seriously when they presented to their GPs. Therefore, psychologists could be utilised within a GP service to bridge the gap in communication between doctors and their patients.

From the participants' talk and from previous research, participants are still being told by their doctors that there is nothing wrong with them and that their symptoms could possibly be psychological. Studies have consistently shown that when patients are referred to as having somatic symptoms this is seen as a negative and possibly has a stigmatising effect (Arnold et al., 2008). Counselling Psychologists could be used to help GPs change the way they communicate with their patients by helping them to understand how their patients feel when they communicate information in a certain way. By educating GPs and other health professionals during MDT meetings, either as guest speakers or as in-house counsel, in employing patient-centred communication styles that focuses on validating and empathising with their patients' experiences and illness beliefs, doctor-patient relationships could be improved, as research has shown that these techniques increase patients' rating of interpersonal care (Epstein et al., 2007).

In addition, during patients' diagnostic journeys Counselling Psychologists could be used to help mitigate these potential negative feelings of being dismissed by helping them understand the psychological factors involved in CPP. Thus, in helping clients understand the possibility of a psychological element may reduce their search for a medical explanation by integrating their existing medical knowledge with a psychological perspective towards their symptom experience. Moreover, in having someone to talk to about their symptom

experience may allow the clients to further feel validated in their experiences and may help reduce their potential feelings of isolation within society. However, it may not be so easy for Counselling Psychologists to challenge their clients' commitment to a biomedical discourse, as clients may feel that, despite a psychological explanation of their symptoms, it is only when they are recognised as suffering from a biomedical condition that they will be seen to have a legitimate claim to being ill. Thus, it may be difficult within the diagnostic stage to invite clients to mobilise different discourses to those they have already invested in, therefore such conversations may only be possible once a diagnosis has been made.

Overall, to operationalise psychologists being part of the conversation when patients visit their GPs, more psychologist could be present within primary care services such as local General Practices, whereby referrals to psychologists could be made sooner in order to help patients who are having difficulties with CPP which impact their emotional and functional well-being. Interventions earlier on may reduce the frustration patients feel within a medical model that possibly leads them to feel that their symptoms are not taken seriously. Instead, Counselling Psychologist could help patients deal with the challenges they may be facing within their medical journey and possibly introduce a new way of dealing with their symptoms. Pearson et al.'s (2021) model of care programme supports this idea of social reform whereby those with a long-term condition are treated within the community. This model of care programme has been shown to be cost-effective in managing such patients as well as allowing them to be involved in the process by consulting them about all aspects of their treatment. Therefore, there already seems to be a shift within the NHS towards treatment for long-term conditions such as Fibromyalgia to be handled within a community

setting and therefore it seems appropriate for psychologists to be part of the programme to help these patients when managing this long-term condition.

Psychological Discourse

Following the participants' talk about how their doctors relinquished their responsibilities as medical professionals, through the implication that their doctors could not help anymore from a medical perspective, the participants seemed to take an active role in their treatment to include self-management strategies. After diagnosis and following a period of educating themselves, it could be argued that the focus of the conversation changed to home in on the acceptance of psychological factors in Fibromyalgia. Using a psychological discourse, the participants changed their construction of Fibromyalgia to include psychological symptoms such as stress and anxiety whereas previous constructions focused solely on bodily symptoms. The current findings support the prevalence of mood disorders in Fibromyalgia (Løge-Hagen et al., 2019). However, the participants' constructions involved a co-existence between a psychological and biomedical construct by implying that their symptoms were a connection between the body and the mind. Thus, the findings, suggest that the participants are willing to consider how psychological factors contribute to their Fibromyalgia but only after a diagnosis has been made.

According to Burr (2015), change is possible when individuals are given the right circumstances or are capable of critically analysing the discourses that frame their lives, and in doing so are able to open up marginalised and repressed discourses in which alternative identities are produced. From the participants' talk, it could be argued that some participants

seemed to be able to identify how they were being positioned within a medical discourse as powerless patients, and this may have limited the chance of them receiving medical treatment. It could be implied that for some of these participants, recognising the limitations of occupying the dominant medical discourse available to them possibly restricted what they could do as patients. Therefore, in constructing Fibromyalgia within a psychological discourse after diagnosis through educating themselves and talking about the psychological factors that affected them, the participants may have been trying to occupy a position within a different discourse that was less potentially damaging to them and allowed them to act differently through focusing on self-management strategies instead of further researching medical treatment. For example, participants had been struggling within the biomedical discourse for years, as previously described, but it may not have been until they acquired a diagnosis and possibly realised they could not make any further progress within this discourse that they allowed themselves to act differently. As a result, in occupying a different discourse, the participants were able to empower themselves by being more pro-active individuals through seeking therapy and focusing on self-management strategies such as mindfulness. In doing so the participants opened up new possibilities for action which previously may not have been available to them within a biomedical discourse.

Within a psychological discourse, participants specifically talk about being active in taking part in therapeutic techniques such as ACT instead of CBT, which supports previous research that has shown ACT to be an effective therapeutic technique used in the treatment of chronic pain conditions (Wicksell et al. 2013). The participants suggested that they could understand the connection between mind and body and thus inferred that these psychological services could possibly help them to manage their pain experiences. However, in practice it was implied that

due to poor accessibility such therapeutic services were unavailable to them. This may be due to PMP being a new comprehensive service within the NHS that may possibly not yet be widely available (Grady et al., 2015). Consequently, some participants talked about using self-help techniques such as mindfulness to develop self-growth in order to develop their own coping strategies to reduce their stress. The current findings are concurrent with previous research which has shown the benefits of mindfulness-based stress reduction and that this is effective at reducing subjective illness burden (Lauche et al., 2013). Thus, this study showed that by occupying a different discourse, in this case by drawing on a psychological discourse, the participants seemed to have empowered themselves and given themselves a sense of agency through managing their own symptoms.

In the omission of childhood traumas in their construction of Fibromyalgia, the participants may have revealed that they were unsure about trauma being a predisposing factor in Fibromyalgia, which previous research has supported (Low & Schweinhardt, 2012). For a few participants it seems as if early childhood trauma may have been related to current stressors, however, this association was suggested to participants by their doctors rather than coming directly from them. Thus, the participants seemed to take up the psychological construction of Fibromyalgia as resulting from childhood stressors after it was suggested to them, and then added it to their existing knowledge of the condition. However, in their talk the participants may have been wary of this psychological construction, which may suggest that they were possibly previously unaware of this predisposing factor and thus may not have fully understood the connection. Therefore, the participants may have been left to feel confused by the association proposed to them by their doctors. This study found that as a result,

participants may not have taken up this psychological discourse of Fibromyalgia without it being first constructed by their doctors and their pre-existing knowledge.

Counselling Psychologist perspective

Willig (1999), argued that the results of a discourse analytic study can be used as a guide to develop social interventions. In response to this, I shall consider ways in which practice within a psychological discourse could potentially open up more empowering positions for individuals with Fibromyalgia. As Counselling Psychologists, we tend to assume that when our clients attend therapy this is where the empowerment comes from, as our clients attend therapy, for example, to understand their symptoms or what is going on for them. From here psychologically they can then change. CBT is based on this assumption that clients can learn, evaluate and change their thoughts and beliefs and thus become empowered (Roditi & Robinson, 2011). Yet, from the participants' talk, they did not see the psychological discourse as containing possibilities for empowerment apart from possibly a feeling of relief in having someone to talk to about their symptom experiences. This lack of evidence for finding empowerment from a psychological discourse may stem from participants being referred in their view to psychological services as a final option for treatment. Therefore, it is important for Counselling Psychologists to communicate to clients during the first point of contact how therapy can help them improve their symptom experience and thus help them find empowerment.

Hence, dissemination of this research to specific audiences such as those in positions of power, raises the possibility of this research being used as a guide to social reform. For example, presenting this research to GPs or Pain Management Programmes (PMP) during

MDT meetings could show how patients can become stuck in a cycle of using a medical discourse to talk about Fibromyalgia and how that limits them in what they can do. Through exposing and challenging these existing practices, this study has shown that creating an alternative way of looking at Fibromyalgia through a psychological discourse has the potential to produce different ways of managing Fibromyalgia. Hence, it could be proposed that Counselling Psychologists could be used more within these community settings to empower individuals through communicating the benefits of developing self-management strategies and hence new ways of dealing with Fibromyalgia which are not accessible from within a medical discourse. These proposed changes are supported by recent NHS changes in the care of patients with Fibromyalgia in which such individuals are being encouraged to develop self-management strategies from an early stage to help improve patient functioning (Du et al., 2017), as well as by PMP being based in community settings (Wilson, 2017).

On the other hand, it could be argued that resisting existing structures is complex and, as Parker et al. (1995) proposed, by utilising the same discourses that we are challenging, Counselling Psychologists' opportunities for substantial and radical change are restricted. Thus, Burr (2015) noted that prevailing discourses, such as the medical discourse, are often tied to social practices that maintain the positions of powerful groups. Thus, in challenging or resisting such discourses Counselling Psychologists are implicitly challenging their associated social practice and can therefore expect to find some degree of resistance to attempts to change. In this regard, the data has shown that the participants took up the psychological discourse only after a diagnosis had been made, and therefore, it may be difficult for some individuals to accept another approach to understanding Fibromyalgia if they are comfortable

with the benefits that the medical discourse provide, such as more interventions and the possibility of being seen as ill by society.

The participants constructed psychologists or their version of psychologists, depending on the terminology they used, as professionals who listened to their problems. Bair et al. (2003) noted that psychologists were the most suited profession to deal with chronic pain patients due to their comorbid symptoms being associated with depression and anxiety. It could be argued that participants were possibly made to feel validated in their symptom experience which may have been previously been dismissed and ignored by other people or their doctors. Moreover, as Counselling Psychologists, it is important that we consider the cultural differences that a client might experience. One participant constructed her version of what she believed a psychiatrist does and whom they treat. In her construction, she implied that psychiatrists treat crazy people, which could suggest that clients' perceptions of therapists can differ. Therefore, Counselling Psychologists should be explicit and clarify during the first meeting the purpose of therapy and the aim of a psychologist in treating said patient group in order to establish a mutual understanding of therapeutic progress and to possibly enhance the therapeutic relationship. Furthermore, depending on the modality of the psychological approach used to help clients with their Fibromyalgia, childhood trauma may possibly be referred to, resolved or identified. Therefore, the link between childhood trauma and Fibromyalgia might be explored in depth or referred to as a possible cause of the onset of Fibromyalgia (Roditi & Robinson, 2011).

Social Discourse

Despite the participants having a diagnostic label and therefore able to be socially sanctioned as an ill person, when they approached Fibromyalgia via a social discourse the participants seemed to be pointing to the existence of a discourse that invalidated their illness experience due to Fibromyalgia being considered an invisible condition. In being aware of this discourse, the participants are suggesting that this narrative is possibly responsible for their struggle to be recognised as an ill citizen. The perception they had from society was that Fibromyalgia is not understood by others, which may have led to a disbelief that it is an illness, as it is described as being hidden and therefore unable to be objectively observed. Conrad and Barker (2010) revealed that the invisible aspect of Fibromyalgia may lead to Fibromyalgia patients' social circles and their doctors becoming sceptical regarding the nature of their pain and other symptoms. Therefore, in being aware of other people's constructions of Fibromyalgia, the participants may have been left to feel as though other people had negative perceptions about their condition and as a consequence that they may have held negative beliefs about the participant being ill. It could be argued that other people's negative assumptions consisted of denying that the participant was suffering from an illness at all. This may have left the participants feeling as if their illness experiences were being denied or ignored. As participants looked well, others may possibly have seen them as victims of their condition. Qualitative research has consistently described Fibromyalgia as an invisible illness, leading to the credibility of its patients being questioned by their social circles due to the lack of outwards signs of abnormality (Barker, 2011).

From this position of being aware of a social discourse, participants described their constant battle to prove their illness to others, which may have left them to feel a burden to others

whilst powerless to change people's perceptions of them. McMahon et al. (2012) described the experiences of participants with Fibromyalgia and the negative comments they received from work colleagues about their illness, for example, as it being an excuse not to work. As a consequence of their subjective position, participants may have felt frustrated by this process. For example, some participants described not talking about their Fibromyalgia and instead keeping it a secret. This could possibly be seen as a way for the participants to protect themselves from the negative perceptions they may have come to understand or possibly expect from society. Thus, in keeping their condition a secret, the participants may have been trying to distance themselves from the negative stereotypes they may feel are held by other people. This may have left the participants in a position whereby they were protecting themselves by not putting themselves in a powerless position to change or convince others with regard to their possible disbelief that Fibromyalgia is a real condition.

Furthermore, from their construction of other people's perceptions of Fibromyalgia, the participants seem to be constructed by others as victims, possibly subjected to the misfortune of being ill. However, some participants seemed to reject this positioning in the sick role, which some could argue is imposed on them by a society that socially sanctions them as an ill person. Lempp et al.'s (2009) qualitative study highlighted the consequences associated with Fibromyalgia patients' experiences. They found that patients reported a lack of sense of self whereby they experienced dissonance between how they saw themselves and how others viewed them. Therefore, for those participants who seemed to reject their positioning, as well as for those participants who were possibly made to feel powerless in their position as an ill person by others not believing them to be ill, it could be argued that they may have reclaimed their power by reclaiming their sense of self. It could be inferred that the

participants reclaimed their sense of self by telling only those people with whom they wanted to share this part of their lives about their diagnosis. Other participants simply did not tell anyone, as they did not want those negative attitudes imposed on them.

Overall, it could be argued that how participants experienced themselves or possibly how they managed their symptoms depended on how they constructed other people's perceptions of Fibromyalgia. For example, some participants constructed being ill as possibly having an impact on their social lives and their well-being. Such participants constructed their experience of having Fibromyalgia as isolating. They were possibly made to feel as though their family and friends could not understand what they were going through and consequently may have felt as if they were misunderstood or ignored by those around them. Similar results have been found by other researchers such as Åsbring & Närvänen (2002), who found that those with Fibromyalgia withdrew from social activities due to the unpredictability of their illness. Moreover, Lempp et al. (2009) noted that the reduction in patients' social lives was associated with their participants reporting strained relationships with their family and friends. However, some participants constructed their family to be supportive of their illness. Having a supportive family may have helped the participants to possibly feel that they could manage their symptoms better, as they may have had people around them who understood their symptom experience. Therefore, it could be implied that in practice, other people's perceptions of the participants impacted how they experienced Fibromyalgia.

Interestingly, the participants talked about the social implications of being ill, which for some meant reduced work hours and limited financial support; in practice, if the participants are not seen by society to be ill they cannot claim any benefits such as government aid.

Furthermore, the implications of the participants not being seen as legitimately ill may be dependent on the constructions of what a 'productive member of society' looks like. In not being seen as productive members of society, participants constructed themselves as burdens on their families who were not able to work due to their Fibromyalgia possibly restricting their effectiveness as workers. This may have left the participants feeling as though they could not contribute financially towards their family. Additionally, in being considered ill by society, participants may have been positioned as unemployable due to their condition. This may have left the participants possibly feeling as though their intellect was being ignored. Therefore, it could be argued that although the participants wanted to be considered as productive members of society, this construct may have been restricted by others, thereby limiting the participants' ability to be productive citizens as they were not in a position to oppose the constructions already imposed on them.

Counselling Psychology perspective

Using a social discourse the participants constructed the impact of having Fibromyalgia. They

Using a social discourse, the participants constructed the impact of having Fibromyalgia. They discussed the effects on their close relationships and work environment and in turn how other people's perceptions of their Fibromyalgia may have made them feel. As Counselling Psychologists we need to ensure that the social aspects of being ill or being seen to be ill are discussed in therapy. There are implications within the social discourse that may possibly have an effect on how the participants view themselves as well as how they manage their symptom experiences. It could be reasoned that Counselling Psychologists need to develop more awareness of how people with Fibromyalgia cope with their symptoms and of the

conversations they have with other people about their condition so that they are able to feel empowered rather than victims or a burden.

Moreover, it seems that some participants are searching through social media sites for ways to manage their symptom experiences, but are not always finding the right solutions. Therefore, Counselling Psychologists may need to be more visible within these communities as another resource that can be utilised to help manage their condition. Most participants turned to social media to research or join a Fibromyalgia support group. In their talk, it seemed as if the participants were searching for ways to cope with their new diagnosis as well as for ways to manage their symptoms with the help and advice of others who had the same condition. Some participants suggested that they found these social media sites to be helpful, as to them they implied a sense of community. However, others described these sites as unhelpful by insinuating that the users only complained about their symptoms rather than being supportive, which is what participants wanted from the groups. For example, Participant 3 said:

‘So little is known about Fibromyalgia, there is so few places that you can turn to for good support and yeah there is a lot of places that claim that they give you support but actually I don’t think they do. You know I don’t like to join a group that just has a good moan, I want to find solutions.’ (Participant 3, L48-51).

In her talk, Participant 3 implies that there are limited online sources that can provide information about Fibromyalgia and to her these places do not offer the type of support she is searching for. She is suggesting that Fibromyalgia is not a known condition and therefore the places where she can find information on it do not provide her with the answers she is

looking for. It follows that Counselling Psychologists could use social media platforms to educate the public about Fibromyalgia and provide resources supported by scientific evidence to help the public understand the condition from a biopsychosocial perspective, as well as highlighting for patients how they can manage their pain in order to enhance their quality of life (Tuck et al., 2008). Moreover, on the topic of educating the public, there seemed to be no distinction between a counsellor and a psychologist within the participants' talk. This suggests that the participants and by association the wider community could possibly not know the difference between the members of mental health professions. As a Counselling Psychologist, it seems important to me to help other people understand what we do, how we are different from other mental health professionals, how we can help this particular client group and where they can find us. Thus, by becoming more visible on social media, Counselling Psychologists would also be making psychological discourse more visible and, therefore, available to people with Fibromyalgia to use and make sense of their experiences.

Discourse Dynamics

Burr (2015) argued that there were always a number of different discourses surrounding a construct, each offering an alternative view and bringing with it different possibilities for action. It follows, therefore, that the dominant prevailing discourse is continually subject to resistance. Despite the emergence of alternative subject positions and practices through the construction of different discourses, the data seems to point to an interlink/similarity between the possibility for action within the discourses presented. This seems to go against Frost (2011) who proposed that subject positions may afford multiple and contradicting experiences and practices that may need to be negotiated by the subject. Yet, it could be argued that the similarities in the presentation of the discourses relate to how the

participants may have been using discourse to negotiate their identity. Thus, it could be considered that an important conclusion from this study is that Fibromyalgia patients are in a constant state of action orientation (Stage 3: the function of the construction, see Chapter 2). For example, the participants are telling a story around identity through what they are doing with their talk, how they construct themselves around different people and how this impacts how they feel about themselves.

Across the interviews, all participants constructed themselves as having bodily symptoms and were able to describe their diagnostic journey within a medical context. This possibly allowed them to distance themselves from other people's (mainly health professionals) perceptions of them who constructed their symptom experiences as being psychological or emotional rather than biomedical. However, it could be argued that the participants may have been impacted by the genealogy of the dominant biomedical discourse of Fibromyalgia, as this seemed to have impacted how the participants were seen socially and possibly led other people to invalidate the participants' illness experience. This leads to questions around whether or not it is possible to avoid or escape these interlinking consequences of discourses in how patients construct Fibromyalgia.

Since all participants seem to construct themselves as having an invisible illness, they are forced to engage with the medical discourse. Within a medical discourse, participants' identities as patients within the medical institution positioned them as powerless individuals and subjected them to medical tests that found no presence of any disease or underlying condition. Hence, the participants were constructed by their doctors as psychosomatic, which possibly made them feel frustrated. Davies and Harré (1999, 49) mentioned that 'the

possibility of choice in a situation in which there are contradictory requirements provides people with the possibility of acting agentially'. Furthermore, Drewery (2005) supported this concept by suggesting that through the collaborative production of language to create an individual's lived reality, the agential subject position can find empowerment within the relationship with others which, therefore, affords the possibility of agency. Hence, it could be argued that some participants seemed to reject their positioning and instead used their agency to be viewed as possibly having an undetected medical condition. As such, they wanted to be treated medically, and with their agency possibly empowered themselves to gain access to medical tests and referrals on to specialists which led to their diagnosis, which may have validated their illness experience.

Other participants resisted the medical discourse, as they felt abandoned by their doctors and therefore may have been forced to take up a psychological discourse by becoming an active patient after a period of time of managing their symptoms on their own instead of relying on their doctors. This may explain why the concepts of second-order positioning and action orientation were used by the participants as a way to negotiate their identities as patients and resist against the constraints of what they could do within the medical discourse. Moreover, it could be argued that the participants had no choice but to resist the prevailing medical discourse as it no longer served them, whereas the psychological discourse opened up new possibilities for action.

The social discourse, by contrast, was used by participants to talk about their struggle to be recognised as being ill by society. This struggle to prove their invisible illness is also present to some extent in the medical discourse, which possibly led to the problematic doctor-patient

relationships that characterise Fibromyalgia. Therefore, the consequences of constructing Fibromyalgia within the prevailing medical discourse seem to have societal effects in terms of assumptions around what it means to be ill. When participants cannot prove that they are ill to others through medical testing, other people make judgments related to the participants' supposed medical condition, and therefore the status of the participant's body depends upon social rather than biological criteria, so leaving participants stuck in a cycle of trying to prove the illness to others. Thus, according to Burr (2015), each subject position brings with it its own power implications and thereby to accept or reject a subject position within or away from the medical discourse could be either empowering or oppressive for the participant.

Agency and Power

The sense of agency that participants acquire by negotiating their identity could be seen as problematic in the context of a Foucauldian Discourse Analytic framework. As explained by Burr (2015), FDA denotes that individuals are constantly subject to an interplay of different discourses, each with its own structure of rights, obligations and possibilities for action, and each carrying identity and power implications. The discursive positions available to an individual depend on the extent to which individuals are able to negotiate satisfactory identities of themselves and therefore their ability to behave and take action as they wish is constrained to their available discourses, thus limiting their potential for change. An inevitable result of this concept is that as it is the discourses and not the individual subject that produce knowledge, then the subject is therefore the product of discourse as suggested by Foucault (1980). However, Oksala (2005), a critic of Foucault's work, argued that this perspective is an omission of agency in discursive analysis. Oksala (2005) stated that the rejection of the subject through a denial of their autonomy denies any meaningful concept of

freedom. The scholar goes on to propose that the subject is capable of moral self-reflexivity and critical reflection of their own conditions and therefore able to resist normative practices and ideas.

Thus, in relation to this study, when the participants negotiate their identities within the prevailing discourse by resisting their original positioning (through second-order positioning) and thus seem to reclaim their power by doing something different (requesting more tests), this could be seen as a form of self-reflexivity. Therefore, one way to view the participants reclaiming their power in discourse analysis is to view them as being able to become self-reflective as a way to distance themselves from the taken-for-granted symbolic assumptions of normative social practices. From this point of view, Kögler (1999) argued that discourses are symbolic constructions grounded in individuals' own experiences and interactions with their social environments. Thus, discourses contribute to enforcing and stabilising an individual sense of reality, but it is the individuals themselves who reinterpret and change their worlds by their explicit intentional activities. Examples of this, in my FDA interpretation, can be seen when the participants seem to have challenged their medical professionals' opinions of them in order to be seen and treated as physically ill patients by requesting more investigations as well as by choosing to not tell some members of society about their condition due to previous negative experiences which denied their illness. It could be argued that the participants are aware of their positioning and use their agency through language to act differently as a way to change and reinterpret their reality.

On the other hand, it could be argued that a discursive approach to analysing the data would have allowed for an exploration into how the participants adapt their talk according to their

needs, depending on the situation in which they find themselves (Frost, 2011). However, on a broader scale my FDA research question and analysis focused more on the relationship between discursive formations and the wider institutional practices and did not focus on one particular conversation or discursive context. Thus, the findings highlighted how the participants constructed Fibromyalgia and explored the effects of their constructions on what they could do, and how this could possibly make them feel as they were able to use their reflexivity to negotiate suitable identities amongst different institutional practices that positioned them in a particular way.

Moreover, in terms of power, Burman (1992) noted that subjectivity can be seen not as integrated and static but instead as fragmented and fluctuating between and produced by competing and contrasting discourses. This study has shown that the biomedical discourse seems to be the constraining discourse which the genealogy of Fibromyalgia from expert texts has highlighted and which the participants talked about as a bodily condition that needed medical interventions. Within the discourse, patients are possibly seen to be powerless within society but are not without power. This concept was supported by Lie (2008) who stated that power is seen as relational and therefore cannot exist without the possibility of resistance. Hence, the participants seem to be aware of the discourse and their positioning but actively in their talk seem to resist it. This can be seen in how participants seemed to be aware of how they were being positioned within society and with their doctors, which potentially limited how they could behave. Jones (2017) proposed that agency creates a negotiated space for resistance and potential change for which empowerment represents the actual enactment of agency in a transformative way. In other words, although agency points to the process of negotiating competing discourses, empowerment emphasises the outcome of those

negotiations and therefore, empowerment is resistance successfully realised. This could be another way of viewing agency within FDA. Thus, in discourse analysis terms, the findings of this study show that some of the participants seem to have a skilful ability to understand their positioning and are able to negotiate a more satisfactory identity in order to change the way they experience their syndrome.

Research Evaluation

In terms of evaluating the credibility of my work, Harper (2011) noted that qualitative research should be clear, coherent, well-structured and transparent with the raw material of the extracts used to demonstrate how conclusions were reached and interpretations made. Following this advice, I believe that I have detailed clearly and explicitly how the study was conducted, how interpretations were reached during the analytic stages with extracts from the data include for examples, and a well-structured format that has provided a coherent discussion of my research question. In doing so I hope to have established convincing and coherent claims about how Fibromyalgia is constructed by patients and the consequences attached to these descriptions. As my research does not try to make claims to establish identifiable or objective truth, generalising my findings, as stated earlier, is limited.

For my recruitment and sampling strategy I used the snowballing technique to find my participants through social media. Snowballing sampling is one of the most popular methods in qualitative research. The researcher typically uses a small number of initial contacts to become willing participants who then recommend other potential participants to join through their social networks, which increases the chain of participants wanting to be included in the study (Parker et al., 2019). The benefits of using the snowball sampling technique were that

it allowed me to recruit participants within a hard-to-reach population (Baltar & Brunet, 2012). This would enable me to include those with the syndrome, since the nature of the Fibromyalgia population is that it is geographically dispersed and vulnerable due to the symptoms associated with CPP. However, a critique of this snowballing technique is that it is dependent on selection bias, whereby the sample is dependent on the awareness of others who potentially fit the criteria and who may also be willing and cooperative (Parker et al., 2019). Therefore, it could be argued that the analysis of the participants' talk may have been affected, as the participants could be seen as active patients possibly seeking alternative ways of managing their Fibromyalgia or seeking other forms of intervention online. Had I used my poster within a hospital or in private clinics as first proposed, I may have found that the participants might have constructed Fibromyalgia more within a biomedical discourse, as they could have been in the process of seeking medical help for their syndrome. Thus, different discourses may have been discovered within these participants' talks compared to the ones found in this study. Therefore, it could be suggested that the transferability of the study may be limited to helping those who are active patients possibly starting the process of using different discourses to construct Fibromyalgia. Despite the criticism around using snowballing, Woodley and Lockard (2016) advocated for such a sampling method due to its ability to access previously unheard voices, highlighting that other traditional methods in qualitative research have previously alienated minorities and sensitive groups who are oppressed or marginalised within society. Thus, with the sampling strategy I used for this study I was able to recruit participants from different ethnic backgrounds to take part and thus to offer guidance for social reform for Counselling Psychologists around supporting those from different cultural areas.

Additionally, I could have improved recruitment by widening my analysis to focus on internet chatrooms, social media sites, and autobiographical accounts as a way to widen the range of texts to explore different discourses utilised in how individuals with Fibromyalgia talk about their condition. By extending my analysis, I would have removed my presence as a researcher by eliminating a power dynamic and thus would be able to analyse naturally occurring talk. In doing so I may have had an opportunity to examine any cultural constructions of Fibromyalgia and any historical developments or discursive resources available.

Applicability

Willig (1999) highlighted the applicability of discourse analytic research by addressing three areas: *discourse analysis as social critique*, which explores the way language legitimatises and perpetuates unequal power relations; *discourse analysis as empowerment*, which allows for resistance to dominant discourses; and lastly, *discourse analysis as a guide to reform*, which uses results of discourse analytic studies to develop social interventions. The present study explored how Fibromyalgia was constructed by its patients and the implications of the discourses used. Evaluating the usefulness of this study as a social critique by highlighting the dominant discourses used to construct Fibromyalgia and the implication for practices, subjective experiences and treatment of its patients has highlighted areas where empowerment can be found through a repositioning of power relations. Disseminating this research can be used as a guide to social reform as it can help medical professionals, psychologists, trainees and governmental bodies to bring about changes by challenging existing practices and creating alternative avenues through education for how Fibromyalgia is understood by its patients. Furthermore, as Harper (2006) suggested that discourse analytic findings do not result in direct implementation but can inform novel interventions, it is hoped

that this study has provided new theoretical insight to the field of study, has built upon previous research, and as a result may lead to new research questions being generated (Potter, 1996).

Methodological Limitations and Further Research

Considering the limitations of FDA in terms of its lack of focus on individuals' agency, future research could consider combining FDA and Interpretative Phenomenological Analysis (IPA) to conduct a dual focus methodology. Willig (2013) argued that approaches to knowledge are not necessarily mutually exclusive; therefore, it is possible to combine qualitative methodologies that have different epistemological positions. A dual focus methodology would allow researchers to view the same data but interpret it in different ways. The primary analysis could possibly adopt a discursive approach to how individuals talk about Fibromyalgia and how they position themselves within certain discourses, while the secondary analysis could lead to a better understanding of the subjective experience of the individual in order to understand the personal meaning of the experience, thus counteracting the agency limits of FDA.

IPA permits a more direct and interpretative approach to individual experiences (Colahan, Tunariu, & Dell, 2012). This qualitative methodology studies individuals' experiences and examines how they make sense of their personal and social world (Eatough & Smith, 2017). Phenomenological knowledge therefore does not make claims about the accuracy of individuals' experiences, instead such research aims to understand rather than discover what is really going on for the individual (Willig, 2012). In order to identify how an individual's experience and behaviours are shaped by their social world, Counselling Psychologists employ

a person-centred approach whereby the client's narratives of their experiences are listened to with curiosity, empathy and with an open mind (Tuffour, 2017). From this perspective, such a study would aim to find out what it is like for individuals to live with a diagnosis of Fibromyalgia.

A dual focus methodology could provide a holistic understanding of how individuals position themselves within discourse in addition to understanding their experience of emotional distress in having Fibromyalgia. From this perspective the subjective experience and the construction of the experience would be considered inseparable (Willig, 2013). Thus, individuals cannot make sense of what they are experiencing without drawing on the discourses available to them; whether they choose to take them up or to reject them, they are still making sense of what is happening to them in the context of the discourses (Burr, 2003). Using the strengths of both methodologies to accomplish a more complex understanding of Fibromyalgia, a dual focus methodology could allow researchers to examine the interplay between language and experiences. Willig (2017, 11) wrote: *'Social constructionism proposes that discourses construct experiences, whereas phenomenology argues that discourses constrain how experiences can be spoken about. The middle position argues that discourses shape experiences by providing a context for it.'*

Discussion and Analysis Reflexivity

My motivation for writing this analysis chapter was influenced by what Harper (2003) referred to as a need to write a coherent, linear and consistent argument that tells a particular story. However, it has been suggested that the implication of telling a story is that it is presenting a piece of writing from a particular point of view and as a result may narrow the range of what

could have been said (Rogers, 1991). When reflecting on the three discourses presented in my analysis and discussion chapters, I see that these discourses may have been influenced more by my understanding of Fibromyalgia than the participants' perspectives. When conducting my literature review, I gained my understanding of Fibromyalgia through the multidisciplinary perspective that was described in expert texts. This tended to be broken down into the biopsychosocial perspective. In the introduction, the genealogy took me on the journey to discover how Fibromyalgia came into being from a medical discourse before evolving over time through research into incorporating psychological and social factors as described earlier.

Consequently, before conducting the interviews, I initially thought that my study would be examining the impact of the biopsychosocial perspective on participants and therefore my debrief contains this information on how I would analyse the participants' talk according to these dominant discourses. At the time of presenting the analysis chapter, I understood the term 'discourse' to be a set of institutional bodies that represented particular versions of events in a particular light. Thus, there could be multiple versions of an event, each produced through language, that could tell a different story and have different implications for what could be done. Looking back, I seemed to have followed the multidimensional perspective used in expert texts in using the dominant biopsychosocial discourses that constructed Fibromyalgia within my participants' talk. I am aware that were another researcher to analyse the data they might have found different discourses, such as patient journey or empowerment, as these discursive themes were also used to construct Fibromyalgia by the participants. However, the discursive themes, such as diagnostic journey, experience of symptoms and management of Fibromyalgia, described in the discourse subheadings

highlight the consequences and limitations of what the participants could do when they talked about these themes.

To conclude, I acknowledge that my analysis is not independent of my own experience and positions on chronic pain, both as a chronic pain patient and as a trainee psychologist; what I have produced in the analysis and my interpretations may not be the truth of what the data means. It could be argued that another researcher might have presented the findings in a different manner and constructed different discourses and implications not mentioned above. Nevertheless, by being transparent in my process throughout I hope to have presented a cohesive, clear and convincing narrative.

Personal Reflexivity

Fuhrman and Oehler (1986) highlighted the importance of reflectivity in discourse analysis as it encourages the researcher to reflect upon why they undertook the research, the assumptions made before the research (Willig, 2001), the influences on the conclusions presented and justified, and how the research may have affected the researcher personally. In the methodology chapter, I set out the reasons why I chose to do this study, my assumptions, the epistemological questions concerning the way in which the research question was defined, and the limitations on what could be discovered. In terms of how the research has affected me personally, I began writing discourse analysis as a novice to qualitative research, so I found the beginning process confusing and overwhelming in trying to get grips with the concepts of language, knowledge, power and discourse. I really struggled to understand what these words truly meant and the implications they had for a piece of text or talk. My supervisor guided me through this confusing process by suggesting I read

discourse analysis articles, and recommended particular theses to help me get a sense of how discourse analysis is written and the way in which language is used. I also found it challenging at every single stage in terms of what to do next, as there is no set way of conducting FDA. Yet, when I finally mastered step 2 in the analysis process, my confusion levels started all over again as I was not sure how to conduct the next steps (3-6). This brought about a lot of anxiety and my motivation levels kept fluctuating because I struggled emotionally to get to grips with finding the time to understand how to conduct the analysis whilst balancing other assignments, managing work, family life and maintaining a social life for sanity. The whole process felt like a never-ending journey of struggling, learning, then understanding. However, during the summer when I became overwhelmed with the deadline of having to complete my analysis chapter, and not knowing how to convert my raw data into a coherent summary, I became so anxious that I took a break and forgot to ask for help. When my supervisor reached out to see how I was getting on, this somehow motivated me to get back to work and my sense of enthusiasm for my project returned. Moreover, the chapter seemed easier for me to complete after this much-needed break. Overall, looking back I enjoyed the writing process and I've really learned about what discourse analysis is, what it entails, and how it can be conducted, which has changed how I view other discourse studies. Looking forward, I appreciate the importance of language and have a new perspective on the impact language has when spoken or written, which I hope to be mindful of in my practice as a psychologist and researcher.

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Appendix A: Participant Recruitment Poster

Department of Counselling Psychology
City, University of London

PARTICIPANTS NEEDED FOR RESEARCH IN 'HOW DO PATIENTS WITH A DIAGNOSIS OF FIBROMYALGIA TALK ABOUT FIBROMYALGIA'

I am looking for volunteers to take part in a study of
how Fibromyalgia is talked about.

As a participant in this study, you would be asked to take part in an interview lasting 60 minutes. This will involve your experience of having fibromyalgia and what it means to you.

For more information about this study, or to volunteer for this study, please contact:

Researcher: Amanda Agyare, Trainee Counselling Psychologist

Email: [REDACTED]

Supervisor: Dr Julianne Challenor

Email: [REDACTED]

Psychology Department
at

[REDACTED]

This study has been reviewed by, and received ethics clearance through the Psychology Department Research Ethics Committee, City, University of London (ETH1819-0084).

If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on [REDACTED]

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk

Appendix B: Participant Information Sheet

PARTICIPANT INFORMATION SHEET



Title of study: A qualitative study on the construction of Fibromyalgia by patients.

Name of principal investigator:

Amanda Agyare, Email: [REDACTED]

Supervised by: Julianna Challenor; Email: [REDACTED]

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to explore how patients diagnosed with Fibromyalgia talk about fibromyalgia and the implications this has for their sense of self and the actions that occur as a result. The finding of this study hope to inform the work of counselling psychologists with other patients in order to enhance therapeutic relationships with medical doctors. This study is party of a thesis for the Professional Doctorate in Counselling Psychology at City University and will last for two years with a proposed completion date in September 2020.

Why have I been invited?

I am recruiting individuals with fibromyalgia over the age of 18 who have been diagnosed by an experienced clinician more than three months and are able to effectively communicate in English. Exclusion criteria include individuals who are severely psychologically and physically unwell. A pre-telephone conversation will determine eligibility for the study. I will be conducting 6-8 individual interviews with those who are happy to talk about their experiences of fibromyalgia and what it means to you. The method of this study is discourse analysis and therefore the focus on the study will be how you choose to talk about fibromyalgia and not your personal experiences.

Do I have to take part?

Participation is voluntary and you may withdraw from the study at any point or avoid answering questions that you find too personal or intrusive without giving a reason. You will not be penalized from withdrawing from the study and no future treatment will be affected.

It is up to you to decide whether or not to take part. All participants will be asked to take part in a pre-screening phone conversation in addition to the interview. If you do

decide to take part, you will be asked to sign a consent form, however, you are still free to withdraw at any time without giving a reason. Once the data has been anonymised, analyzed or published participants will no longer be able to withdraw their data.

What will happen if I take part?

Details of the participation are listed below if you wish to take part:

TIME: you will be required to attend a 60-minute interview at City University.

LOCATION: the interview will be conducted in a room provided by City University. Details will be arranged in accordance with researcher safety provisions. If you have difficulties in traveling due to the nature of your fibromyalgia symptoms yet you wish to take part, a skype interview can be offered.

INTERVIEW: The interview is a one-off meeting with the researcher. Personal information will be collected during the pre interview screening. If you do not meet the criteria, all personal information will be destroyed. The interview will be semi-structured, whereby pre-selected questions will be asked. You will have the opportunity to elaborate answers at any time. Although I am interested to hear your personal experiences, the study itself will be concerned with the language used when talking about fibromyalgia.

RECORDING: The interview will be audio taped with your consent. All recordings will be kept securely and will only be accessed by the researcher.

DATA ANALYSIS: After the interview has been recorded, it will be transcribed. To ensure your identity remains anonymous, any identifying and personal details will be changed using a pseudonym of your choice. Discourse analysis will be the methodology used to analyze data. This form of analysis focuses on language and how it is used to convey meaning. In the final analysis quotes will be used but identifying details will be removed so that those reading the analysis will not be able to identify you. At the end of the study, resources such as tapes and recordings will be destroyed.

CONSENT: You will be asked to sign a consent form once you are satisfied that you understand the study and its rationale.

What do I have to do?

Participants will be asked a set of questions which you can choose to answer or not, regarding your experience of having Fibromyalgia.

What are the possible disadvantages and risks of taking part?

During the course of the interview, the topic may cause some emotional distress. At all stages of the interview process, you will be reminded that participation and answering question is voluntary and you can withdraw at any time.

What are the possible benefits of taking part?

The interview is a safe space for you to talk about fibromyalgia and think about what fibromyalgia means to you. Your participation will contribute to research that hopes to be part of a wider discussion about patients' representation (or lack thereof) within the medical discourses and the implications it may have within the psychological care for future patients.

What will happen when the research study stops?

When the thesis is complete, participants' data kept in storage in a secure location will be deleted and destroyed a few months after submission.

Will my taking part in the study be kept confidential?

Access to data before and after it has been anonymized will be restricted to the researcher and research supervisor. All information disclosed by you will be treated as private and confidential. The research aims to comply with BPS ethical guidelines and all participants will be consenting adults whose anonymity will be assured. Confidentiality will only be broken if participants report violence, abuse, self-inflicted harm, harm to others, criminal activity. I will inform you if this occurs and will explain what the necessary procedure will be afterwards. Audio recordings and transcripts will be encrypted and stored securely in a locked drawer which only the researcher will have access to. Records of the study will be stored at City University for a maximum of 10 years, after this length of time, all records will be destroyed. Any future use of personal information will only be with the participant's signed consent. There will be no sharing of data with other universities or researchers. Beyond this study, there are no plans for future use of participants' personal information, no data sharing agreements or third party organizations included.

What should I do if I want to take part?

If you wish to participate in this study please email me at:

or email my supervisor at:

What will happen to results of the research study?

The findings of this study will be reported for a Professional Doctorate in Counselling Psychology. Future publications may be disseminated through journal publications; *BPS Journal*, *Journal of psychosomatic research* and *Journal for Counselling Psychology Review*, as well as academic conferences. This thesis and any future reports may include direct quotes from the participants' interview. Anonymity will

always be maintained. Please note that the thesis will be made available on the City Research Online as stated on the consent form. Some information may be redacted before the thesis is uploaded, in order to maintain anonymity. If participants wish to receive a copy of the publication/summary of the results upon completion, please contact me directly.

What will happen if I do not want to carry on with the study?

Participants are free to withdraw from this study at anytime without an explanation or penalty up to the point of analysis. To withdraw please notify me or my supervisor using the contact details below.

Who has reviewed the study?

This study has been approved by City, University of London *Psychology Department* Research Ethics Committee.

Further information and contact details

Researcher: Amanda Agyare, email: [REDACTED]

Supervisor: Julianna Challenor, email: [REDACTED]

Data Protection Privacy Notice: What are my rights under the data protection legislation?

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this notice. The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

The rights you have under the data protection legislation are listed below, but not all of the rights will apply to the personal data collected in each research project.

- right to be informed
- right of access
- right to rectification
- right to erasure
- right to restrict processing
- right to object to data processing
- right to data portability
- right to object

- rights in relation to automated decision making and profiling

For more information, please visit www.city.ac.uk/about/city-information/legal

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at dataprotection@city.ac.uk or phone [REDACTED], who will liaise with City's Data Protection Officer [REDACTED] to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

What if there is a problem?

If the research is undertaken in the UK if you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [REDACTED]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is:

.....

.....
You could also write to the Secretary at:

[REDACTED]
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: [REDACTED]

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Thank you for taking the time to read this information sheet.

Date 22nd October 2018, Version 2.

Appendix C: Consent Form



CONSENT FORM

Title of Study: A qualitative study on the construction of Fibromyalgia by patients.

Please initial box

1	I confirm that I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be audiotaped • making myself available for a further interview should that be required	
2	This information will be held by City as data controller and processed for the following purpose(s): • As part of a study which discusses how fibromyalgia is constructed by patients. • This study is part of the researchers' thesis for a Professional Doctorate in Counselling Psychology • The data will be analyzed using discourse analysis and quotes will be used in the results sections. All personal and identifiable information will be anonymized using the participants chosen pseudonym. Under <i>lawful basis for processing under General Data Protection Regulation (GDPR) for personal data and special category data.</i> Public Task: The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinized and approved by one of City's Research Ethics Committees.	
3	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organization.	

	I understand that for quotes my chosen pseudonym will be used to protect my identity from being made public.	
4	I understand that my participation is voluntary, that I can choose not to participate in part of or all of the project, and that I can withdraw from the study at any point up without explain why up until the data has been analyzed, without being penalized or disadvantaged in any way.	
5	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
6.	I agree to the arrangements for data storage, archiving and sharing.	
7	I agree to the use of anonymised quotes in publication.	
8	I agree to take part in the above study.	

Name of Participant Signature Date

Name of Researcher Signature Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix D: Debrief Form

A qualitative study on the construction of Fibromyalgia by patients.

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it is finished, we would like to tell you a bit more about it.

The information provided during your interview will be analyzed using discourse analysis. The focus of this study is on language and seeks to consider the social, medical and psychological discourses within a Foucauldian framework. This method will seek to provide an understanding of how fibromyalgia is constructed by patients and what the consequences are attached to these definitions. The implications may be on patients' sense of self and subjectivity. This approach hopes to enhance therapeutic relationships between doctors and patients by focusing on philosophy rather than science.

Once again, you are free to withdraw from the study at any point up without explain why up until the data has been analyzed. Participation is voluntary and you can withdraw without being penalised or disadvantaged in any way. If you wish to withdraw, please contact me with your chosen pseudonym.

If participation in this research has raised any emotional concerns for you, please contact your GP for support. For further support, please contact the following services: Mind (0300 123 3393), Samaritans (116 123), your local IAPT, Pain concern (**0300 123 0789**) or www.getselfhelp.co.uk/chronicfp. To find a Counselling Psychologist or therapist go to the BPS website (www.bps.org.uk) and click on "Find a Psychologist", or visit the British Association for Counselling and Psychotherapy website (www.bacp.co.uk) and click on "Find a Therapist". If you wish to contact me or my research supervisor in relation to this research, please find contact details below.

We hope you found the study interesting.

If you have any other questions, please do not hesitate to contact us at the following:

Researcher: Amanda Agyare, [REDACTED]

Supervisor: Julianna Challenor, [REDACTED]

Ethics approval code: ETH1819-0084.

Appendix E: Interview schedule

Introduction

- Greetings and introducing the topic being investigated
- Why the participant was selected
- Review issues of confidentiality and anonymity
- Signing of consent form

Questions

- Tell me about having fibromyalgia?
- What does FM mean to you?
- How would you define FM?
- Could you describe how you speak about fibromyalgia to your friends, family and other in your life?
- Did you know anything about fibromyalgia before you were diagnosed?
- Who do you see clinically on a regular basis?
- How do professionals talk to you about FM?
- Do you feel you can challenge your doctor about what they tell you?
- Have you been referred to any psychological services in relation to having FM?
- How did you feel?
- What did the referral mean to you?
- Tell me about your experience of having FM?

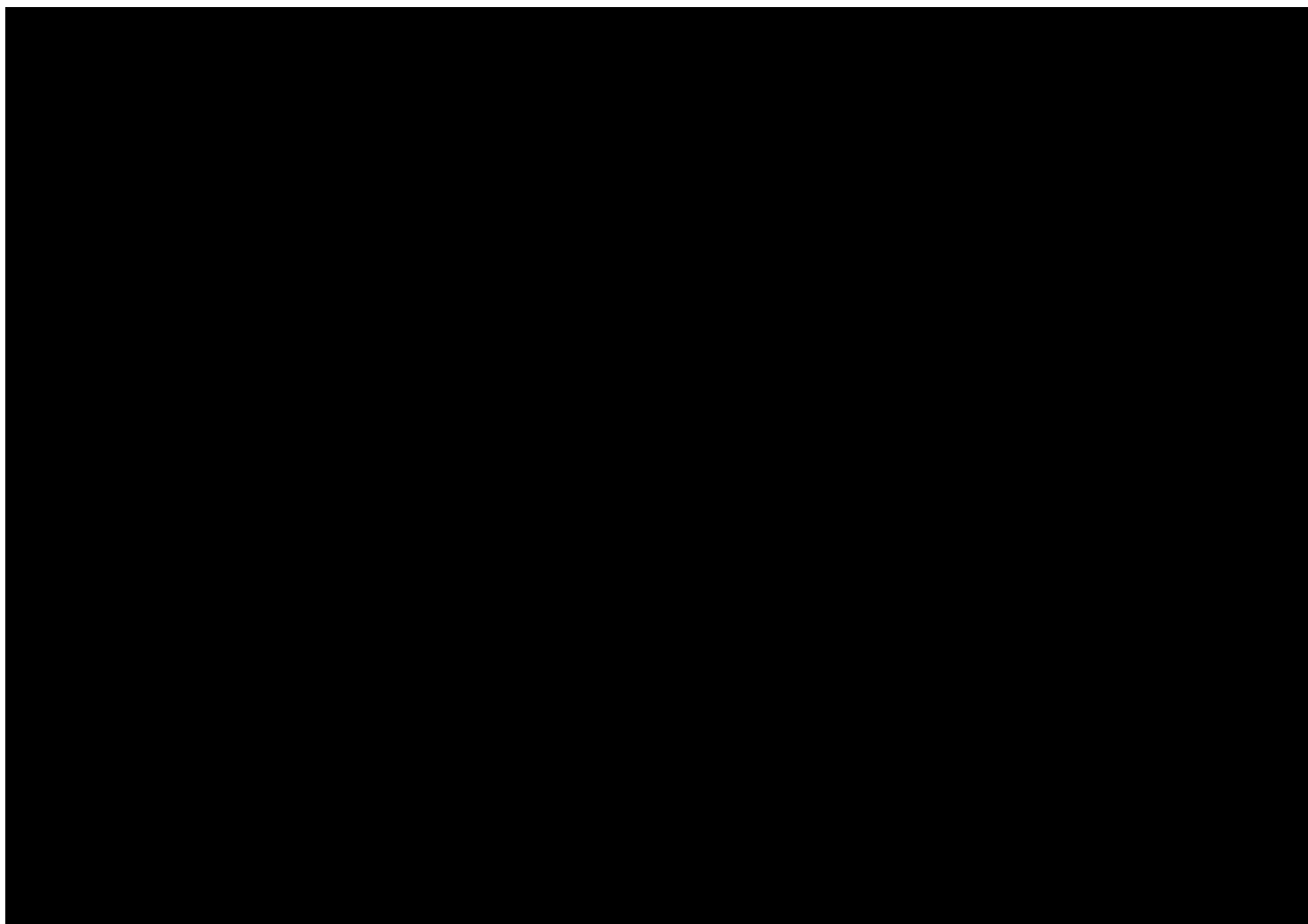
Ending

- Is there anything further you would like to add?
- Is there anything that you feel I should have asked?

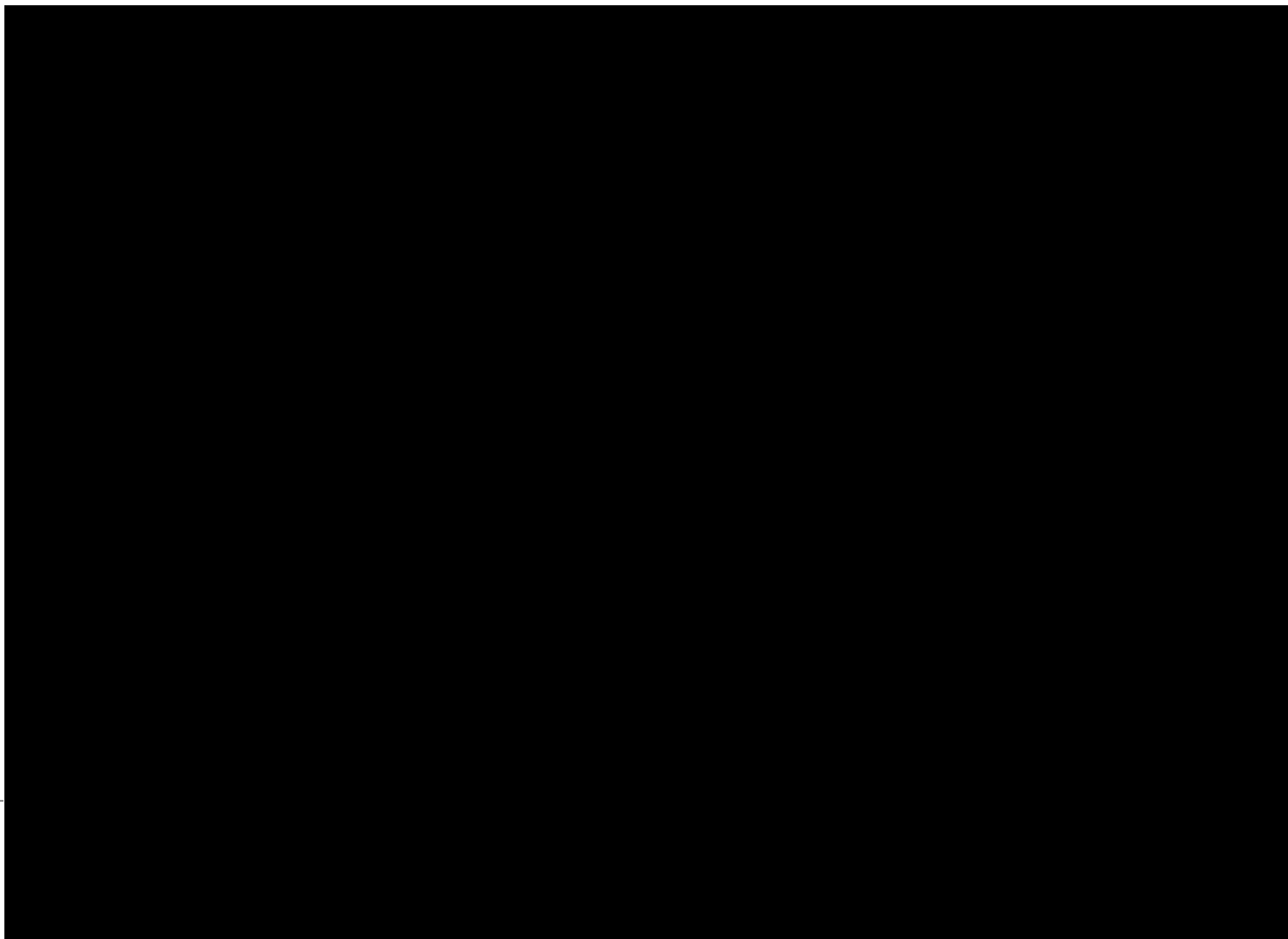
Debriefing

- Debrief participant and send form
- Further information about the study
- Sources of support
- Feedback

Appendix F: Transcript with colour coded six-stage analysis (By Hand)



Appendix G: Transcript with colour coded six-stage analysis (By Adobe)



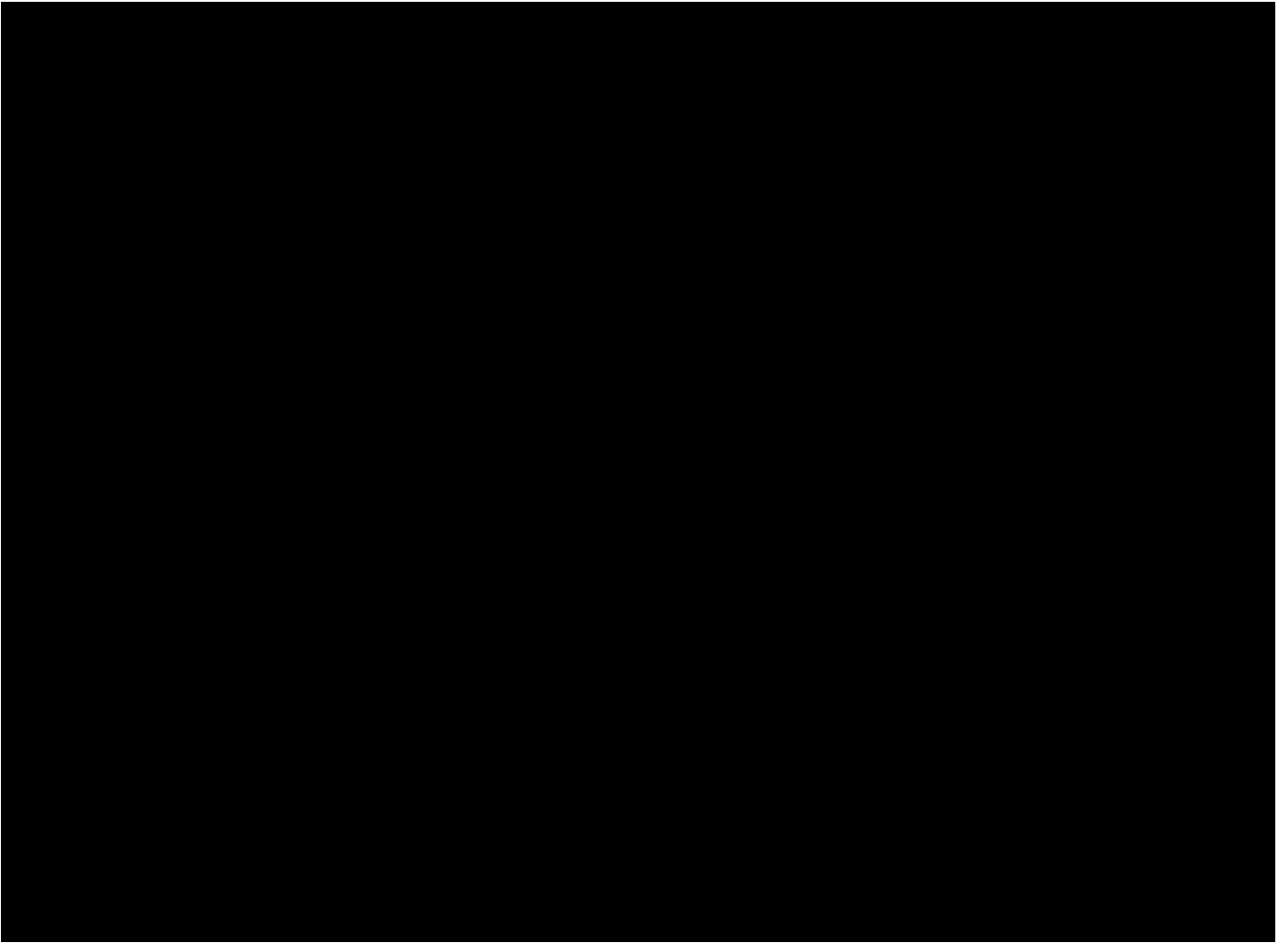
Publishable Paper

Intended Journal of Publication: Social Science and Medicine

Author: Amanda Agyare

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of London, London, UK

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Client Study/ Process Report

Title: Reaching Insight Through Empathy: A Person-Centred Case Study.

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