VOLUME ONE: RESEARCH COMPONENT

PSYCHOLOGICAL TREATMENT FOR FIBROMYALGIA: A META-ANALYSIS & QUALITATIVE EXPLORATION

By

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A Thesis Submitted to The University of Birmingham for the Degree of DOCTOR OF CLINICAL PSYCHOLOGY (ClinPsyD)

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July 2020

DEDICATION

This thesis is dedicated to the people that have supported me on my long road to clinical training. I could not have reached this point without the care and love I received from my parents, family, and in-laws. Without the pep-talks, cards, thoughtful gifts, food, time, effort and years of encouragement from all of you I would not be where I am today. You have my eternal thanks and gratitude.

Special thanks to my partner Rachna Shah for the uncountable ways you have been there for me, backed me up, helped me, fought my corner and for the multitude of kindnesses you have bestowed upon me. I love you unconditionally. Say, should we get married?

Overview

This thesis is submitted as part of a three-year Doctorate of Clinical Psychology (ClinPsyD) at the University of Birmingham. It comprises two volumes including a meta-analysis, research study and reports of clinical work from placements during clinical training.

Volume One

This volume contains two papers. Paper one is a meta-analysis of research evaluating the effectiveness of pain management programmes for the treatment of fibromyalgia. Paper two is a qualitative research study exploring the experiences of people with fibromyalgia of psychological treatment for their condition. Finally, Volume One also contains two press releases detailing the findings of the meta-analysis and research study for members of the public.

Volume Two

Five Clinical Practice Reports (CPR's) are presented in this volume. CPR one presents a cognitive-behavioural and psychodynamic formulation of a 27-year-old woman with a mild learning disability and obsessive-compulsive disorder (OCD). CPR two presents a service evaluation of a treatment pathway aiming to support people with learning disabilities that experienced trauma and abuse. CPR three is a single-case experimental design evaluating the effectiveness of a cognitive-behavioural assessment and intervention with a seventeen-year-old boy with symptoms of OCD. CPR four presents a case study of a 26-year-old man experiencing OCD and depression that includes a cognitive-behavioural formulation, intervention, and evaluation. CPR five is in the form of an abstract outlining a case study of a psychodynamic assessment, intervention, and evaluation for a 69-year-old man with social anxiety and co-morbid depression. All names and identifying features have been changed to ensure confidentiality.

Acknowledgements

I would firstly like to thank all the participants who generously gave their time to be interviewed for this study. I would also like to thank all my collaborators at the pain management service who worked so hard to get the research off the ground and helped me with the one-hundred-and-one considerations I would not otherwise have thought of.

Thanks is also due to my research supervisors Drs Ruth Howard, Andy Fox, Chris Jones, and Alice Kennedy who Sherpa-d me up the thesis mountain with extraordinary patience and alacrity. Without your belief in me this thesis would have been unrealised.

Everyone who supported me during the process of writing this thesis: Dr Gemma Jones, Paul Rees, Dr Anna Everatt, Bhavisa Mistry, Hollie Richards, Joe Spry, Agnieszka Pytlowana, Roy Smith, Dr Amy Smith, Priyanka Batra, Helen Poole, Lauren Wallace, members of the Expert by Experience Steering Committee and the qualitative research group. I am so very thankful for the support you gave me; you were all indispensable.

To my placement supervisors Drs Laura Carrington, Sara Willott, Baljinder Banwait, Mel Read, Aula Meki, Katie Wilkinson and Anne Crawford-Docherty. You have all been individually inspiring, thoughtful, and kind; collectively you have given me more than you know. Keep checking for updates on the wedding.

To my appraisal tutor Dr Liz Kent for your unflagging consideration, warmth, and generosity of spirit. You made the unpleasant training process enjoyable.

To the 2017 Clinical Psychology Doctorate cohort, you guys opened my eyes, challenged me, supported me, and gave so much entertainment over the past three years. We will all meet up again to watch 'Truly, Madly, Deeply' someday.

I would not be here without the support of Drs Laura Dawson, Katie Parker & Nasreen Fazal-Short you never ceased believing in me or giving me a much-needed kick up the bum.

Thanks to all those who went before: Drs Marc Kingsley & Liz Chesters, thank you for getting me started! Dr James Sedgwick & Peter Brogan for keeping my head out of the clouds and keeping the clients first. And especially Dr Eliza Johnson, your belief provided an oasis in the wilderness.

A final thanks to Rachna Shah for her help with the thesis and all the sacrifices you made for me on my journey – you got in here twice!

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Pain Management Programmes for the Treatment of Fibromyalgia: A Meta-Analysis

1. Abstract

Aim: This meta-analysis aimed to review the evidence base for the use of cognitive behavioural 'pain management programmes' (PMPs), to determine the effectiveness of these group programmes for treating people with fibromyalgia.

Methods: The databases 'Psychinfo', 'Psycarticles', 'Medline', 'Embase' and 'Web of Science' were searched systematically for key words 'cognitive behavioural therapy' (CBT), 'fibromyalgia' and 'group psychotherapy' to December 2019. The reference sections of previous systematic reviews and meta-analyses were also reviewed to identify relevant papers. Randomised controlled trials comparing CBT interventions to a control group were analysed. The outcomes reviewed were reduction in fibromyalgia symptomatology and pain. Effect sizes were summarised using standardised mean differences (SMD). Studies were rated for their methodological quality and their fidelity to treatment guidelines for PMPs.

Results: 35 relevant papers were identified of which 17, with a total of 1026 participants, were included in the analysis. Random effects and quality effects meta-analyses were conducted on the included studies. Group CBT showed a significant treatment effect size for both reduction in fibromyalgia symptomatology (SMD= -0.4060, 95%CI= -0.6397 to -0.1723, p = < 0.0007) and pain (SMD = -0.3047, 95% CI= -0.5489 to -0.0606, p = < 0.0144). A subgroup analysis, of studies rated 'poor' and 'average' for fidelity to British Pain Society guidelines, was completed to determine the efficacy of this guidance. For reduction in fibromyalgia symptomatology, studies with average ratings of treatment fidelity produced marginally better outcomes than those with a poor rating (SMD= -0.46 vs. -0.34); this result was not statistically significant (p= 0.6487). Pain reduction outcomes for studies with average treatment fidelity produced slightly worse outcomes compared to those with poor fidelity (SMD= -0.14 vs. -0.50); this result was not statistically significant (p= 0.125). The quality effects model suggested that the methodological quality of the included studies did not adversely impact the meta-analysis.

Conclusion: Results replicated previous meta-analyses on the effectiveness of group CBT in fibromyalgia symptomatology and pain. There is no strong evidence that fidelity to guidelines for PMPs creates an improvement in outcomes for reduction in fibromyalgia symptomatology or pain in people with fibromyalgia. Recommendations for future research and clinical applications of this review are suggested.

2. Introduction

2.1 What is fibromyalgia and how common is it?

This meta-analysis aims to review the literature on the effectiveness of pain management programmes (PMPs) for the treatment of fibromyalgia. Fibromyalgia is a long-term physical health condition characterised by widespread chronic pain often in 'trigger points' around joints with a wide variety of symptoms including increased sensitivity to pain, fatigue, irritable bowel syndrome, headaches, insomnia and cognitive problems (Bennett, 2009). There is no clinical procedure for identifying fibromyalgia and it is usually given as a diagnostic when other somatic diseases have been ruled out (Fitzcharles, et al., 2013).

Fibromyalgia affects twice as many women as men and is known to have increased prevalence those aged 35 – 45 (Rahman et al., 2014). In the UK, the estimated incidence of fibromyalgia is 40 cases per 100,000 people (Collin, et al., 2017) and the estimated prevalence in the general population is estimated to be between 5 – 8% (Clauw, 2014). It is recognised by the World Health Organisation as a diagnosis (WHO, 2004; M79.7) where it is classified as a rheumatological condition. In rheumatology it is estimated that 25% of patients have fibromyalgia, along with 15% of hospital inpatients and approximately 2% of patients seen in general practice (Creed et al., 2011). People with fibromyalgia spend extended time seeking a diagnosis because fibromyalgia is frequently diagnosed only after all other diagnoses have been rejected (Macfarlane et al., 2016).

Fibromyalgia is a controversial diagnosis (Wolfe, 2009), sometimes associated with discredited conditions such as 'neurasthenia' (Wolfe & Walitt, 2013) or with conditions that are 'medically unexplained' e.g., 'chronic fatigue syndrome' (Tack, 2019). As fibromyalgia is a heterogenous condition with a significant psychosomatic component (Ghiggia et al., 2017) the diagnosis itself has often been contested. Some clinicians and researchers have argued that, as fibromyalgia is a diagnosed only when other disease have been ruled out, it does not exist outside of its diagnostic criteria and cannot be independently verified (Ehrlich, 2003). Other researchers suggest that a fibromyalgia diagnosis causes iatrogenic harm as it promotes unhelpful healthcare seeking behaviours (Bass & Henderson, 2014). More recently a consensus has begun to develop that fibromyalgia can be explained through a ‘biopsychosocial model’ (Häuser & Fitzcharles, 2018), that there are biological markers for the condition (Malatji et al., 2017), that it is useful for clinicians and patients for the diagnosis to exist (Fitzcharles et al., 2013) and that iatrogenic harm occurs less than feared (Petzke, et al., 2017). As fibromyalgia has become better understood the aetiology of the condition is thought to be due to ‘acquired central sensitisation’ to pain (Sluka & Clauw, 2016).

2.2 What is the impact of fibromyalgia on individuals, health services and society?

Fibromyalgia has a deleterious impact on those that experience it in terms of quality of life, disability, general health, co-morbidity, and an increase in common mental health conditions (e.g., Häuser et al., 2015). Lichtenstein et al. (2018) reviewed the literature for co-morbidities with fibromyalgia finding that people with fibromyalgia experienced higher levels of psychiatric co-morbidity such as anxiety and depression compared to control groups. In the same review (Lichtenstein et al., 2018) found that fibromyalgia was associated with a higher prevalence of health co-morbidities such as: ankylosing spondylitis, osteoarthritis, Behçet’s disease, gout, Sjögren’s syndrome, vasculitis, polymyalgia rheumatica, systemic sclerosis, coronary heart disease, hypertension, hyperlipidaemia, IBS, and diabetes mellitus. They also found inconclusive evidence linking fibromyalgia to inflammatory bowel disease and cancer. Häuser et al. (2015) reviewed the literature for the health impact of fibromyalgia and found that people with fibromyalgia rated their quality of life lower than other conditions such as inflammatory arthritis, lower back pain, gout, osteoarthritis, irritable bowel syndrome (IBS), migraine, anxiety, and depression.

Annemans et al. (2009) reviewed the burden of fibromyalgia for people and society. They found that 31% of people with fibromyalgia described themselves as being disabled compared to just 10% of the matched controls with pain, sleep disturbance and motor difficulties being the most cited reasons for disability. They also noted a decrease in productivity with people with fibromyalgia reducing hours at work by 50-75%. The impact of fibromyalgia and related conditions on society is estimated at £14 billion lost per year in the UK due to sickness absence and decreased quality of life (Bermingham et al., 2010). In the USA people with fibromyalgia cost over $6000 more per person to treat than people with other forms of chronic pain (Berge et al., 2007) and the cost of treating somatisation (including fibromyalgia) in the UK has been estimated at £3 billion (Bermingham et al, 2010).

2.3 How is fibromyalgia treated, what are the aims of treatment?

There are no definitive best practice guidelines for treating chronic pain or fibromyalgia and the National Institute of Health and Care Excellence (NICE) is preparing to release guidance in 2021 (NICE, 2020). Häuser et al. (2010) reviewed recommendations from The American Pain Society (APS; 2005), the European League Against Rheumatism (EULAR; 2008), and Association of the Scientific Medical Societies in Germany (AWMF; 2008). Häuser et al (2010) found that there was broad agreement between these three organisations on the use of amitriptyline - a pain killer which is also used to treat depression. The two organisations that based their recommendations on systematic reviews and meta-analyses also recommended aerobic exercise, cognitive behavioural therapy (CBT) and multi-modal treatment. In their review of the research literature on treatment for fibromyalgia, Ablin et al. (2013) found the consensus on treatment approaches to be focused on symptom reduction and functional improvement. For people with fibromyalgia this is often conceptualised in treatment research as reduction in pain and fibromyalgia symptomatology.

2.4 Pain management pathway

In the UK fibromyalgia is mainly treated in primary care, rheumatology, and pain management clinics. People with fibromyalgia are referred to pain management or rheumatology where they are assessed and usually receive medical interventions as first line treatments (Fink et al., 2011). These medical interventions include analgesics, opioids, and antidepressants (e.g., amitriptyline, pregabalin, gabapentin and duloxetine; Rahman et al., 2014) as well as lidocaine infusions (Marks & Newhouse, 2015). A secondary line of ‘non-drug’ treatments, including physical therapies, acupuncture and psychological therapies is usually provided concurrently or following unsuccessful drug treatment (Rahman et al., 2014). Psychological treatment uses CBT techniques to: provide education about the nature of fibromyalgia; set realistic goals for work, social activities and involvement with family and friends; relaxation training; pacing of activities to not overdo or underdo activity levels; identification of dysfunctional thought patterns and techniques to counter negative automatic thoughts; communication skills; strategies for acquisition maintenance, and generalisation of skills and relapse prevention (Bennett & Nelson, 2006). The British Pain Society (BPS) regularly conducts systematic reviews of pain management literature in order to make recommendations on the treatment and management of chronic pain, including fibromyalgia (British Pain Society, 2013). The review authors evaluated the level of extant evidence according to procedures described by the Scottish Intercollegiate Guidelines Network (SIGN, 2015). Using the results of studies with the 'highest level of evidence' (i.e., those that were methodologically rigorous meta-analyses, systematic reviews, or randomised controlled trials) they produced guidelines on treatment best practice. The report authors, and by extension the BPS, advocated the delivery of CBT interventions through group 'Pain Management Programmes' (PMP; British Pain Society, 2013). The BPS recommend the following components for a PMP (a full summary can be found in Appendix 1):

1. Graded activation guided by participant goals
2. Cognitive therapy methods
3. Graded exposure
4. Methods to enhance acceptance, mindfulness, and psychological flexibility
5. Skills training and activity management
6. Physical exercise
7. Education about pain
8. Equal or greater to 36 hours in length
9. Group size 8-12
10. Multi-disciplinary facilitators

Providing pain relief or reducing other symptoms is typically not a primary aim of psychological treatment, though this is often a consequence of it. The aims for the outcomes of these groups are to:

1. Improve the physical, emotional, and social dimensions of health and functioning for people with chronic pain.
2. Improve participation in daily activities and enhance 'quality of life'.

People with fibromyalgia are commonly referred to PMPs when they have received medical interventions that have been ineffective in reducing their symptoms.

2.5 What have been the outcomes of previous meta-analyses and systematic reviews?

There have been numerous previous meta-analyses focusing on the topic of fibromyalgia. Recent reviews have focused on medication (Cooper et al., 2017; Derry et al., 2016; Moore et al., 2015), exercise (Bidonde et al., 2019; Busch et al., 2007; Kim et al., 2019), multi-component treatments (Häuser et al., 2009; Lami et al., 2013), complementary/alternative treatments (e.g., Deare et al., 2013) and psychological interventions (Bernardy et al., 2013; Theadom et al., 2015).

Bernardy et al. (2013) analysed the literature for CBT fibromyalgia interventions, focusing on the outcomes: pain, mood, disability, and withdrawal from treatment. They found that CBT interventions were superior to controls for pain, mood, and disability with effect sizes in the small – medium range (Cohen, 1988; -0.29, -0.33 and -0.3 respectively). They also found no significant difference in withdrawal from treatment compared to controls. Theadom et al. (2015) analysed the literature for 'mind and body therapy' for fibromyalgia, which included psychological therapies such as CBT, humanistic and psychoanalytic therapy. The outcomes analysed were physical functioning, pain, mood, and withdrawal from treatment. They found that psychological therapies were superior to controls for physical functioning, pain, and mood with similar effect sizes to Bernardy et al. (-0.4, -0.3 and -0.5). However, they found that psychological therapies had greater withdrawals from treatment compared to controls, though they did note that this finding was based on very poor-quality evidence.

The authors of the studies above noted that the evidence available for reviewing the effectiveness of the above treatments was generally small, of low quality and that the positive impact of interventions is modest. Each group of authors reported that more research was necessary to determine the relative effectiveness of each treatment and to ensure their long-term effectiveness. There are currently no published meta-analyses on the effectiveness of pain management groups as defined by the BPS.

2.6 What is the rationale for this meta-analysis?

Previous meta-analyses and systematic reviews of the treatments for fibromyalgia have noted that CBT-based group interventions are effective in improving the physical, emotional, and social dimensions of health and functioning for people with fibromyalgia. However, there have been no reviews of the literature based upon the current best practice guidelines for treating fibromyalgia. Therefore, the aim of this meta-analysis will be to review the effectiveness of PMPs as defined by the BPS. As recommended in the guidelines themselves and the literature more broadly, the primary outcome for this analysis will be the reduction in fibromyalgia symptomatology. Most studies on treatment for fibromyalgia also report the impact of interventions on pain, therefore a secondary outcome of pain will be analysed through a variety of psychometric measures.

2.7 What are the aims of this meta-analysis?

The aim of this meta-analysis will be to review the extant literature on PMPs to determine the effectiveness of these group programmes. This is a novel meta-analysis because previous reviews have not focused on CBT groups specifically or on the features of pain management groups. It is the hope of the author that this meta-analysis will help to determine whether the current best practice guidelines for the treatment of fibromyalgia are fit for purpose.

3. Method

3.1 Search strategy

Papers for review were identified via the databases 'Psychinfo', 'Psycarticles', 'Medline', 'Embase' and 'Web of Science'. Where possible the specific terminology used for each research database was used and search terms were 'exploded' to provide greater returns. Limitations applied to the search results aimed to create a cohort of high-quality papers that were as homogenous as possible. For this reason, only papers published in peer reviewed journals were considered as well as those in the English language with adult participants (over the age of 18).

The search term 'pain management programme' and its derivations were not specific enough to generate relevant search results. It was therefore necessary to operationalise pain management programmes (PMP) in order to increase the sensitivity of the search terms. According to the British Pain Society's recommendations (BPS, 2013) PMPs should be group programmes consisting of methods designed to promote behaviour change including methods based on cognitive behavioural therapy. Therefore 'pain management programmes' in this meta-analysis were operationalised as group CBT programmes for people with fibromyalgia. The broad search terms used (see Table 1 for specific wording) were:

- Fibromyalgia
- Cognitive behavioural therapy
- Group psychotherapy

Table 1

Search Strategy for Research Databases

Construct	Free Text Search Terms	Method of Search	Limits
Fibromyalgia	‘Fibromyalgia’ [OR] ‘fibromyalgia syndrome’ [OR] ‘fms’ [OR] ‘Somatoform Disorders’ [OR] ‘somatoform pain disorder’ [OR] ‘psychogenic rheumatism’ [OR] ‘psychogenic pain’ [OR] ‘fibrositis’	Free search terms All constructs combined with *AND*	Peer reviewed articles From start of records to December 2019 English language Adult (18+)
Cognitive behavioural therapy	‘Cognitive Behavioural Therapy’ [OR] ‘Cognitive Behavioral Therapy’ [OR] ‘cbt’		
Group psychotherapy	‘Psychotherapy, Group’ [OR] ‘group psychotherapy’ [OR] ‘Group Psychotherapy’ [OR] group therapy		

3.2 Inclusion and exclusion criteria

The complete selection strategy, using PRISMA guidelines is described in Figure 1. Papers on CBT were included if they purported to use cognitive behavioural therapy, and a protocol for the intervention was included to corroborate this. Papers were excluded if they were literature reviews, duplicated elsewhere in the search, used individual CBT or if they did not describe an intervention study e.g., a theoretical paper (see Table 2 for summary of justification for inclusion and exclusion criteria). When sufficient papers were gathered (n>10) any intervention studies without a control group were excluded to select papers with the strongest methodological rigour. Of the remaining 23 papers six were excluded: Goldenberg et al. (1994), Lidbeck (1997), Lumley et al. (2017), Sánchez et al. (2012), Thieme et al. (2016) and, Williams et al. (2002). Goldenberg et al. (1994), Williams et al. (2002) and Thieme et al. (2016) were excluded as they did not report the post-intervention outcomes for pain or the reduction in fibromyalgia symptomatology and therefore data extraction was impossible. Lidbeck (1997), Lumley et al. (2017) and Sánchez et al. (2012) were excluded as they did not report the target outcomes. van Koulil et al. (2010) divided their participants into two different tailored group programmes, both using CBT techniques but varying approaches e.g., planning of sessions, focus on material etc for each group. For this reason, though van Koulil et al. (2010) had identical ratings of quality, the outcomes of the interventions are different and are therefore reported twice as 'van Koulil 2010a' and 'van Koulil 2010b'.

Nine of the seventeen included studies (Alda et al., 2011; Castel et al., 2009; Castel et al., 2012; Falcão et al., 2008; Jensen et al., 2012; Miró et al., 2011; Redondo et al., 2004; Thieme et al., 2006; Vlaeyen et al., 1996) were included in previous meta-analyses (Bernardy et al., 2013; Theadom et al., 2015) though the focus of these reviews were not the same as this analysis (individual and group CBT and mind/body therapy for fibromyalgia respectively).

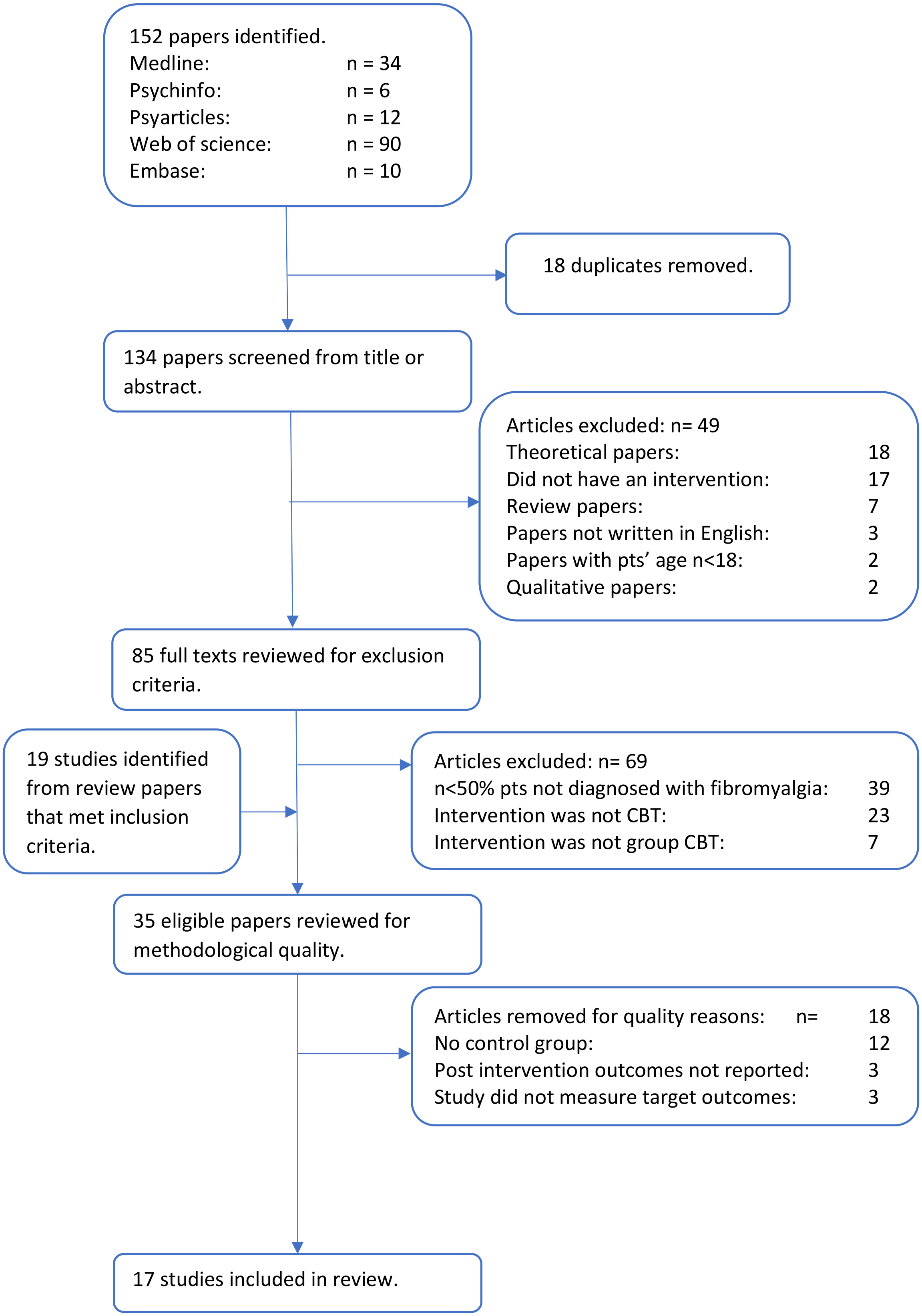

Figure 1 - PRISMA Chart for Included Studies

Table 2

Inclusion and Exclusion Criteria

Inclusion criteria	**Justification**
Intervention study	The aim of the meta-analysis is to review the extant literature on treatment for fibromyalgia using a meta-analytic framework. For this reason, only papers that included an intervention were included in the analysis.
Intervention is group CBT based	In order to answer the question posed in the introduction to this review it was necessary to include papers based on group CBT interventions as this is the recommended standard set by the British Pain Society (BPS, 2013).
Majority of participants have a diagnosis of fibromyalgia	Much of the published literature on fibromyalgia dovetails with research focused on participants with medically unexplained symptoms (MUS), somatisation or related syndromes. For this reason, many relevant studies included participants with fibromyalgia amongst participants with other conditions. Studies with a majority (n>50%) of participants with fibromyalgia were included to provide a practical cut-off and so as not to unnecessarily exclude studies with useful data.
Outcomes measured: reduction in fibromyalgia symptomatology and pain	The clinical aims of psychotherapeutic treatment for fibromyalgia are debatable, partly due to the condition's previous designation as a medically unexplained symptom. Previous review papers and meta-analyses have focused on reduction in fibromyalgia symptomatology and pain. Both outcomes are also used in most clinical studies on participants with a diagnosis of fibromyalgia. Reduction in fibromyalgia symptomatology was measured using the 'Impact of Fibromyalgia Questionnaire' (FIQ) (Burckhardt et al, 1991).
Exclusion criteria	**Justification**
Aged under 18	Studies with participants aged <18 were excluded to create a combined sample of participants that was as homogenous as possible. In addition, PMPs are provided in pain management services provided for adults therefore the BPS guidelines are not designed for a child/adolescent population.
Qualitative papers	Qualitative papers were excluded as they do not include data required.
Studies without a control group	In research studies without a control group, it is impossible to determine whether changes in participant outcomes are due to the experimental condition. Studies that included pre/post results only were therefore excluded for lacking the necessary level of methodological rigour.
Unavailable in English	Studies published in a language other than English were included only if a complete translation of the published paper was available.
Intervention is not CBT	The BPS guidelines for PMPs are that they are based on CBT and are group based. Studies that included group programmes that were not primarily based on CBT were therefore excluded. Studies including group programmes

	based on interventions derived from CBT (e.g., 'Third wave' therapies like Acceptance and Commitment Therapy; ACT) were excluded due to their difference from CBT. Studies that included elements of third wave therapies were included as the BPS recommendations include elements of ACT.
Review papers	Systematic literature reviews and meta-analyses were excluded as they did not provide the requisite level of study-level detail in order determine methodological quality or extract data.

3.3 Data extraction

3.3.1 Primary and secondary data

All data was extracted by the author. Data extracted from each paper included the methodology of each paper; participant numbers; the diagnoses of the participants; the type of control group; the protocol for the group intervention; the outcomes measured; the psychometric instrument(s) used to measure the outcome and the pre/post intervention outcomes. See Table 3 for the summary of data extracted from papers. The primary outcome reviewed was the reduction in fibromyalgia symptomatology, which was measured using the Fibromyalgia Impact Questionnaire (FIQ; Burckhardt et al., 1991) in all papers that measured this outcome. The Fibromyalgia Impact Questionnaire is a 10 item self-report measure, which assesses physical functioning; work status; depression; anxiety; sleep; pain; stiffness; fatigue, and wellbeing. It has good test-retest reliability, credible construct validity, is sensitive to therapeutic change (Bennett, 2005) and is used frequently in the evaluation of fibromyalgia (Bennett, et al, 2009). A secondary outcome was pain, which was assessed using a variety of measures (see Table 3).

Table 3

Characteristics of Included Studies

Study ID	Study	Country of Origin	Randomisation	*N* Group CBT	*N* CG	Diagnosis	Control Group	Intervention duration and frequency	Outcomes	Outcome measure(s)
1	Alda 2011	Spain	RCT	57	56	Fibromyalgia	TAU	10 weekly 1.5-hour	Pain Reduction in fibromyalgia symptomatology	FIQ Pain VAS
2	Anderson 2007	USA	None	35	21	Fibromyalgia	Coping skills group	14 weekly 1.5-hour	Pain Reduction in fibromyalgia symptomatology	FIQ Pain VAS
3	Castel 2009	Spain	RCT	16	7	Fibromyalgia	TAU	12 weekly 1.5-hour sessions	Pain Reduction in fibromyalgia symptomatology	FIQ MPQ
4	Castel 2012	Spain	RCT	34	30	Fibromyalgia	TAU	14 weekly 3-hour sessions	Pain Reduction in fibromyalgia symptomatology	FIQ Pain 0-10
5	Falcão 2008	Brazil	RCT	25	26	Fibromyalgia	Weekly medical visits	10 weekly	Pain Reduction in fibromyalgia symptomatology	FIQ SF-36
6	Jensen 2012	USA	RCT	25	18	Fibromyalgia	WLC	12 weekly 1.5-hour sessions	Pain	Pain VAS
7	Karlsson 2014	Sweden	Pseudo-randomised	24	24	Fibromyalgia	WLC	20 weeks 3-hours (over six months)	Pain	MPI
8	Keel 1998	Switzerland	Pseudo-randomised	14	13	Fibromyalgia	Relaxation group	15 weekly 2-hours	Pain	MPQ-SF

Study ID	Study	Country of Origin	Randomisation	*N* Group CBT	*N* CG	Diagnosis	Control Group	Intervention duration and frequency	Outcomes	Outcome measure(s)
9	Martinez 2014	Spain	RCT	30	29	Fibromyalgia	Sleep hygiene	6 weekly 1.5-hour sessions	Pain Reduction in fibromyalgia symptomatology	MPQ FIQ
10	Miró 2011	Spain	RCT	20	20	Fibromyalgia	Sleep hygiene	6 weekly 1.5-hour sessions	Pain Reduction in fibromyalgia symptomatology	FIQ MPQ
11	Redondo 2004	Spain	RCT	21	19	Fibromyalgia	Exercise group	8 weekly 2.5-hours	Pain Reduction in fibromyalgia symptomatology	FIQ MPQ
12	Schroder 2012	Denmark	Pseudo-randomised	54	66	Functional somatic symptoms (65% FMS)	Enhanced usual care	9 weeks 3.5-hours (over three months)	Anxiety Pain	SF-36
13	Thieme 2006	USA	RCT	42	40	Fibromyalgia	Discussion group	15 weekly 2-hours	Pain Reduction in fibromyalgia symptomatology	MPI FIQ
14	Vallejo 2016	Spain	RCT	20	20	Fibromyalgia	WLC	10 weekly 2-hour	Reduction in fibromyalgia symptomatology	FIQ
15	van Koulil 2010a	Netherlands	Pseudo-randomised	36	42	Fibromyalgia	WLC	16 biweekly 4-hour sessions. Tailored to 'pain persistence' group.	Pain Reduction in fibromyalgia symptomatology	IRGL Multiple measures FIQ
16	van Koulil 2010b	Netherlands	Pseudo-randomised	25	39	Fibromyalgia	WLC	16 biweekly 4-hour sessions. Tailored to 'pain	Depression Anxiety Pain	IRGL Multiple measures

Study ID	**Study**	**Country of Origin**	**Randomisation**	***N* Group CBT**	***N* CG**	**Diagnosis**	**Control Group**	**Intervention duration and frequency**	**Outcomes**	**Outcome measure(s)**
								avoidance' group.	Reduction in fibromyalgia symptomatology	FIQ
17	Vlaeyen 1996	Netherlands	RCT	46	39	Fibromyalgia	WLC	12 weekly 2-hours sessions	Pain	Multiple measures
18	Zonneveld 2012	Netherlands	RCT	61	72	MUS (61% FMS)	WLC	13 weekly 2-hour sessions	Pain	SF-36

CG: Control group; **FIQ**: Fibromyalgia Impact Questionnaire; FMS: Fibromyalgia syndrome; **IRGL**: Influence of Rheumatic Disease on General Health and Lifestyle; **MPI**: West Haven-Yale Multidimensional Pain Inventory; **MPQ**: McGill Pain Questionnaire; **MPQ-SF**: McGill Pain Questionnaire (Short Form); **MUS**: Medically unexplained symptom; **RCT**: Randomised and controlled trial; **SF-36**: Short-Form Health Survey; **VAS**: Visual analogue scale; **WLC**: Waiting list control

***** van Koulil 2010 is included twice on this table as the study reported two treatment interventions

3.3.2 Treatment fidelity

The protocols for each group intervention described by the papers were reviewed by the author to provide a rating of their fidelity to BPS guidelines described in Section 2.4 and Appendix 1. Ratings of treatment quality were awarded depending on the inclusion of the ten listed components. Individual components were not weighted for their importance. As there is no extant system for reviewing adherence to BPS guidelines a simple rating system was developed with ratings ranging from ‘poor’, ‘average’ and ‘good’ depending on the number of components reported. If one to three components were reported the study was rated as ‘poor’, four to seven was rated as ‘average’ and eight to ten rated as ‘good’. It was not possible to divide the ten components into three as whole numbers the category ‘average’ was larger than the ‘poor’ and ‘high’ categories. The component ‘cognitive therapy’ from the BPS guidelines refers to cognitive therapeutic techniques such as cognitive restructuring or behavioural experiments (see Appendix 1). It was therefore possible for a study to be included in the analysis of CBT interventions even though it did not include ‘cognitive therapy’ as defined by the BPS. This is an important distinction as the interventions from four studies (see Table 4) did not include ‘cognitive therapy’. Of the 17 studies reviewed for treatment quality no study rated ‘good’, nine rated as ‘average’ (Alda et al., 2011; Anderson & Winkler, 2007; Castel et al., 2009; Castel et al., 2012; Karlsson et al., 2014; Keel et al., 1998; Thieme et al., 2006; van Koulil et al., 2010a & b) with the remaining eight rated as ‘poor’ see Table 4 for summary.

Table 4

Included Studies Ratings of Fidelity to British Pain Society Recommendations

Study ID	Study name	Graded activation	Cognitive therapy	Graded exposure	Acceptance, mindfulness, flexibility	Skills training	Exercise	Education about pain	≥ 36 hours	Group size 8-12	Multi-Disciplinary Facilitators	Treatment Fidelity – Raw Score (0-10)	Fidelity Rating: n≤3 = poor, n=≥4 = average n≥8= good)
1	Alda 2011	🟥	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟥	5	Average
2	Anderson 2007	🟥	🟩	🟥	🟩	🟩	🟥	🟥	🟥	🟩	🟥	4	Average
3	Castel 2009	🟥	🟩	🟥	🟩	🟩	🟥	🟩	🟥	🟥	🟥	4	Average
4	Castel 2012	🟥	🟩	🟥	🟩	🟩	🟥	🟩	🟥	🟥	🟥	4	Average
5	Falcão 2008	🟥	🟩	🟥	🟥	🟩	🟩	🟥	🟥	🟥	🟥	3	Poor
6	Jensen 2012	🟩	🟥	🟥	🟩	🟩	🟥	🟥	🟥	🟥	🟥	3	Poor
7	Karlsson 2014	🟩	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟥	🟥	6	Average
8	Keel 1998	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟥	🟥	🟥	6	Average
9	Martinez 2014	🟥	🟩	🟥	🟥	🟩	🟥	🟩	🟥	🟥	🟥	3	Poor
10	Miró 2011	🟥	🟩	🟥	🟥	🟩	🟥	🟩	🟥	🟥	🟥	3	Poor
11	Redondo 2004	🟥	🟥	🟥	🟩	🟩	🟥	🟩	🟥	🟥	🟥	3	Poor
12	Schroder 2012	🟥	🟥	🟥	🟥	🟥	🟥	🟩	🟥	🟩	🟥	2	Poor
13	Thieme 2006	🟥	🟩	🟩	🟩	🟩	🟥	🟩	🟥	🟥	🟥	5	Average
14	Vallejo 2016	🟥	🟩	🟥	🟥	🟩	🟥	🟩	🟥	🟥	🟥	3	Poor
15	van Koulil 2010a	🟩	🟩	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟥	7	Average
16	van Koulil 2010b	🟩	🟩	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟥	7	Average
17	Vlaeyen 1996	🟥	🟥	🟥	🟩	🟩	🟩	🟩	🟥	🟥	🟥	4	Average
18	Zonneveld 2012	🟩	🟩	🟥	🟥	🟩	🟥	🟥	🟥	🟥	🟥	3	Poor

3.4 Methodological quality ratings

Each paper was assessed for methodological quality using criteria adapted from the Cochrane Collaboration's tool for assessing risk of bias in randomised trials (Higgins et al., 2011). For summaries of the risk domains and explanations for ratings of methodological quality see Table 5. Papers were initially rated for methodological quality by the author before all were reassessed by an independent reviewer, an acquaintance of the author and a clinician in the NHS trained in evaluating research evidence. The percentage difference between the ratings of the author and independent reviewer was 3% indicating high inter-rater agreement on quality ratings. Due to the negligible differences between the ratings quality ratings of the author and independent reviewer the author's ratings were used for this report because of their increased familiarity with the studies rated. Ratings of quality were given a numerical value through assigning the following values: 'high risk = -14, 'unclear risk' = 7, 'low risk' = 14 and tallying the combined scores of the seven risk domains.

Table 5

Methodological Quality Rating Criteria

Risk Domain	**Explanation**	**Rating**	**Description of Rating**
Selection Bias	Bias can emerge in the selection period of research through unrepresentative or idiosyncratic sampling or through assigning participants to intervention or control group without randomisation. Randomisation can be random, pseudo-randomised or not randomised. Participant characteristics should be reported, and representative of the population being assessed. Randomisation procedure should be reported and clearly described.	High risk	Participants are not randomised to groups. Participant characteristics are not reported or are highly idiosyncratic.
		Unclear risk	Participants are pseudo-randomised. Randomisation procedure is not reported. Participant characteristics are reported but are idiosyncratic.
		Low risk	Participants are randomised to groups. Randomisation is reported. Participant characteristics are reported and representative of the target population.
Performance bias	Participants' or facilitators' awareness of participant experimental allocation may bias the findings. 'Blinding' participants/facilitators to the	High risk	Blinding is absent or not reported.
		Unclear risk	Either participants or facilitators are not blinded.

Risk Domain	Explanation	Rating	Description of Rating
	experimental allocation can help to control for this.	Low risk	Participants and facilitators are blinded to the experimental allocation.
Treatment Fidelity	Poor treatment fidelity can affect the generalisability of research findings. The researchers must report that they have attempted to ensure that the intervention procedure is representative of group CBT for fibromyalgia. The content and procedure of the intervention should be reported. The researchers should also make efforts to measure and report the treatment fidelity e.g., through independent assessment of the interventions. Group facilitators should be appropriately trained in CBT.	High risk	Group procedures and CBT methods may be reported. Treatment fidelity is not reported. Professionals facilitating group are not reported or their training is not reported/inappropriate.
		Unclear risk	Group procedures and CBT methods are reported. Treatment fidelity is undertaken but not described. Training of facilitators is not reported.
		Low risk	Group procedures and CBT methods are reported. Treatment fidelity is assessed and reported. Group facilitators are trained in CBT.
Detection Bias	The researchers' processing/reviewing participant outcomes awareness of experimental condition may lead to bias. 'Blinding' of these researchers can control for this. There is a hierarchy of study designs based on the likelihood that the null hypothesis can be rejected. For this review only the following designs will be considered (in order of their place in the hierarchy): 1. Randomised controlled trials, 2. Controlled clinical trial. 3. Cohort analytic (two groups pre/post).	High risk	Researchers are not blinded, or blinding is not reported. The study design was cohort analytic or weaker.
		Unclear risk	Blinding is not reported or unclear. The study design is controlled clinical trial.
		Low risk	These individuals are blinded to the experimental condition. The study design is randomised controlled trial.
Statistical Bias	Appropriate analyses selected to analyse data and to manage impact of attrition. Intention-to-treat (ITT) analysis is used. Schulz et al (2011) <5% attrition good 5-19% average 20%> risk of bias	High risk	High attrition and only completer analyses reported.
		Unclear risk	Low attrition with completer or ITT analyses reported, non-completers described
		Low risk	No or very low attrition and appropriate analyses selected
Reporting Bias	Selective reporting of findings can lead to bias favouring the experimental condition. Good quality studies should report all findings reported in the study's method.	High risk	Not all descriptive and/or summary statistics are presented. Only significant findings are reported.
		Unclear risk	Not all descriptive and/or summary statistics are presented.

Risk Domain	Explanation	Rating	Description of Rating
		Low risk	All results explained in method are reported.
Generalisability	The generalisability of the study refers to how confident we can be that the results of the research are applicable to the wider population they are meant to represent. Small samples and participants taking from an unrepresentative group e.g., students can create bias.	High risk	Sample is n<20. Participants are sampled from an unrepresentative population or not reported.
		Unclear risk	Sample is n>20 but may have some idiosyncratic features.
		Low risk	Sample is n>20 with no idiosyncratic features.

3.4.1 Selection bias

The selection bias of the included studies was unclear in the most part with only four studies being rated as low risk (see Table 6). One study was rated as high risk of selection bias (Anderson & Winkler, 2007) due to their use of a quasi-experimental methodology, which did not include randomisation to intervention or control groups. Most studies were rated as 'unclear risk' due to the use of pseudo-randomisation such as cluster or block randomisation or a lack of reporting of the randomisation procedure.

3.4.2 Performance bias

Most of the included studies were rated at high risk of performance bias due to a general lack of blinding participants and researchers. Keel et al. (1998) was rated as unclear risk as the participants were blinded in this study. The only study to be rated as low risk of bias in this area was Vlaeyen et al. (1996) where both researchers and participants were blinded to the experimental conditions.

3.4.3 Treatment fidelity

The ratings for the treatment fidelity of the included studies presents a mixed picture. Five of the studies did not report procedures to assure treatment fidelity and were rated as an unclear risk. An additional five also did not report training of the facilitators and were rated high risk. The remaining studies reported both treatment fidelity and the training of facilitators. All studies described the content of the CBT intervention allowing for the evaluation of fidelity to BPS guidelines.

3.4.4 Detection bias

All studies had a control group and all but one (Anderson & Winkler, 2007) included some form of randomisation. The studies that were rated as 'unclear' for detection bias were those that claimed to be a randomised controlled trial (RCT) but did not report the method of randomisation or used 'pseudo' randomisation. Eight of the studies used the most rigorous form of the methodological design (RCT) and were thus at low risk of detection bias.

3.4.5 Statistical bias

Nine of the included studies did not report an intention to treat (ITT) analysis (not considering the participants who left the study before completion). Three studies were rated as an unclear risk due to high percentage rates of attrition (Redondo et al., 2004: **23%**; Thieme et al., 2006: **20%**; Zonneveld et al., 2012: **18%**) but mitigate this bias with ITT analysis. Jensen et al. (2012) did not use ITT and had a high rate of attrition (21%) meaning that this study was rated at high risk of bias. One study (Anderson & Winkler, 2007) reported neither ITT nor the rate of attrition are thus at high risk of bias. The remaining were rated as low risk of bias due to their low attrition rates and use of ITT. Excepting those did not use ITT, all studies used appropriate statistical methods.

3.4.6 Reporting bias

This aspect of the study quality review returned the lowest risk of bias with all but two studies achieving a low-risk rating. These two papers (Anderson & Winkler, 2007; Keel et al., 1998) received a rating of unclear risk of bias as some of their findings were not reported. Anderson and Winkler (2007) did not report the outcomes for the visual analogue scales for anxiety or depression, and Keel et al. (1998) did not report participants' ratings for the effectiveness of the treatment programme.

3.4.7 Generalisability

All the included papers included sample size of 20 plus (mean number: 64; SD: 32; range: 23 – 133; median: 56). The majority of the papers suffered from an overrepresentation of female participants with only Schröder et al. (2012), Vlaeyen et al. (1996) and Zonneveld et al., (2012) having representative samples (i.e., samples including male participants). This overrepresentation is justifiable due to the greater prevalence of fibromyalgia in the female population (Walitt et al., 2015). However, the lack of male participants in 14 of the 17 studies means the results of the meta-analysis may be less generalisable to the fibromyalgia population.

Table 6

Methodological Quality Ratings

Study ID	Study	Selection Bias	Performance Bias	Treatment fidelity	Detection Bias	Statistical Bias	Reporting Bias	Generalisability	Total Quality Rating
1	Alda 2011	🟩	🟥	🟩	🟩	🟩	🟩	🟧	79
2	Anderson 2007	🟥	🟥	🟧	🟧	🟥	🟧	🟧	29
3	Castel 2009	🟧	🟥	🟥	🟨	🟨	🟩	🟧	43
4	Castel 2012	🟧	🟥	🟥	🟩	🟩	🟩	🟧	57
5	Falcão 2008	🟧	🟥	🟧	🟩	🟧	🟩	🟧	57
6	Jensen 2012	🟧	🟥	🟩	🟧	🟥	🟩	🟧	50
7	Karlsson 2014	🟧	🟥	🟩	🟧	🟩	🟩	🟧	64
8	Keel 1998	🟧	🟧	🟥	🟧	🟧	🟧	🟧	43
9	Martinez 2014	🟩	🟥	🟩	🟩	🟧	🟩	🟧	71
10	Miró 2011	🟩	🟥	🟧	🟩	🟧	🟩	🟧	64
11	Redondo 2004	🟩	🟥	🟥	🟩	🟧	🟩	🟨	57
12	Schroder 2012	🟧	🟥	🟩	🟧	🟩	🟩	🟩	57
13	Thieme 2006	🟧	🟥	🟩	🟧	🟩	🟩	🟩	71
14	Vallejo 2016	🟧	🟥	🟧	🟧	🟧	🟩	🟧	50
15	van Koulil 2010a	🟧	🟥	🟩	🟧	🟩	🟩	🟧	64
16	van Koulil 2010b*	🟧	🟥	🟩	🟧	🟩	🟩	🟧	64
17	Vlaeyen 1996	🟧	🟩	🟧	🟩	🟧	🟩	🟩	79
18	Zonneveld 2012	🟩	🟥	🟥	🟩	🟧	🟩	🟩	64
Mean									59

*van Koulil 2010 was included once for the mean calculation

3.4.8 Summary

Overall, the level of bias across studies was mixed (see Table 6). The mean quality rating was 59 (SD 13) indicating that the research methodologies employed for this body of literature are of medium quality. No individual study scored as low risk for all assessed areas of bias. Performance bias was an area of weakness in the reviewed studies with many failing to blind participants or researchers to the arm of the experiment in which they were included. A study particularly outside of the mean score of quality was Anderson and Winkler (2007), which is to be expected as that study used a quasi-experimental design. Due to the high risk of bias from this study it was excluded from the meta-analysis. An additional area of concern arises from the use of simple 0-10 rating scales or VAS in the measurement of pain in several of the studies. These methods of measuring pain are very subjective in nature and have not been assessed for reliability, validity, and other psychometric properties as with other measures of pain. Due to the low number of studies in this field, studies with medium to high risk of bias were included in the analysis. Therefore, the results of this analysis should be interpreted with caution.

3.5 Data analysis strategy

The data analysis strategy follows the guidelines for the Centre for Applied Psychology, University of Birmingham and are paraphrased below. The random effects and quality effects meta-analysis models were conducted for both of outcome variables. The procedure for these meta-analyses is described below.

3.5.1 Handling of data that violates analysis assumptions

In meta-analyses with relatively small sample of papers a bias towards overestimating the standardised mean difference (SMD) can emerge. This bias is due to Cohen's d systematically overvaluing the absolute value of the SMD (Borenstein, 2009). This bias was corrected by transforming Cohen's *d* into an unbiased estimate, Hedge's *g* (Hedges, 1981) for meta-analytic calculations. Hedges g was then transformed back into Cohen's d for interpretation and reporting in tables and figures.

3.5.2 Normalisation and variance stabilisation

To calculate the between studies variation (tau) the method of moments (or DerSimonian and Laird method) was used. The method of moments is the most used and easiest to explain method of calculating between studies variation (Borenstein et al., 2011) for fitting the random effects model. However, this method assumes that random effects are normally distributed. A QQ-chart of the effect sizes for the primary studies was used to determine the normality of the sample. If the QQ-chart did not suggest normality the between studies variation was calculated using the Restricted Maximum Likelihood Estimator (REML) which is known to be robust to violations of the normality assumption (Higgins et al., 2019).

3.5.3 The omnibus test

There are two methods of calculating the omnibus test: the fixed effects and random effects model. The fixed effect model is used when a 'typical intervention effect' is expected (Higgins et al., 2019) and the true effect of the intervention is expected to be the same with variation in effect size ascribed to sampling errors. Psychological research is usually conducted with a variety of methodologies from researchers working independently of each other. For this reason, variation in effect sizes can emerge through differences in methodology, intervention, participants, facilitators etc. In these instances, the random effects model is the most appropriate method of calculating the omnibus test as it weights the analysis based on the number of participants and amount of variation between studies. Due to the variations in interventions and methodologies in the included studies the random effects model was used in this analysis.

3.5.4 Handling problematic variance

3.5.4.1 Defining problematic variance

Heterogeneity in the meta-analytic synthesis develops when effect sizes become heterogenous due to variation that cannot be attributed to true variation in participants' response to treatment. This heterogeneity can result from methodological variations, measurement error or uncontrolled variables in the literature. Higgins I^2 is a commonly used measure of heterogeneity (Higgins & Thompson, 2002), with greater values of I^2 indicating variation in effect that cannot be attributed to true variation in the distribution of the effect. Due to the considerable variation in methodologies in the included studies problematic heterogeneity was defined as a Higgins I^2 value greater than 75%.

3.5.4.2 Estimation of unexplained variance due to methodological factors and uncontrolled covariates

When problematic heterogeneity was identified a leave-one-out analysis was conducted to identify papers that exerted a disproportionate influence on the meta-analytic synthesis. Disproportionately influential papers were reviewed regarding the possibility of exclusion due to risk of bias. In addition, subgroup analyses and meta regression were used to attempt to identify the source(s) of problematic heterogeneity and the attenuated estimate of the synthesis will be reported.

3.5.4.3 Identifying influential studies

To examine whether any study or studies exerted a disproportionate influence on the overall meta-analytic effect, a leave-one-out sensitivity analysis was conducted. This procedure identifies individual studies with a disproportionate influence on the quantitative synthesis, by observing the impact of removing each study in turn. If omitting a study results in an effect that lies outside of the 95% CI for the complete meta-analysis, then that study is deemed to have a disproportionate influence and is removed from the omnibus test.

3.5.5 The quality effects model

In the random effects model the precision of the effect size of the intervention is estimated as a function of the sample size from which the effect is derived. The quality effects model (Doi & Thalib, 2008) extends the random effects model by explicitly including rating of methodological quality in addition to the size of the sample in the estimation of precision. In this review the quality effects model was calculated using the total score from the risk of bias quality ratings set out in Section 3.4 and are reported in Section 4.1.3 and 4.2.3. The results of the quality effects model can be interpreted as the meta-analysis that would have been produced had all the included studies been of the same methodological quality. The quality effects model provides a measure of attrition attributable to methodological variation.

3.5.6 Identifying publication bias and small study effects

Publication bias occurs when papers that report higher effect sizes are published in preference to those that report lower ones (Borenstein et al, 2011). This creates a bias in the evidence base so that interventions will tend to be viewed as having a greater impact than they do. Smaller studies are also less likely to be published if they report lower effect sizes, which can present a problem for the random-effects model as it assigns greater weight to smaller studies affecting the mean effect reported by the meta-analysis. These two factors can cause meta-analyses to reproduce a bias in the literature, overestimating the 'true' effect size.

To assess the impact of publication bias and small studies effects a statistical and visual inspection of a 'funnel plot' was performed. A funnel plot is a scatterplot of the effect sizes against a measure of study precision, which is used to visually represent systematic heterogeneity in reported effect sizes. In a funnel plot illustrating the 'true' effect size studies with higher precision would be clustered close to the average (the meta-analytic synthesis) with studies with less precision plotted on both sides of the average creating a funnel shaped distribution. An inverted funnel shape indicates a lower risk of publication bias, whereas a deviation from this shape indicates publication bias. This is especially true when there is an absence of studies in the region of the chart associated with smaller studies with non-significant or lower effect sizes.

When publication bias was identified a 'trim and fill' procedure (Duval & Tweedle, 2000a; Duval & Tweedle, 2000b) was undertaken. The trim and fill procedure works on the assumption that an asymmetric funnel plot is due to publication bias and that therefore there are missing studies which should be included in the analysis. The procedure then uses an iterative algorithm to eliminate smaller studies with positive outlying effect sizes then recalculating the effect size of the data set until the funnel plot returned is symmetrical. This provides an estimate for an effect size unaffected by publication bias. Whilst this trimming yields an adjusted effect size, it also reduces the variance of the effects, yielding a too narrow confidence interval. The trim and fill procedure then recreates the original funnel plot but adds in mirror studies on each on the side of the funnel plot associated with negative effects. In addition, the fail-safe N ‘file drawer analysis’ (Rosenthal, 1979) was calculated. The fail-safe N estimates the number of missing studies that would need to be discovered for the effect to be no longer significant. If this number is large (relative to the number of primary studies in the meta-analysis) then the omnibus test can be considered robust to the effects of publication bias.

3.5.7 Planned contrasts and analysis of sub-groups

The current evidence base suggests that studies that are closer to the recommendations of the BPS (2013) will have greater effect sizes for the reduction of fibromyalgia symptoms and pain. Therefore, the studies were categorised by their fidelity to BPS treatment guidelines and rated ‘poor’, ‘average’ or ‘good’ (see Section 3.3.2). Inclusion of PMP components was also compared, to ascertain what factors improve intervention outcomes. Summary effects and associated heterogeneity measures were calculated for each of these sub-groups. The significance of the difference between the sub-groups was evaluated by comparison of their 95% confidence intervals.

4. Results

4.1 Reduction in fibromyalgia symptomatology

The treatment effects described in the included studies on the reduction in fibromyalgia symptomatology are displayed as a forest plot in Figure 2. Eleven studies were included in the meta-analysis with a total of 506 participants. Participants were recruited from outpatient pain and rheumatology clinics and primary care centres.

4.1.1 Omnibus Test

A random effects models was calculated using the generic inverse variance method. A weighted average standardised mean difference of SMD= -0.6629 (z= -2.82, p= < 0.0048) was suggested by the random effects model, with a 95% confidence interval of between -1.1241 to -0.2018. This is considered a medium treatment effect size (Cohen, 1988).

There was an unacceptable level of unexplained variance or heterogeneity found within the studies analysed for this outcome, (tau^2= 0.5176, Higgin's I^2= 87%, χ^2= 77.54, p= <0.0001). This suggests that the estimated effect size obtained in the analysis is biased by the presence of confounding or uncontrolled variables.

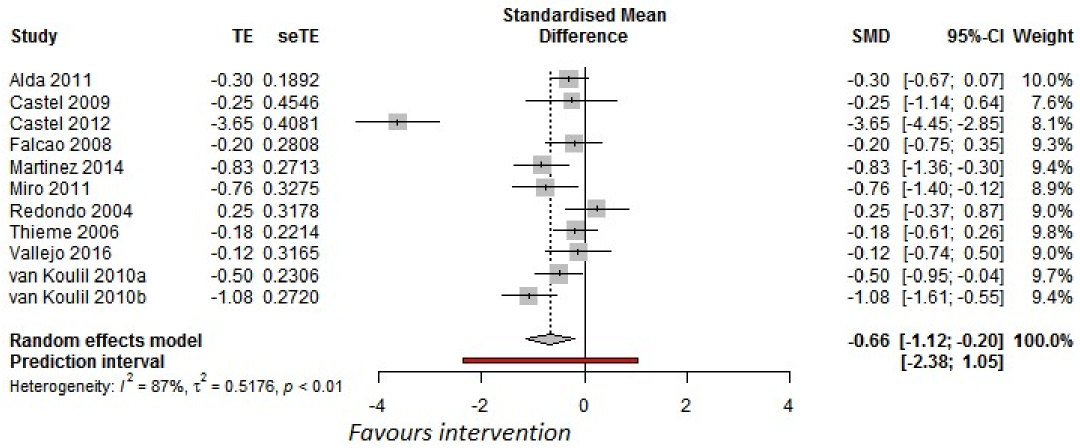

Figure 2 - Forest Plot Displaying Reduction in Fibromyalgia Symptomatology Effect Sizes

4.1.2 Impact of influential studies

As illustrated in Figure 2, one study (Castel et al., 2012) had an unusually large effect size of -3.65 compared to the meta-analytic average of -0.66. Further analysis of this study was required to assess its influence upon the overall effect size found and problematic heterogeneity. This was achieved using a 'leave-one-out' analysis, in which the random effects model was calculated with each of the primary studies removed in turn. This measure of influence is depicted in forest plot of 'leave-one out' effect sizes shown in Figure 3. The 95% confidence interval for Castel et al. (2012) did not include the value of the synthesis from the complete data set (when removed from the synthesis). Therefore, it can be inferred that removing Castel et al. (2012) results in quantitatively different conclusions and the study is exerting excessive influence on the outcome. The random effects model was recalculated with the results of Castel et al. (2012) omitted. The corrected random effects model reported SMD= -0.4060 (95%CI= -0.6397 to -0.1723), a 39% decrease in the meta-analytic average and a Higgin's I^2 of 47% (a moderate level of heterogeneity (Higgins et al., 2011)). Accordingly, Castel et al. (2012) was removed from all subsequent analyses.

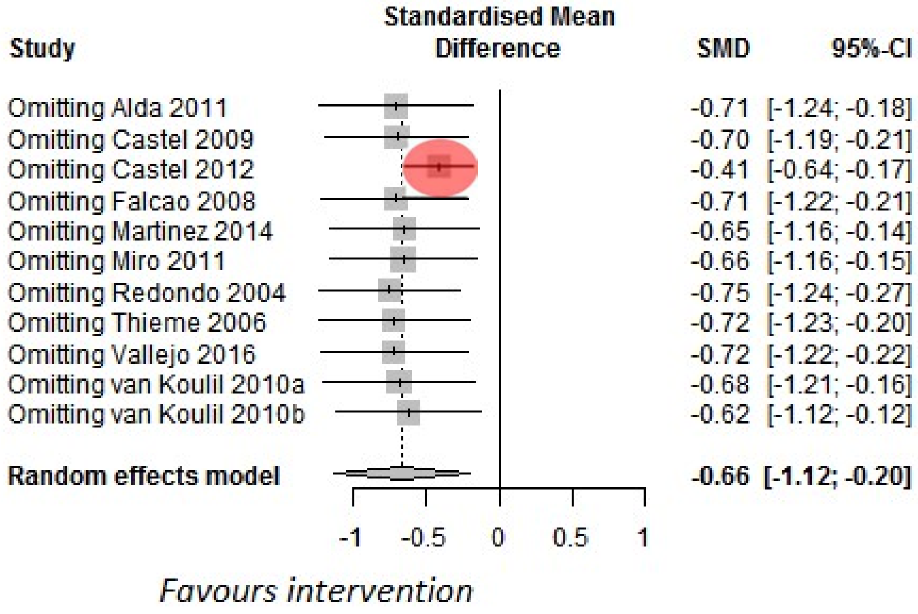

Figure 3 - Forest Plot Displaying Leave-one-out Analysis (Reduction in Fibromyalgia Symptomatology)

4.1.3 Quality effects model

The quality effects model was calculated using the total score from the risk of bias ratings reported in Section 3.4. The quality effects model can be interpreted as the meta-analytic result that would have been obtained had all studies been of the same methodological quality as the best study in the review. The quality effect model reported a synthesis of SMD= -0.4265 (z= -3.5177, p= <0.0004) with a 95% confidence interval of between -0.6642 to -0.1889. The quality effects model shows an approximate 5% increase relative to the random effects estimate. Accordingly, when the synthesis includes information about the methodological quality of the studies there is no important change in the synthesis of these studies. To better understand the impact that methodological variation may be having upon heterogeneity, a series of subgroup analysis were conducted on the risk of bias for each type of methodological bias. The results of this subgroup analysis are depicted in Table 7.

Table 7

Subgroup Analysis According to Methodological Quality Ratings

	Low Risk			**Unclear Risk**			**High Risk**				
	N	***SMD***	***CI***	***N***	***SMD***	***CI***	***N***	***SMD***	***CI***	χ^2	***p***
Selection Bias	4	-0.4115	-0.8476 – 0.0245	6	-0.4031	-0.7026 – -0.1036				0.01	0.9751
Performance Bias							10	-0.4060	-0.6397 - 0.1723	N/A	N/A
Treatment Fidelity	4	-0.6387	-0.9821 – -0.2953	4	-0.2759	-0.5467 – -0.0051	2	-0.0851	-0.4255 – -0.0051	5.79	0.0554
Detection Bias	5	-0.3700	-0.7171 – -0.0229	5	-0.4431	-0.7985 – -0.0877				0.08	0.7730

Statistical Bias	3	-0.5929	-1.0252 – -0.1605	7	-0.3032	-0.5841 – -0.0223		1.21	0.2708
Reporting Bias	10	-0.4060	-0.6397 -0.1723					N/A	N/A
Generalisability				10	-0.4060	-0.6397 -0.1723		N/A	N/A

Key: **N**: number of studies, **SMD**: Standardised Mean Difference, **CI**: 95% confidence interval

As can be observed in Table 7 there were no statistically significant differences between the SMDs grouped by methodological quality ratings. This suggests that methodological quality did not unduly impact on the meta-analysis of the omnibus test.

4.1.4 Publication Bias and Small Study Effects

A funnel plot is used primarily as a visual aid for detecting systematic heterogeneity and is presented as a scatterplot of the effects from the primary studies against a measure of study precision. In the absence of publication bias, it is assumed that studies with high precision will be plotted near the average (i.e., the meta-analytic synthesis), and studies with low precision will be spread evenly on both sides of the average, creating a roughly funnel-shaped distribution where the distance from the average is inversely proportionate to the precision of the study. A symmetric inverted funnel shape arises from a 'well-behaved' data set, in which publication bias is unlikely whereas deviation from this shape can indicate publication bias especially if there is an absence of studies in the region associated with small samples sizes and non-significant effects. The funnel plot of the correlation between standard error and standardised mean difference is presented in Figure 4.

As can be seen from Figure 4 there does not appear to be asymmetry in the funnel plot suggesting low risk of publication bias publication bias. A ‘trim and fill’ procedure was completed to determine whether this potential bias could be corrected. This procedure did not suggest the inclusion of any new studies indicating that the asymmetry observed below to be slight. The Rosenthal 'fail-safe' method was used to calculate the number of studies averaging null results that would be required to reduce the combined significance level ($p < 0.0001$) to a target alpha level of 0.05. The Rosenthal method estimates that 71 unpublished null studies would be required to reduce the meta-analytic effect to non-significance (based on the ten included studies). Accordingly, this effect can be considered robust to the effects of publication bias.

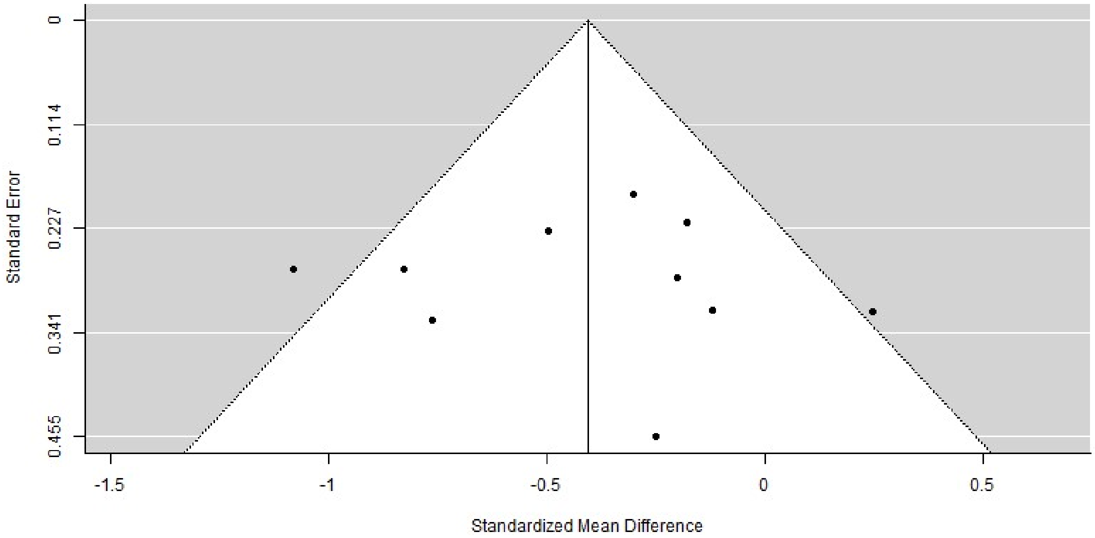

Figure 4 - Funnel Plot Displaying Estimate of Publication Bias (Reduction in Fibromyalgia Symptomatology)

4.1.5 Subgroup analysis – Impact of treatment fidelity

There were ten studies with outcomes related to the reduction in fibromyalgia symptomatology and the SMD of these studies were compared using a subgroup analysis.

The analysis contrasted studies by their ratings of treatment quality and the inclusion of PMP components in their treatment protocol. A random effects models was calculated using the generic inverse variance method. No studies were rated 'good' for fidelity to treatment guidelines therefore only studies of 'average' and 'poor' quality were compared. The five studies of 'average' fidelity (Alda et al., 2011; Castel et al., 2009; Thieme et al., 2006; van Koulil

2010a & van Koulil 2010b) returned an SMD of -0.4574 through the random effects model, with a 95% confidence interval of between -0.7652 to -0.1496. The remaining studies with a 'poor' rating returned a SMD of -0.3406 with a 95% confidence interval of between -0.7380 and -0.0568. See Figure 5 and Table 8 for a summary of these findings. Studies with average treatment fidelity reported a greater SMD than those with average ratings but this difference was not statistically significant (χ^2= 0.21, p= 0.6487).

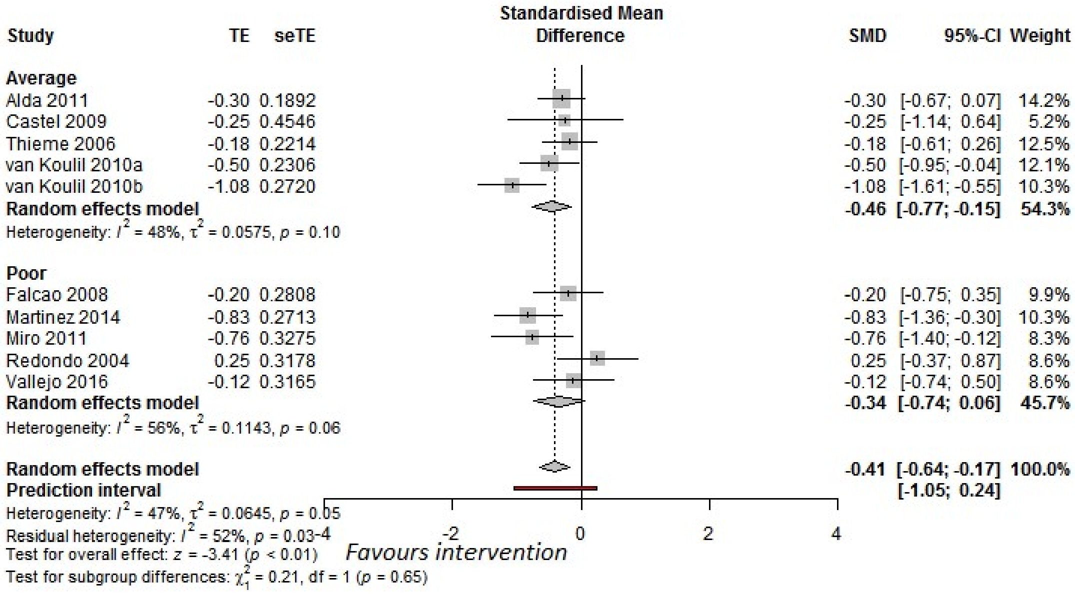

Figure 5 - Forest Plot Displaying Subgroup Analysis of Treatment Quality

Table 8

Subgroup Analysis According to Treatment Quality

	Good			**Average**			**Poor**				
	N	***SMD***	***CI***	***N***	***SMD***	***CI***	***N***	***SMD***	***CI***	***χ2***	***p***
Treatment Quality				5	-0.4574	-0.7652 – -0.1496	5	-0.3406	-1.7380 – -0.0568	0.21	0.6487

The results of the subset analyses for each of the PMP components is summarised in Table 9. One of the components (skills training) was present in each of the ten included studies with two more (having a group size of 8-12 and multi-disciplinary facilitators) present in none of the studies. Therefore, it was not possible to compare these components as subgroups. Two of the remaining seven components returned a statistically significant difference between the two subgroups: cognitive therapy (χ2= 4.47, p= 0.0344) and acceptance, mindfulness, flexibility (χ2= 4.53, p= 0.0333).

Table 9

Subgroup Analyses According to Individual Treatment PMP Components

	Yes			**No**				
	N	***SMD***	***CI***	***N***	***SMD***	***CI***	***χ2***	***p***
Graded activation	2	-0.7709	-1.3429 – -0.1988	8	-0.3030	-0.5286 – -0.0774	2.22	0.1359
Cognitive therapy	9	-0.4647	-0.6845 – -0.2450	1	0.2481	-0.3748 – 0.8711	4.47	0.0344
Graded exposure	4	-0.4839	-0.8352 – -0.1325	6	-0.3323	-0.6775 – 0.0130	0.36	0.5464
Acceptance, mindfulness, flexibility	4	-0.1710	-0.4177 – 0.0758	6	-0.5878	-0.8818 – -0.2937	4.53	0.0333
Skills training	10	-0.4060	-0.6397 – -0.1723				N/A	N/A
Exercise	3	-0.5920	-1.0739 – -0.1101	7	-0.3177	-0.5780 – -0.0575	0.96	0.3263
Education about pain	6	-0.3216	-0.6567 – 0.0135	4	-0.5039	-0.8568 – -0.1511	0.54	0.4627
≥ 36 hours	3	-0.5929	-1.0252 – -0.1605	7	-0.3032	-0.5841 – -0.0223	1.21	0.2708
Group size 8-12				10	-0.4060	-0.6397 – -0.1723	N/A	N/A
Multi-Disciplinary Facilitators				10	-0.4060	-0.6397 – -0.1723	N/A	N/A

4.2 Reduction in pain

The treatment effects described in the included studies are displayed as a forest plot in Figure 6. Fifteen studies were included in the meta-analysis with a total of 975 participants. Participants were recruited from outpatient pain and rheumatology clinics, primary care centres, secondary care mental health clinics, advertisements, and peer support groups.

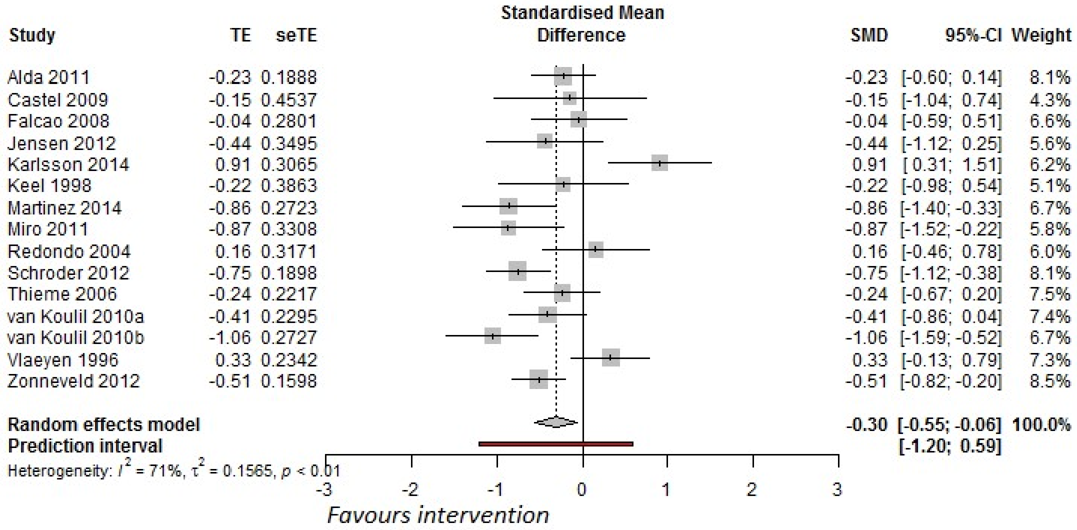

Figure 6 - Forest Plot Displaying Impact of Pain Effect Sizes

4.2.1 Omnibus test

A random effects models was calculated using the generic inverse variance method. A weighted average standardised mean difference of SMD = -0.3047 (z = -2.45, p = < 0.0144) was suggested by the random effects model, with a 95% confidence interval of between -0.5489 to -0.0606. This is considered to be a small to medium treatment effect size (Cohen, 1988).

There was a substantial but acceptable level of unexplained variance or heterogeneity found within the studies analysed for this outcome, ($tau^2 = 0.1565$, Higgin's $I^2 = 71.1\%$, $\chi 2= 48.5$, p = <0.0001). This suggests that the estimated effect size obtained in the synthesis is affected by the presence of confounding or uncontrolled variables within the included studies.

4.2.2 Impact of influential studies

The impact of disproportionately influence studies was assessed using a 'leave-one-out' analysis, in which the random effects model was calculated with each of the primary studies removed in turn. This measure of influence is depicted in forest plot of leave-one out effect sizes shown in Figure 7. As no study's 95% confidence interval was outside of the value for the synthesis of the complete data set it may be inferred that no study is exerting excessive influence on the outcome.

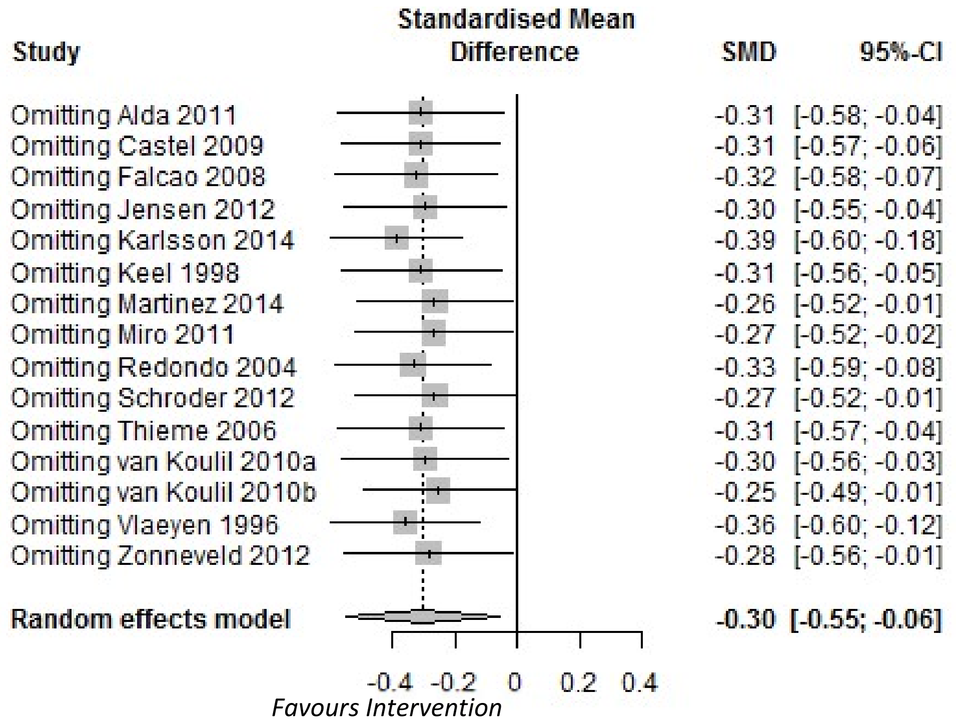

Figure 7 - Forest Plot Displaying Leave-one-out Analysis (Reduction in Pain)

4.2.3 Quality effects model

The quality effects model was calculated using the total score from the risk of bias ratings reported in Section 3.4. The quality effect model reported a synthesis of SMD = -0.2977 (z = -2.3693, p = <0.0178) with a 95% confidence interval of -0.5439 to -0.0514. The quality effects model estimated a decrease in the meta-analysis of 2% (in favour of the control group) compared to the random effects model. This insignificant difference shows that there is no important change in the synthesis of these studies when methodological quality is corrected.

To better understand the impact that methodological variation may be having upon heterogeneity, a series of subgroup analysis were conducted on the frequency of low, unclear, and high risk of bias for each of the seven types of methodological bias. The results of this subgroup analysis are depicted in Table 10.

Table 10

Subgroup Analysis According to Methodological Quality Ratings

	Low Risk			**Unclear Risk**			**High Risk**				
	N	***SMD***	***CI***	***N***	***SMD***	***CI***	***N***	***SMD***	***CI***	***χ2***	***p***
Selection Bias	5	-0.4541	-0.7703 – -0.1380	10	-0.2176	-0.5653 – -0.1300				0.97	0.3239
Performance Bias	1	0.3333	-0.1257 – 0.7923	1	-0.2217	-0.9790 – 0.5355	13	-0.3643	-0.6155 – -0.1132	6.83	0.0328
Treatment Fidelity	7	-0.4188	-0.8348 – -0.0027	4	-0.1682	-0.6191 – 0.2826	4	-0.2824	-0.6040 – 0.0392	0.65	0.7228
Detection Bias	7	-0.2826	-0.6049 – 0.0397	8	-0.3182	-0.7109 – 0.0745				0.02	0.8908
Statistical Bias	5	-0.3272	-0.8639 – 0.2095	9	-0.2706	-0.5499 – 0.0087	1	-0.4392	-1.1241 – 0.2458	0.21	0.8999
Reporting Bias	17	-0.3086	-0.5645 – -0.0528	1	0.2217	-0.9790 – 0.5355				0.05	0.8312
Generalisability	3	-0.3277	-0.8987 – 0.2433	12	-0.2956	-0.5804 – -0.0107				0.01	0.9214

Key: N = number of studies, SMD = Standardised Mean Difference, CI = 95% confidence interval.

As can be observed in Table 10 the quality rating factor 'performance bias' reported a statistically significant difference between the SMDs of the included studies (χ2= 6.83; p= 0.0328). This result suggests that had all the included studies controlled for the risk of performance bias the reported effect sizes would be significantly lower than those reported in the meta-analytic synthesis in Section 4.2.1.

4.2.4 Publication bias and small study effects

The funnel plot of the correlation between standard error and standardised mean difference is presented in Figure 8.

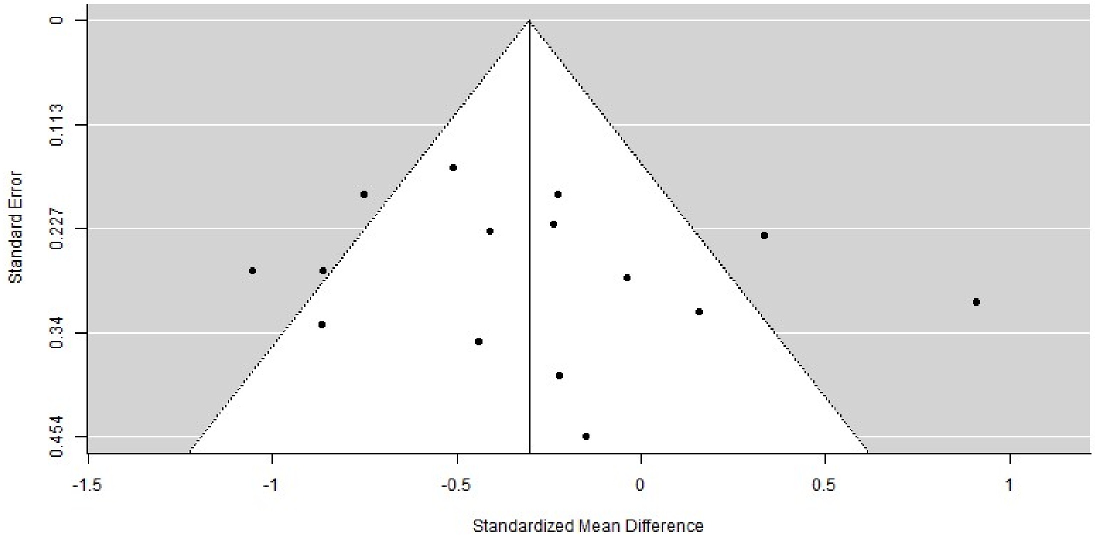

Figure 8 - Funnel Plot Displaying Estimate of Publication Bias (Reduction in Pain)

As can be seen from Figure 8 the effects from the primary studies conform to normal expectations and there is no evidence of substantial publication bias. The Rosenthal 'fail-safe' method estimated that 109 unpublished null studies would be required to reduce the meta-analytic effect to non-significance (based on the 15 included studies). Accordingly, this effect is robust to the effects of publication bias.

4.2.5 Subgroup analysis – Impact of treatment fidelity

The 15 studies were compared using subgroup analyses. Random effects models were calculated using the generic inverse variance method. Eight studies were rated as having ‘average’ fidelity and seven ‘poor’.

The eight studies of average fidelity to guidelines (Alda et al., 2011; Castel et al., 2009; Karlsson et al 2014; Keel et al., 1998; Thieme et al., 2006; van Koulil 2010a; van Koulil 2010b; Vlaeyen et al., 1996) returned an SMD of -0.1396, with a 95% confidence interval of between -0.5153 to 0.2361. The remaining studies returned a SMD of -0.4973 with a 95% confidence interval of -0.7630 to -0.2317. See Figure 9 and Table 11 for a summary of these findings. Studies with ‘poor’ treatment fidelity reported greater improvement in pain due to interventions than those with ‘average’ ratings but this difference was not statistically significant (χ2= 2.32, p= 0.125).

Table 11

Subgroup Analysis According to Treatment Fidelity

	Good			**Average**			**Poor**				
	N	***SMD***	***CI***	***N***	***SMD***	***CI***	***N***	***SMD***	***CI***	***χ2***	***p***
Treatment Fidelity				8	-0.1396	-0.5153 – 0.2361	7	-0.4973	-0.7630 – -0.2317	2.32	0.125

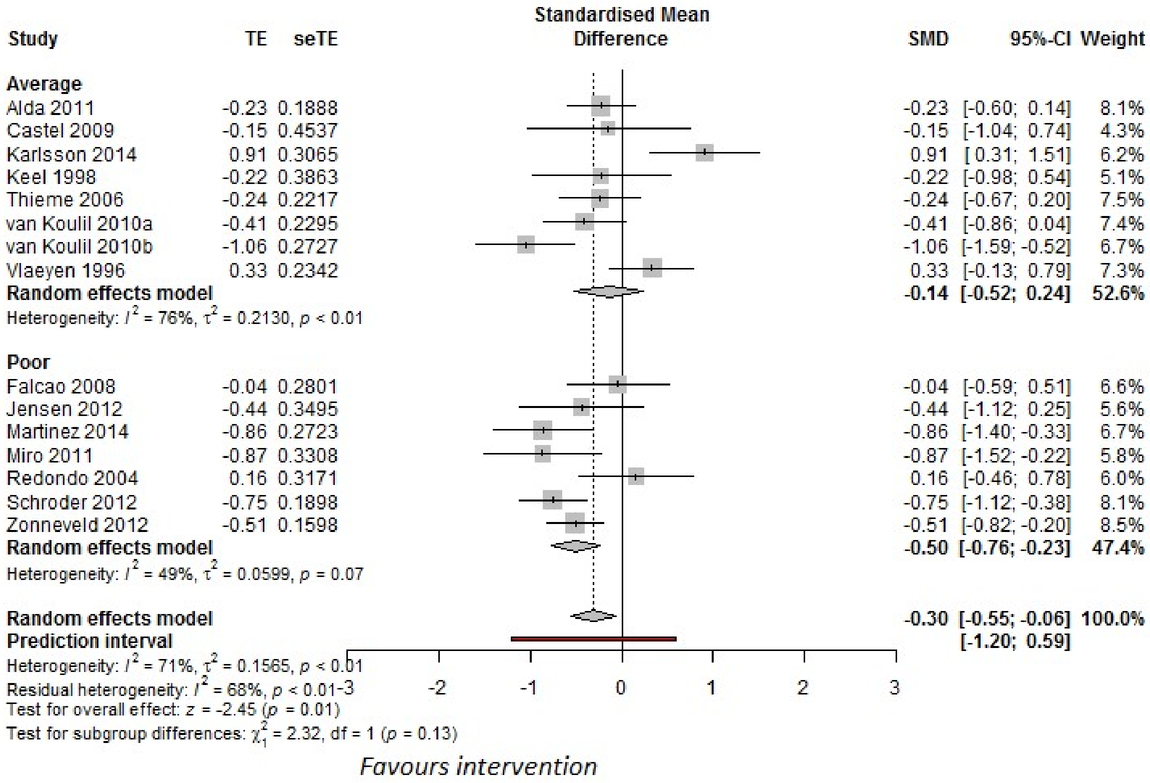

Figure 9 - Forest Plot Displaying Subgroup Analysis of Treatment Fidelity

The results of the subset analyses for each of the individual Pain Management Programme (PMP) components is summarised in Table 12. One of the components (skills training) was present in each of the 15 included studies with another component (multi-disciplinary facilitators) present in none of the studies. There was a statistically significant difference between the subgroups of studies that included elements of acceptance, mindfulness and promoting psychological flexibility (χ2= 5.59, p= 0.0180). This subgroup analysis suggests that PMPs that did **not** include acceptance, mindfulness or flexibility produced better pain reduction outcomes.

Table 12

Subgroup Analyses According to Individual Treatment PMP Components

	Yes			No				
	N	*SMD*	*CI*	*N*	*SMD*	*CI*	*χ2*	*p*
Graded activation	6	-0.3054	-0.5892 – -0.0089	9	-0.3054	-0.7787 – 0.1678	0.01	0.9819
Cognitive therapy	11	-0.3479	-0.6272 – -0.0685	4	-0.1836	-0.7625 – 0.3953	0.25	0.6164
Graded exposure	4	0.4497	-0.7908 – -0.1086	11	-0.2336	-0.5636 – 0.0947	0.80	0.3711
Acceptance, mindfulness, flexibility	9	-0.0822	-0.4517 – 0.2512	6	-0.6012	-0.8729 – -0.3295	5.59	0.0180
Skills training	15	-0.3047	-0.5489 – -0.0606				N/A	N/A
Exercise	5	-0.2746	-0.7529 – 0.2036	10	-0.3206	-0.6174 – -0.0237	0.03	0.8730
Education about pain	9	-0.1955	-0.5967 – 0.2057	6	-0.4386	-0.6868 – -0.1935	1.03	0.3108
≥ 36 hours	3	-0.1957	-1.2349 – 0.8435	12	-0.3303	-0.5508 – 0.1098	0.06	0.8039
Group size 8-12	1	-0.2280	-0.5979 – 0.1420	14	-0.3099	-0.5781 – -0.0418	0.12	0.7253
Multi-Disciplinary Facilitators				15	-0.3047	-0.5489 – -0.0606	N/A	N/A

5. Discussion

5.1 Are Pain Management Programmes effective for the treatment of fibromyalgia?

The aim of this meta-analysis was to determine the effectiveness of Pain Management Programmes (PMP) for reducing fibromyalgia symptomatology and pain. Most of the group cognitive behavioural therapy (CBT) programmes reviewed had poor fidelity to the British Pain Society (BPS) guidelines, which limits the conclusions that can be drawn from this meta-analysis. For the primary outcome (reduction in fibromyalgia symptomatology) studies rated ‘average’ for fidelity to guidelines (SMD= -0.46) produced marginally better outcomes than those rated ‘poor’ (SMD= -0.41) though this was not statistically significant (p= 0.6487). For the secondary outcome (reduction in pain), studies with ‘average’ ratings of fidelity produced slightly worse outcomes compared to studies with ‘poor’ fidelity (SMD= -0.14 vs. -0.45) but again, this was not statistically significant (p= 0.125). In terms of the aims of this meta-analysis these results suggest that for the primary and secondary outcomes, greater fidelity to BPS PMP guidelines does not produce a statistically significant improvement in treatment outcome. The lack of a statistically significant difference in treatment outcomes between ‘average’ and ‘poor’ fidelity to BPS guidelines implies that generic group CBT performs equally well to structured PMP in treating the symptoms of fibromyalgia and pain.

After correcting for an outlying study (Castel et al., 2012) the results of the meta-analysis for both outcomes indicated that group-based CBT produced a small-medium treatment effect (SMD= -0.41 and -0.30). The reasons for the outlying result from this study is unclear but it is likely due to a treatment fidelity or performance bias as the study was rated as high risk in both areas. The quality effects model for both outcomes indicated no important change in the meta-analysis when methodological quality is considered. There was no impact from publication bias on the reported results for either outcome.

There were some interesting findings from the subgroup analyses of individual treatment elements. Interventions that included cognitive therapy produced statistically larger effect sizes in reduction of fibromyalgia symptomatology ($\chi 2$= 4.47, p= 0.0344). This result may suggest that cognitive therapy is a key element of PMPs for reducing fibromyalgia symptomatology. However, this result was reached through a subgroup analysis of nine studies including cognitive therapy versus one without, so it should be approached with caution. The subgroup analyses of the PMP element of acceptance, mindfulness and promoting psychological flexibility for fibromyalgia symptomatology (χ2= 4.53, p= 0.033) and pain (χ2= 5.59, p= 0.0180) showed statistically larger effect sizes if these elements are **not** included. These subgroup analyses are based on comparisons between nine studies including these elements and eight without. This result suggests that this element impacts negatively on people with fibromyalgia and should be investigated further. The studies that included elements of acceptance, mindfulness and promoting psychological flexibility (Alda et al., 2011, Castel et al., 2009, Castel et al., 2012, Jensen et al., 2012, Karlsson et al., 2014, Keel et al., 1998, Redondo et al., 2004, Thieme et al., 2006, Vlaeyen et al., 1996) had an average methodological quality rating of 60% compared to 61% for those that did not contain this element suggesting that methodological quality cannot explain this surprising result. All of the studies that rated 'average' treatment fidelity included this PMP element, though due to the imprecision of the fidelity rating in this analysis this is inconclusive. For more detail on this result see Section 5.2.

5.2 Comparison to other reviews

This meta-analysis is the first to examine the specific criteria for PMPs recommended by the BPS to determine the effectiveness of this intervention. A previous meta-analytic review by Häuser et al. (2009) considered the evidence for 'multi-modal' treatments (any treatment including two non-pharmacological interventions) for fibromyalgia. This review did not consider the outcome of reduction in fibromyalgia symptomatology but did include the similar outcome 'health-related quality of life' (SMD= -0.59; 95% CI= -0.90 to -0.27) and pain (SMD= -0.37; 95% CI= -0.62 to -0.13) finding a medium and small-medium effect size respectively. This matches the findings of the current meta-analysis for reduction in fibromyalgia symptomatology (SMD= -0.46, 95%CI= -0.77 to -0.15) and pain (SMD = -0.14, -0.52 to -0.24) when considering the interventions with better fidelity to BPS standards. The similarity of the effect sizes between these two meta-analyses implies a modest finding for multi-modal treatments.

As indicated in Section 2.5 there have been several meta-analytic reviews considering the effectiveness of CBT as a treatment for fibromyalgia. Relevant comparators to this study are Bernardy et al. (2010), Bernardy et al. (2013) and Glombiewski et al. (2010). The two studies with the lead author Bernardy examined CBT treatments for fibromyalgia with Glombiewski et al (2010) considered all psychological treatments. None of the analyses listed above included the reduction in fibromyalgia symptomatology as an outcome measure, though Bernardy et al (2013) and Glombiewski et al (2010) included disability and functional status, which are broadly analogous terms. For pain, Bernardy et al (2010) reported an SMD of -0.24 (95% CI= -0.54 to 0.05), Bernardy et al (2013) SMD= -0.29 (95% CI= -0.49 to -0.17) and Glombiewski et al (2010) SMD= -0.29 (95% CI= -0.49 to -0.17); the present meta-analysis reported SMD= -0.30 (95% CI= -0.55 to -0.06). These results all indicate that CBT is effective in reducing pain in people with fibromyalgia. The difference in effect sizes may be due to the focus of this analysis on CBT groups rather than CBT generally. This may imply better outcomes for CBT in a group format compared to individually, though these two approaches have not yet been directly compared. For the reduction in fibromyalgia symptomatology Bernardy et al (2013) reported an SMD of -0.30 (95% CI -0.51 to -0.08) and Glombiewski et al (2010) reported Hedges' g= 0.42 (95% CI: 0.25 to 0.58) though this was for psychological interventions in general; the present meta-analysis reported SMD= -0.41 (95%CI= -0.6397 to -0.1723). All analyses reported a reduction in fibromyalgia symptomatology post-treatment though there is variation in the reported effect size. This is possibly due to the differences in outcome but, as above, could be due to this analysis' focus on group CBT.

Finally, relating to the significant difference between treatment effect sizes for interventions with/without mindfulness, acceptance, and psychological flexibility. There have been several meta-analyses focusing specifically on this topic: Haugmark et al. (2019), Lakhan and Schofield (2013), Lauche et al. (2013) and Theadom et al. (2015). In contrast to findings of this meta-analysis these reviews report that acceptance and mindfulness-based therapies have a clinically significant impact on reducing pain in people with fibromyalgia. The effect sizes vary depending on the review (see Table 13), but all are small to medium in size, with the Cochrane review (Theadom et al., 2015) falling between the rest at -0.3. The reason between the discrepancy between this analysis and those previously published is unclear but may be because the studies included in this study were primarily CBT interventions with Acceptance and Commitment Therapy (ACT) elements rather than pure ACT. In addition, the clinicians delivering the experimental interventions were primarily trained in CBT and may not have received adequate training in ACT theory or methods. More research may be justified in exploring the difference in outcomes between CBT and ACT.

Table 13

Summary of Previous Meta-Analytic Reviews for Acceptance and Mindfulness Based Treatments for Pain

Review	**SMD and 95% CI for Interventions on Pain**
This meta-analysis	SMD = -0.3047, CI= -0.55 to -0.01
This meta-analysis, subgroup: Including acceptance, mindfulness, and psychological flexibility training	SMD =-0.0822, CI= -0.4517 to 0.2512
Haugmark, Hagen, Smedslund & Zangi (2019)	SMD= -0.46, 95% CI= -0.75, -0.17
Lakhan & Schofield (2013)	SMD= -0.21, 95% CI= -0.37, -0.03
Lauche, Cramer, Dobos, Langhorst & Schmidt (2013)	SMD=-0.23, 95% CI -0.46 to -0.01
Theadom, Cropley, Smith, Feigin & McPherson (2015)	SMD= -0.3, 95% CI= -0.5 to -0.2

5.3 Limitations

There were several limitations of this meta-analysis, which may impact on the conclusions that can be drawn from it. Firstly, the studies included in this review had generally poor-quality methodologies with particularly high risks of performance bias. Unfortunately, there were insufficient studies extant in the literature base to focus only on those with more rigorous methodologies. As this meta-analysis included only a small number of papers it seems likely that the effect sizes reported in this review are some way from the 'true' effect size. Related to the imprecision of the methodologies is the heterogeneity of the measures used to record ratings of pain.

The method for assessing PMP treatment fidelity (measuring the inclusion or exclusion of PMP components) provided a crude estimate of how faithful interventions were to BPS recommendations but conceals the variability between interventions. It is unclear how similar 'average' interventions were to each other or how loyal they were to the recommendations the BPS had envisaged. This means that the results of this meta-analysis are at best a crude estimate of the effectiveness of PMPs for treating fibromyalgia.

Many studies did not use a measure with reported psychometric properties (many using a visual analogue scale), which reduces the reliability and validity of the results from these measures. Another weakness of this analysis is that the long-term effectiveness of the interventions was not considered. This means that it is uncertain whether the interventions reviewed maintained the positive results in the long-term. Finally, many of the studies that were gathered during the systematic literature review were excluded as they did not include the outcomes of reduction in fibromyalgia symptomatology or pain. This means that other outcomes relevant to the treatment of fibromyalgia, such as anxiety, depression, quality of life and disability were not included in this review. It is worth noting that the BPS guidelines were published in 2013 so studies completed before then are unlikely to follow them. This meta-analysis used CBT fidelity to BPS guidelines as proxy for PMPs as there are no published studies on these.

5.4 Future research and clinical implications

None of the studies included in this meta-analysis met all the BPS's recommendations for PMPs meaning that average and poor fidelity studies were used instead. Further research could be focused on comparing a BPS adherent PMP with a control group to determine its effectiveness. It would also be beneficial to widen the scope of this analysis to include other outcome measures relevant to fibromyalgia (see above). The current evidence base, as reviewed in Section 2, and the outcome of this meta-analysis indicate that group CBT programmes are effective in reducing fibromyalgia symptomatology and pain. Though this analysis was unable to support the use of BPS style PMPs as more effective than generic group CBT, until further research is completed it would be sensible to continue using these recommendations. The results of this analysis do support the use of cognitive therapy techniques as an element of PMPs and this should be a focus of future programmes.

6. Conclusions

This meta-analysis adds to the weight of evidence supporting the use of group CBT for the treatment of fibromyalgia. The treatment effect sizes discussed in Section 5.1 indicate a small-medium effect size in favour of these interventions. Though the included studies suffered from a lack of methodological rigour, this was controlled by the quality effects model. In relation to the aims of this review the results suggest that there is no significant difference between multi-modal group PMP style interventions and pure CBT. However, due to the paucity of studies using interventions meeting the British Pain Society guidelines for pain management programmes it is difficult to accept this result conclusively. Further high-quality research into multi-modal CBT based treatments for fibromyalgia is required to clarify and support the results of this review.

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What are People with Fibromyalgia’s Experiences of Psychological Treatments for their Condition

1. Abstract

Background: People with fibromyalgia experience mental health issues related to their condition, which is frequently treated within pain management settings. The Improving Access to Psychological Therapies (IAPT) programme is expanding to provide psychological treatment to people with fibromyalgia within primary care. There is little qualitative research exploring the experiences of people with fibromyalgia accessing mental health services.

Aim: The aim of this research was to describe and explore the experiences of psychological treatment of people with fibromyalgia.

Method: Eight female participants (mean age= 43 years; SD= 11), who had previously attended psychological treatment as part of a pain management programme (PMP), were recruited from a pain management service and interviewed about their experiences. The study took a phenomenological approach to enquiry, aiming to describe the meaning and sensemaking people with fibromyalgia made of their lived experiences of psychological treatment. Interview transcripts were analysed using Template Analysis (TA) to provide a detailed exploration of the participants' experiences of psychological treatment and the services in which these treatments were based.

Analysis: The analysis produced nine iterations of the research template. The final template yielded three superordinate themes, with ten ordinate themes and nine subordinate themes. The three superordinate themes were 'Frustration and uncertainty about psychological approaches', 'Ambivalence about the group setting' and 'Making sense of and reactions to psychological approaches'.

Conclusion: The clinical and service applications of this research are discussed. The contribution of this study to the literature is described, with the strengths and limitations of the research and directions for future research in this area.

2. Introduction

2.1 What is fibromyalgia?

Fibromyalgia is a long-term health condition characterised by widespread and persistent pain, often focused on the joints (Abeles et al., 2007). Other symptoms include sleep disturbances, fatigue, stiffness, headaches (World Health Organisation, 2004) and cognitive symptoms (e.g., forgetfulness, problems concentrating or language difficulties) sometimes called 'fibro-fog' (Kravitz & Katz, 2015). It is estimated to affect 40 per 100,000 people in the UK (Collin et al., 2017) and disproportionately affects women (Walitt et al., 2015) with estimates of gender imbalance between 2:1 (Rahman et al., 2014) and 9:1 (Neumann & Buskila, 2003). People with fibromyalgia are often unable to work (Palstam & Mannerkorpi, 2017), suffer isolation and develop depression and/or anxiety (Arnold et al., 2008). The aetiology of fibromyalgia is a topic of contention (White & Harth, 2001) but is thought to be due to neurochemical imbalances, which lead to an amplification of pain perception leading to allodynia (experiencing innocuous stimuli as painful) and hyperalgesia (a heightened response to the experience of pain; Clauw et al., 2011). This process is sometimes referred to as 'central sensitisation' (Sluka & Clauw, 2016). Other explanations focus on the links between psychological distress and the experiences of pain, suggesting that the condition is at least partially psychosomatic in origin (Ghiggia et al., 2017) and that fibromyalgia could be thought of as 'depression with somatisation' (Di Tella & Castelli, 2016). People with fibromyalgia often reject psychological or mental health explanations for their condition (e.g., van Houdenhove & Luyten, 2008). Partly for this reason and because fibromyalgia is frequently a diagnosis of exclusion, people with fibromyalgia are often referred to various medical specialities before they receive a diagnosis (Macfarlane et al., 2017). This extended diagnostic process is estimated to cost the health service more than with average patients (Annemans et al., 2008; Bermingham et al., 2010), cause stress for patients and their doctors (Nettleton, 2005) and increase the risk of iatrogenic harm (Fink et al., 2015 in Fink & Rosendal).

2.2 How is fibromyalgia treated in the NHS?

There are no definitive best practice guidelines for treating fibromyalgia and the National Institute of Health and Care Excellence (NICE) is currently developing guidance (NICE, 2020). Recommendations from current research include:

Exercise (Busch et al., 2007)
Medication – including pain killers and anti-depressants (Rahman et al., 2014)
Pain management programmes (Price et al., 2013)
Psychotherapy (Williams et al., 2012)
Education about pain/fibromyalgia (Goldenberg et al., 2004)
Combinations of the above (Macfarlane et al., 2017)

The NHS currently bases treatment for fibromyalgia on the recommendations of the British Pain Society (BPS, 2013) using multi-modal Pain Management Programmes (PMP). These programmes are typically based on the principles of cognitive behavioural therapy (CBT) including graded activation guided by participant goals, cognitive therapy methods (e.g., cognitive restructuring and behavioural experiments), graded exposure and methods to enhance acceptance, mindfulness, and psychological flexibility. PMPs are delivered by facilitators drawn from multiple professional groups including physiotherapy, anaesthesia, mental health, nursing, and others**.** The aims of treatment for fibromyalgia include improving quality of life and the physical, emotional, and social dimensions of health and functioning (BPS, 2013). These treatments are most often provided as secondary care outpatient appointments in pain management clinics based on hospital sites. However, the success of the Improving Access to Psychological Therapies (IAPT) programme has led to the attempted integration of people long-term health conditions (including fibromyalgia) into primary care mental health services (England NHS, 2016), ostensibly to treat mental health issues resulting from fibromyalgia (Galvez-Sánchez et al., 2019). Treatment within primary care mental health services is problematic for patients with fibromyalgia due to their frequent rejection of biopsychosocial explanations of their condition (e.g., van Houdenhove & Luyten, 2008).

2.3 Qualitative research including people with fibromyalgia

There have been a number of published articles in this field based on qualitative research methods (e.g., Armentor, 2017; Dennis et al., 2013; Diver, et al., 2013; Lempp et al., 2009; McMahon et al., 2012; Madden & Sim 2006; van Gordon et al., 2016). Topics explored have included experience of diagnosis, living with fibromyalgia, living with a stigmatised condition, receiving pain management treatment, quality of life and participants' explanations of their symptoms. Two meta-ethnographies, Sim and Madden (2008) and Mengshoel et al. (2018) have attempted to synthesise the findings of approximately 28 qualitative studies on fibromyalgia. Sim and Madden (2008) aimed to synthesise research exploring the subjective experience of fibromyalgia, excluding all papers focusing on specific co-morbidities (e.g., depression, social isolation) and treatment. The authors identified four central themes: experience of symptoms, search for a diagnosis, legitimacy, and coping. Mengshoel et al. (2018) specifically focused on people with fibromyalgia's experience of the process and consequences of receiving a diagnosis. They noted two intertwining themes pre/post diagnosis: the diagnosis validating and make sense of individuals' illness experience and legitimatising their being sick in social contexts.

More broadly participants in these meta-ethnographies spoke about their experiences of symptoms, particularly of their debilitating nature, the ambiguous nature of their pain (e.g., diffuse vs. localised) and the inadequacy of language to describe the physical sensations. Common themes included the journey to receiving a diagnosis, which participants described as a process of looking for an explanation for their symptoms and of seeking to prove the legitimacy of their condition through the expertise of professionals. Participants often felt an ambiguity about the diagnosis of fibromyalgia, feeling that it does not provide an adequate explanation for other people and that the uncertainty of looking for a diagnosis is replaced with the uncertainty of seeking treatment. Also, described in these reviews was the struggle participants experienced establishing a new identity and the loss of faith in clinicians (see Table 1 for summary). Neither of the meta-ethnographies above focused on people with fibromyalgia's experiences of mental health treatment, which prevents researchers from gauging the barriers and facilitators to treatment or the acceptability of these interventions.

Table 1 - Summary of Themes from Qualitative Literature Reviews

Ordinate theme	Subordinate theme	Summary
Experience of symptoms*	Pain	The most frequently discussed theme. The nature of the pain is often experienced by participants as ambiguous or conflicting (e.g., constant vs varying, specifically located vs diffuse and shifting). Pain is difficult to reduce to a single description or quality.
	Describing pain	The language participants use is often inadequate to describe their pain. Attacking and aggression metaphors (e.g., 'stabbing' or 'biting') are used frequently. Clinical interpretations of pain fail to match up with the experiences of participants.
	Fatigue	Participants found fatigue to be debilitating and incapacitating, sometimes more so than the pain. Fatigue, weariness, and lack of strength impact negatively on relationships.
	Psychological problems	Not as widely reported as the symptoms above. Common problems reported were low mood, insomnia, and cognition (e.g., memory, problem solving).
Searching for a diagnosis*	Pre-diagnosis	Confusing and disruptive period characterised by multiple consultations with various professionals. Negative results of tests were common, leaving participants experiencing dissonance and uncertainty.
	Receiving a diagnosis of FMS	Characterised by relief at finding an explanation and feeling validated followed by a feeling of uncertainty when new treatments were not forthcoming.

	Post diagnosis	Participants received a number of treatments for their condition but did not experience relief or gain further understanding.
	Legitimacy	The lack of clear outward signs of an illness creates a sense of illegitimacy for participants. Participants can experience judgement from others and attempt to conceal their difficulties. Frequently a lack of knowledge about fibromyalgia is blamed.
	Coping	Participants' experiences of coping go through stages of struggling, adapting and. giving up
	Re-evaluation of life	Life is reassessed due to the strain of living with fibromyalgia and attempting to maintain existing relationships and responsibilities. People experience a loss of identity, which is generally negative though some participants appreciated being able to re-evaluate their lives.
Role of fibromyalgia diagnosis in validating and making sense of bodily experiences**	Endeavouring to confirm the reality of the illness	Attempting to make sense of their pain and fatigue, relying on the competency of their doctor. Participants frequently waited a long time before seeking medical help and received a diagnosis only after multiple assessments.
	Diagnosis has ambiguous validity and meaning	Search for diagnosis replaced by a trial-and-error process to find effective treatment and better coping strategies. Uncertainty as to the nature of the illness is replaced by uncertainty as to what the diagnosis means.

Role of diagnosis in legitimating sickness**	Diagnosis affects personal credibility and dignity	Diagnosis of fibromyalgia does not convey a clear meaning to others and does not help participants to express what is wrong. The participants experienced an ‘invisible illness’ that cannot be detected through medical test or observed by others.
	Questioning the diagnosis and medical authority	Participants begin to question their doctors’ competence and expertise. Fibromyalgia is an ‘empty diagnosis’ that does not support a greater understanding of the illness or provide a clear treatment direction.
*Sim and Madden (2008), **Mengshoel et al (2018)		

There is a paucity of research on people with fibromyalgia's experiences of psychological treatment for their condition. Kashikar-Zuck et al. (2016) interviewed 17 adolescents with fibromyalgia following the successful completion of a group intervention combining CBT with 'neuromuscular exercise training'. The interviews were analysed using thematic analysis, with two themes, 'format' and 'perceived efficacy', that are relevant to this study. All participants were positive about the group format due to the support and encouragement of their peers though some commented they would have preferred individual appointments. In the 'perceived efficacy' theme, many participants reported feeling increased confidence and self-efficacy such that they felt happier and slept better. Rasmussen et al. (2017) interviewed adults with fibromyalgia following their attendance at a multidisciplinary group programme including two sessions of pain management facilitated by a psychologist. The researchers identified four core themes that emerged from the research: 'learning to accept pain', 'increased self-acceptance', 'experiencing acceptance from others' and 'developing new coping strategies'. The participants emphasised the importance of acceptance from their peers in the groups and especially of being acknowledged and taken seriously. From the psychotherapeutic elements, participants reported increased self-acceptance and knowledge of their condition. Miranda et al. (2016) interviewed and observed participants of an 'integrated community therapy group', a multidisciplinary psychological intervention aiming to "promote welfare, health and social rights, seeking to arouse the therapeutic dimension of the actual group" (Miranda et al., 2016, p.1053). These researchers analysed the data using content analysis and found that participants experienced feelings of empowerment from the group and that it was a key component in their developing knowledge of self-care. Bourgault et al. (2015) interviewed the participants of a randomised controlled trial using CBT to reduce pain and improving functioning and quality of life. A thematic analysis of the interview data again generated themes of empowerment and experiencing acceptance from others. However, there were also themes of dissatisfaction with healthcare professionals involved with their care (including group facilitators) and blaming professionals for their lack of knowledge and ability to treat fibromyalgia.

Two studies in the UK have examined people with fibromyalgia experiences of psychological treatment in the UK. Pearson et al. (2020) observed participants of a fibromyalgia self-management programme and interviewed them post-intervention. The subsequent data was analysed using framework analysis and generated themes around the beneficial elements of the group. Themes focused on specific elements of the course that were useful to participants such as, goals setting, problem solving and practical information on sleep, medication nutrition and pain. Van Gordon et al. (2016) analysed transcripts of interviews with participants of mindfulness based psychotherapeutic programme. The emergent themes indicated that participants had reservations about the spiritual aspect of participation but that the treatment itself produced improvements in their wellbeing. Interestingly themes of ‘spiritual growth’, ‘awareness of impermanence’ and an ‘increased sense of citizenship’ were also raised frequently by participants. Most of the research participants were recruited from specialist rheumatology or pain management clinics. Typically, of fibromyalgia research the overwhelming majority of the participants in these studies were female.

Gerskowitch et al. (2015) explored the experiences of people with medically unexplained symptoms (MUS) receiving CBT treatment for comorbid anxiety and depression in an IAPT service. The researchers interviewed 11 people of which three had a diagnosis of fibromyalgia with the remainder experiencing chronic pain or chronic fatigue syndrome. The authors used thematic analysis to analyse the transcripts of semi-structured interviews with participants that had attended at least two psychotherapy sessions. There were four superordinate themes: ‘Something has to change’, ‘Sharing experiences and being understood’, ‘Connections between physical and mental health’, and ‘Reflections on treatment’. Participants emphasised the difficulties they had experienced seeking treatment but expressed appreciation of having the therapist on their side and helping them to develop a new understanding of their condition. Participants reported an initial scepticism that faded when they began to receive knowledge that helped them to make new meaning from their symptoms and to learn new ways of coping.

2.4 Research aim

This research project aims:

> To describe and explore the experiences of psychological treatment for people with fibromyalgia.

There is dearth of research exploring the views of people with fibromyalgia and a lack of research focused on the experiences of this patient population accessing mental health treatment. Given that the expansion of the IAPT programme will include people with fibromyalgia being treated in primary care, it is important that the views of people with fibromyalgia on mental health care are explored. This research is aimed towards supporting policy makers, commissioners, managers, and clinicians to provide appropriate and acceptable psychological treatment for people with fibromyalgia. The overall aim of this project is to allow this patient group to describe the unique challenges they experience in accessing and making use of psychological treatment, with a view to improving mental health services for them.

3. Method

3.1 Approach to enquiry

This qualitative research project explored the lived experiences of psychological treatment of eight women with fibromyalgia. The study took a phenomenological approach to enquiry, aiming to describe the meaning and sensemaking people with fibromyalgia made of their lived experiences of psychological treatment. The researchers approached this subject from a position of critical realism (Maxwell, 2012) holding that there is a real world which exists independently of our perceptions, whilst acknowledging that our understanding of the world is a construction based on our own perspectives and phenomenology.

3.2 Procedure Summary

Participants were recruited from a pain management service based within a metropolitan hospital. They were invited to participate via email or through a face-to-face meeting with a Local Collaborator following the completion of a Pain Management Programme (PMP). Participants agreeing to participate were interviewed by the Lead Researcher at the pain management clinic. Interviews were semi-structured, recorded on an encrypted Dictaphone and lasted approximately 90 minutes. Interview recordings were transcribed by the Lead Researcher and a transcription service. Transcripts were sent to participants to review for accuracy. Transcripts were analysed using Template Analysis (TA) and the first template was based on previously completed qualitative analyses and discussions with the research team. Transcripts were coded for themes by the Lead Researcher and supported by co-researchers. As transcripts were coded for themes, the templates were adjusted iteratively in order that emerging themes could be considered for all transcripts. The final template was applied to all themes previously coded to rationalise the themes and give precedence to those better supported by participant quotations. These themes were shared with members of a qualitative research group to ensure their plausibility.

3.3 Analysis

3.3.1 Template analysis

This research study aimed to explore and describe people with fibromyalgia's experiences of psychological treatment for their condition. As detailed in Section 3.1 the Lead Researcher approached this aim from a primarily phenomenological perspective to best capture the lived experiences of participants. Despite a dearth of research focusing on mental health treatment for people with fibromyalgia there is an existing body of research looking at their experiences in general (see Table 1). This research offers a description of some of the experiences of fibromyalgia, which might be related to the experience of psychological care. As such, a qualitative method was required that could capture the lived experiences of the participants alongside their descriptions of the processes of the services. This study also aimed to describe participants' experiences of the services and treatments they received. Therefore, the analytical method needed to be able to:

Integrate previous research and knowledge of this phenomena with the data generated in this study.

Be able to capture information beyond the immediate experiences of the participants (i.e., the services they accessed).

Interpretative Phenomenological Analysis (IPA) and Thematic Analysis were considered as methods of qualitative analysis but were rejected. IPA was rejected as the method is primarily focused on making sense of direct experiences and being wholly inductive (i.e., past knowledge and research is 'bracketed off' to remain focused on the sense-making of the participants experiences). Thematic Analysis was rejected as although it is broader in its scope than IPA and can incorporate a deductive approach there are other methods that remain as broad in scope as Thematic Analysis but have processes and principles built in specifically to allow for deductive analysis to be balanced with inductive. Template Analysis is one of these.

Template Analysis (TA; Brooks et al., 2015) was employed as the method of data analysis due to its ability to capture the experiences of participants, the contexts around them and previous research findings. TA is a method of thematic analysis that can be adapted for use with a variety of qualitative approaches to enquiry (Brooks et al, 2015). It can be used to examine the lived experiences of participants as well as creating new theories similar to grounded theory. As such it is a theoretically neutral tool for approaching data that can be flexibly applied to most epistemologies and research methodologies. It is used in this study as a method of capturing the pre-existing qualitative research base including people with fibromyalgia, as the themes and concepts described there are likely to be replicated in this research. TA allows for the integration of pre-existing themes into the data collected during this study without losing focus on the data collected from this study's participants. In the TA approach, a template is created before the data analysis begins of themes and topics that are likely to appear in the data. Transcript data is coded with this template in mind, allowing for large amounts of data to be quickly sorted into relevant themes. This does not mean that TA is an entirely deductive process as new codes emerging from the data are included within each new template iteration. The new template is applied to the next group of data, revised and so on until a final template emerges that contains all the pertinent themes emerging in the data. The iterative nature of TA allows researchers to provide a record of the themes that emerged during the analysis process.

3.3.2 Analysis procedure

None of the researchers had prior experience of TA though all were familiar with other phenomenological approaches (e.g., interpretive phenomenological analysis) and one was familiar with TA theoretically. The first template was devised using themes identified in two meta-ethnographies of qualitative research or people with fibromyalgia (Mengshoel et al, 2018; Sim and Madden, 2008). The themes of these reviews were combined with the expert knowledge of a member of the research team to create the first template (see Appendix 5a). The Lead Researcher coded the text, identified new themes, and revised the template. They were supported throughout by members of the research team who helped to ensure the plausibility of the themes emerging from the data. Analysis began with a detailed line by line reading of each of the interview transcripts before the initial template was applied to the transcripts of the first two participants. During the line by line reading of the data no distinction was made between psychological treatments provided via PMPs or through other methods. Therefore, group and individual psychological treatments were analysed together, creating themes relating to both methods of delivery.

Passages of text were coded and then assigned to relevant themes within template 1, codes that did not have a place within the template were set aside as provisional new themes. These new themes served as the basis for the first revision of the template (see Appendix 5b), which was then applied to transcripts of participants three – five. The process of refining the template was then completed a second time (see Appendices 5c and d) and applied to the data of participants six – eight. This template was then re-applied to the coded text of the first five interviews and further refined (see Appendices 5e – 5g) to ensure that all possible themes were identified and to strengthen the existing themes with further supporting quotes. Next the template was shared with a qualitative research group to check the plausibility and strength of the themes. The research group was based at the University of Birmingham and was comprised of clinical psychology doctoral students. The comments of the research group were incorporated into a penultimate template (see Appendix 5h), which was further adapted during write-up to a final version (see Appendix 5i).

3.4 Researchers

3.4.1 Researchers' backgrounds and experiences of fibromyalgia

The Lead Researcher spent 18 months planning and supporting an outpatient mental health service for people with fibromyalgia and people with medically unexplained symptoms (MUS). The Lead Researcher also received a six-day training programme in cognitive behavioural therapy (CBT) for people with chronic health conditions (including fibromyalgia) at one of the Improving Access to Psychological Therapies (IAPT) pilot sites for the long-term conditions and MUS pathway (England, 2016). During this time, the Lead Researcher was employed to provide high intensity CBT for clients with chronic health conditions. The Lead Researcher did not have contact with people with fibromyalgia during these employments, though did provide psychological therapy for people with chronic fatigue syndrome, a client group who have been noted as having similar characteristics to people with fibromyalgia (e.g., Aaron et al., 2000).

The Lead Researcher is sceptical towards the provision of mental health services for people with fibromyalgia. This is because people with fibromyalgia are often resistant and unreceptive to psychological or mental health interpretations of their condition. For this reason, psychological interventions are often not acceptable treatments for people with fibromyalgia. The Lead Researcher is also sceptical towards the expansion of IAPT services to include this patient group as the complex nature of their condition often benefits from a multi-disciplinary approach (e.g., Burckhardt, 2006). These beliefs are based on time spent interpreting the existing research literature for the treatment of fibromyalgia coupled with the opinions of senior clinical colleagues from the employments listed above.

The other named researchers were involved in the design and management of the study but were not directly involved in either data collection or analysis. Local Collaborators at the recruitment site comprised of a physiotherapist and two psychologists specialising in the treatment of chronic pain. The Local Collaborators approached potential participants following a group pain management programme to promote the study but were not otherwise involved in the study design or analysis.

3.4.2 Managing impact of prior understanding of fibromyalgia on analysis

The Lead Researcher conducted the analysis of the interview transcripts, making sure to document decisions on emerging themes in a research journal (see Appendix 7 for a sample). Each template produced during the research was retained so that it is possible to track the development of emerging themes. To avoid the opinions of the Lead Researcher overly influencing the themes emerging from the transcript data they received analysis support from a qualitative research group and their research supervisors who had no pre-existing knowledge of fibromyalgia. The members of the qualitative research group provided a 'reality check' to ensure that themes were directly supported by participant quotes.

3.5 Participant Recruitment

3.5.1 Recruitment

To determine the size of the sample several factors were considered:

Sample is large enough to allow for 'new and richly textured understanding' of the experience of fibromyalgia (p. 183; Sandelowski, 1995).
Sample is small enough to allow 'deep, case-oriented analysis' of data (p. 183; Sandelowski, 1995).
The study design (retrospective semi-structured interviews)
The accessibility of participants
The complexity of the topic (experience of psychological treatments for fibromyalgia)
The sample of size of studies using similar methodologies
The practical limitations of the research

In terms of allowing for the development of a rich understanding of the data without losing the depth of analysis Guest et al. (2006) suggest that saturation of themes in qualitative research was commonly reached by the twelfth interview. A typical sample for an Interpretative Phenomenological Analysis (IPA) study is less than ten (Smith et al., 2013) whilst template analysis studies accommodate samples between seven to 70 plus (Brooks et al., 2015). Recent studies using template analysis (e.g., Blissett et al., 2020; McEllistrem et al., 2020; McGarry et al., 2020) tend towards samples of 10 – 30 participants. As the target sample was so specific (see below) it was anticipated that participants would be difficult to identify and recruit suggesting a smaller sample size. Taking into consideration the factors above and the limited time for recruitment (four months) a sample of twelve participants was sought as this provided an acceptable balance between being able to capture new themes across cases whilst considering the depth and richness within cases and allowing saturation to occur; this also falls within the sample size range typically used in Template Analysis research.

The inclusion criteria for participants were:

Diagnosed with fibromyalgia
Previously attended a pain management clinic
Previously attended a PMP based within a pain clinic
Attended at least three sessions of a PMP
Speak English fluently
Aged over 18 years
Able to provide informed consent.

Potential participants were excluded from participation if they were unable to comfortably sit for at least 30 minutes. As participants with fibromyalgia can be difficult to recruit no exclusions were placed on the length of time elapsed since the completion of the PMP in order to maximise recruitment. For this reason, the length of time since participants were diagnosed or received treatment was not recorded. Though this aided the recruitment of participants this is a limitation of this study (see Section 5.5.2). Potential participants were approached in the final session of a PMP and by a promotional email (see Appendix 1) through a mailing list of previous PMP participants that had previously agreed to further contact from the pain management service. Participants were provided with an information sheet about the project (see Appendix 2) and had at least two weeks to read the information before meeting the Lead Researcher to ensure informed consent.

3.5.2 Participants

Twenty people responded to the promotional email of which nine participants were recruited. All participants were female, aged between 20-58 years (mean= 43; SD= 11), five participants were White British, two were Black British and two Asian British. One participant was interviewed but opted to withdraw from the research and have their data destroyed due to an illness in their family. The remaining participants had been living with a diagnosis of fibromyalgia for two years or more and all had received at least three sessions of psychological treatment through PMPs. All participants were recruited through email contact. The Lead Researcher had no previous relationship with any of the participants either in a professional or personal capacity. All participants received psychological treatment through a PMP; additionally, two had seen CBT therapists through IAPT, one had seen a psychologist at the pain management clinic, one had seen a child psychologist, one had seen a counsellor through their workplace, and one had attended a third-sector mental health group.

3.5.3 Covid-19

Recruitment for this research study began in December 2019 and continued until March 2020. Of the twenty potential participants who responded to the promotional email, 19 agreed to participate and thirteen were scheduled for interviews. The recruitment target of twelve participants was expected to be met in the second week of March 2020. However, the recruitment process was prematurely halted due to participant anxieties about the spread of the coronavirus and the UK government's initiation of a lockdown on 23rd March 2020. For these reasons, recruitment was closed at this point rather than seek amendments to the research protocol from the Health Research Authority (HRA).

3.6 Data collection procedure

Participants were met at the pain management clinic they had previously attended to provide them with a familiar environment for the interviews and to promote recall of their treatment. The Lead Researcher explained the research to the participants and took informed consent (see Appendix 3). All interviews were semi-structured with an interview schedule created by the Lead Researcher with the support of the research team (see Appendix 4). The interviews were planned to be 90 minutes in length and participants could request two shorter interviews if preferred (no participants opted for two interviews). During the interview participants were asked at 30-minute intervals if they were comfortable and happy to continue. Following the interview, participants were debriefed and reminded of their rights as research participants. Participants had two weeks to exercise their right to withdraw from the project and have their data destroyed. Interviews were recorded using an encrypted Dictaphone to maintain data protection. Five recordings were transcribed by the Lead Researcher and three were transcribed by a transcription service. All participants received a copy of their transcript to review for accuracy. Transcripts were amended if any comments were made by the participants about their accuracy.

3.7 Ethics and confidentiality

The study was sponsored by the University of Birmingham as part of a doctoral thesis in clinical psychology. Research oversight was provided by the University of Birmingham and ethical approval was sought and granted before data collection commenced. The study also received ethical oversight from the HRA (see Appendix 9) and the NHS Trust that hosted the research. Participant facing materials were reviewed by an Expert by Experience prior to the contacting of any participants. All identifying information was removed from the transcripts during the process of analysis and no participant names or place names are included in this report.

4. Analysis

The template of themes went through nine iterations ending with the final template 5.5 (see Appendix 5 for each version of the template). The final template included three superordinate themes, with ten ordinate themes and nine subordinate themes (see Figure 1).

4.1 Superordinate theme 1: Frustration and uncertainty about psychological approaches

All participants contributed to this theme. Most participants wanted psychological treatment and felt frustrated they were not offered it sooner. When programmes were offered participants were intrigued and uncertain about what treatment entailed. For half of the participants there was a perception they were obliged to attend the PMP to receive treatment in the future.

4.1.1 Ordinate theme 1.1: I needed support for my mental health

Many participants felt that they needed support for their mental health at some point during their illness and one participant felt strongly that they should have been offered mental health support immediately following their diagnosis.

> *'in that period of 18 months to two years when I said that it would be beneficial if I'd have had someone to speak to then that would have been (pause) a useful tool to have had um (pause) to have been seen or, you know, participated in something…um (pause) pretty much straight after diagnosis, but obviously that didn't happen…'* (Participant 1)
>
> *[positive outcome of the group] 'it's helped me because I've taken some of them onboard so yeah so it, so it helped um definitely the emotional side cause like I said um when I got diagnosed it was just like I was left in limbo for a couple of years not really (pause) knowing what was going on.'* (Participant 1)

The sense participants made of the lack of mental health support was that they were left to cope on their own and that asking for support did not yield adequate mental health support.

Some participants received some mental health support but found that the support was insufficient for their needs, arrived after crises had passed or were discharged early.

> *'yes so (pause) they referred me to the mental health team…and the mental health team go "you don't need it" and then I get discharged. I've been waiting for the mental health team for about two years now.'* (Participant 2)
>
> *[did you ever have any other kind of mental health support] 'Um, no not really I can remember seeing the team and they would have- I think there was [name of doctor] the consultant and at the time it was [name of psychologist] who was the psychologist here and I saw all of them together. That would be about the only other (pause) psychological input.'* (Participant 3)
>
> *'I think my last uh counselling session was probably about maybe eighteen months ago roughly something like that um (long pause) yeah so it's intermittent with myself…um when it comes to uh mental health support whether it's just coping and things like that, just managing things and you know it, it, it can be hard…so yeah it's been intermittent with myself, but I've always had to reach out yeah.'* (Participant 4)
>
> *[did anyone offer you any support for the kind of, like you said, the breakdown days?] 'No, nothing.'* (Participant 8)

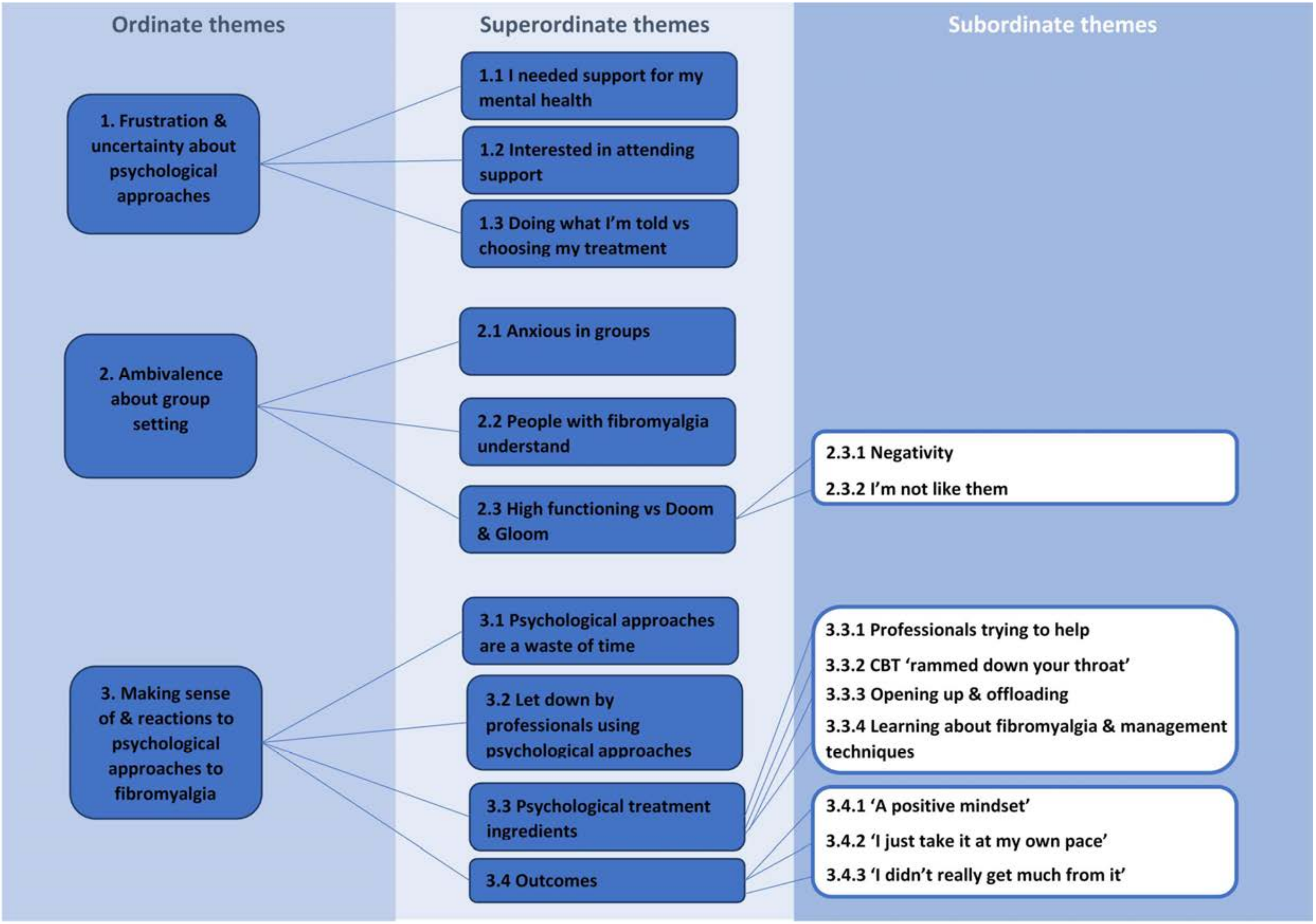

Figure 1 - Summary of Final Themes

4.1.2 Ordinate theme 1.2: Interested in attending

All but two of the participants were intrigued about attending the group and being able to take away useful information. Several participants were happy at being offered the programme and were keen to attend to learn how to manage their pain.

> *[what was your reaction to being offered the PMP?] 'Intrigue. Erm, definitely. Because, I'd not had… nothing had been geared specifically at Fibro, to me, whereas that was. So, I'm very interested and I, you know, really wanted to do it because I knew that it was something that would direct… it was directly about what… it was specific. It wasn't sort of, a general.'* (Participant 6)
>
> *'I felt, I was happy actually when I heard I was gonna go to (pause) a group how to manage the pain.'* (Participant 8)

Several participants had negative expectations of the group, worrying that they did not know '*what they were walking into*' or that they did not '*expect to get anything out of it'*.

> *'when the group came up it was like "oh I don't know if I want to go to that" but (pause) talking it over with you know with [wife's name] it's just like "actually this would probably do you real…", you know so I'm glad that I did it.'* (Participant 1)
>
> *'before, I didn't think that I would be able to go and do anything. And, thought process… you know, I couldn't… I didn't expect to get anything out of pain management programmes or anything.'* (Participant 5)

Those participants that were daunted at the prospect of attending the group decided to give the group a try with three specifically commenting that they tried to keep an 'open mind'.

> *'I would go with an open mind cause I always think that "okay maybe not everything will apply to me, but I'll take away what I can use" so there's always going to be some value in.'* (Participant 3)
>
> *'You just don't know what to expect… you just to have an open mind sometimes uh when you're dealing with some- certain things where you don't know what you're walking into. So yeah, um it's a bit daunting.'* (Participant 4)

4.1.3 Ordinate theme 1.3: Doing what I'm told vs choosing my treatment

Participants spoke about accepting the confusing offer of psychological treatment with stoicism, feeling that mental health interventions (and particularly the PMP group) were something that they had to get through.

> *"you don't know what to expect unless you try something so um and you, if don't turn up you lose your remaining appointments as well because…obviously someone else could have had them.'* (Participant 4)
>
> *[on going for treatments to be able to access the next treatment] 'Yeah, that's what it felt like at the time, you know. You've got to do that to get to the next stage, to… it's as if you've got to meet each stage, to get where you needed to get.'* (Participant 5)

These participants deferred to their clinicians and agreed to attend the group with an attitude that the clinicians must know best and that they should do what they were told.

> *[about treatment in general] 'I've done everything that the doctors have asked me'* (Participant 1)
>
> *did anyone explain why you were being referred to the PMP?] Not really, no. I think… 'I think I was just like… I was just told it was just one of the things that I've got to do, sort of thing.'* (Participant 5)

One participant was resentful of the lack of choice of treatment feeling that they would have preferred psychological treatment earlier or without having to try medication first.

> *'They don't put us on the pain management programme straight away…they first do the treatments and that's the last option. But one of the questions in the group was "why don't why have that first instead of straight away going to the medicine?"'* (Participant 2)
>
> *'….because I'd- I'd rather have no medicine and do the pain management group first and if that doesn't work then go on medicine because I don't like relying on medicine too much. Yeah, I would rather first be offered the pain management programme.'* (Participant 2)

A minority of participants were grateful that they had been offered choices in their treatment.

> *'I saw [name of physiotherapist] and he said, "how about coming on the pain- the pain management course the fibromyalgia one?" and I said, "okay yep that would be good" and I also got referred to [name of psychologist] the psychologist who was here at the time.'* (Participant 3)
>
> *'So, when I had the option of doing erm, a pain management course here, erm, originally, they put me on the pain management, or I could wait a few months to be able to go onto the Fibro pain management. So, because I'd been diagnosed with the Fibromyalgia, I decided to wait and do the specifics.'* (Participant 6)

4.2 Superordinate theme 2: Ambivalence about group setting

All participants contributed to this theme. Many participants expressed their anxiety about attending a group programme with some commenting on their reasons for disliking groups e.g., finding it difficult to trust, concerns about confidentiality, concerns about being understood. Several participants commented that they would rather have individual psychology therapy than group work in the future. However, these comments are tempered by near unanimous approval of groups allowing them to meet other people with fibromyalgia. Participants expressed a sense of community and being understood that was valued by all. Despite this community atmosphere there was a feeling amongst the participants that there were differences between members of the group. Participants tended to feel either that they were better off than other members of the group (in terms of symptomology, disability, and resources) or that they were struggling the most and needed additional support. For some participants this led to an 'us and them' mentality.

4.2.1 Ordinate theme 2.1: Anxious in groups

Almost all participants said that they were '*not good in groups'* and that when they saw that they had walked into a group setting thought *'I just want to turn around and walk out'*. Opinions varied between the participants as to why the group setting provoked such anxiety, but all could be condensed into the concept of not feeling secure because of *'not knowing what to expect'.*

> *'I wasn't really sure what (pause) what to expect I was a bit nervous when I came in, just thinking "oh…"'* (Participant 1)
>
> *'so you're just walking into a big field and you know there's no fence around you to help you feel secure and stuff.'* (Participant 4)
>
> *'But, you know, I think if they'd have told me it was a group to start with, I probably wouldn't have set foot in the room. So, maybe it was for the best that I wasn't told that it was that… that, you know…'* (Participant 5).

A significant minority of participants noticed the anxiety and hesitancy of some group members but did not feel that there was anything they could do to alleviate this.

> *'Yeah but I think the group were brave to do that but for me I wasn't able to because my trust has been broken in the past…I did not know whether it was going to stay in the group or go outside the group.'* (Participant 2)
>
> *'One or two who didn't, sort of, say a lot (pause)…but um you know it that- if they don't feel comfortable enough to then obviously there's nothing you can do about that…you can only offer like they did to go and speak to somebody if you want to.'* (Participant 3)

One participant noticed that some group members were more dominant and tended to monopolise the conversations. They were content to '*sit on the edge'* and not get involved.

> *'But obviously if you go into the group and you're quiet to start with, there's that many loud people in there that want to speak out, that you do sit at the back and you do let them speak first. Because, you know, they like to rule. Some like to rule the group and think that they know it all.'* (Participant 5)

4.2.2 Ordinate theme 2.2: People with fibromyalgia understand

This was the area that participants spoke about most often and all contributed to this theme. Participants felt that being amongst a group of peers gave them access to a community of people that they had been lacking. Participants spoke about feeling lonely, isolated and like they were the 'only one' with fibromyalgia and contrasted this with the pleasure of belonging to a group again.

> *'like I said it is it was a lonely place, for two years because I didn't know anybody who'd got it'* (Participant 1)
>
> *'It's just like, like I didn't know anyone else had fibromyalgia apart from myself but then like when I see other people it's like I'm not the only person who's going through this there's other people out there who are going through this.'* (Participant 2)

Many participants reported that the other people in their life do not understand their fibromyalgia and contrasted their day-to-day experiences of being misunderstood and second guessed with the easy understanding that came during their group psychological treatment.

> *'But other people just think, 'oh, you're just being a lazy so and so', you know. But it is sometimes how it's perceived, because they don't understand that Fibro is painful, does make you more tired and more fatigued than you know, than normal.'* (Participant 6)
>
> *'I think that apart from those ladies and apart from my kids and my husband nobody else actually understands the extent (pause) of pain I'm going through (pause) they don't really understand I don't think so.'* (Participant 8)

Participants felt that they could relate their experiences of struggling with fibromyalgia with those of their peers. Being with the group, hearing about their stories and experiences gave participants an opportunity to learn from their knowledge to manage their condition better.

> *'it was nice to be with other people who also had fibromyalgia……and to make contact with them because it's not very often probably that you find other- come across other people with fibromyalgia and it was nice to- that other people would understand.'* (Participant 3)
>
> *'I think it's more a sense of relief, that you know they're going through similar things to you. And, you shouldn't be frightened of speaking out, because they're all in the same position as what you are.'* (Participant 5)

Participants also experienced inspiration from those that were coping well and the warmth of being with '*likeminded people*'.

> *'which is, once it's there "okay let's, let's, let's get you in with some likeminded people because you're not actually alone" …'* (Participant 1)
>
> *I just, just remember just having the warmth and support from the people in the group, you know and the, the people around me helped….'* (Participant 4)

4.2.3 Ordinate theme 2.3: 'High Functioning' vs 'Doom and Gloom'

Not all participants felt that the group environment was positive, and most participants contributed to the theme of 'High Functioning vs. Doom and Gloom'. These participants felt that many of their peers in the PMP group had negative attitudes and appeared depressed in mood. They contrasted themselves with these 'negative' group members feeling that they were in a better position or were coping better than the majority. A minority of participants considered this difference to be one of attitude that the 'negative' group members were responsible for in some way.

4.2.3.1 Subordinate theme 2.3.1: Negativity

One of the participants particularly noticed the negativity of the group coining the description *'doom and gloom'* and referring to a kind of 'negative camaraderie' that encouraged group members to focus on their negativity.

> *'I can remember sitting next to a guy and he said (pause) "are you- what are you here for?" and I said, "oh fibromyalgia" and he said… "there's nothing they can tell me" he said, "I might as well go home and weight train" I was like "what?" and you've got a back problem! And he'd gone by lunchtime.'* (Participant 3)
>
> *'Whereas they, you know… if you're in an environment where everybody is doom and gloom, and got something wrong with them or whatever else, then you're unable to… you can't see the light at the end of the… you can't even see the tunnel [laughs]. You're just in the pits of doom, maybe.'* (Participant 7)

Two participants felt that the negative attitude of some of their peers made it harder to cope as it was difficult to manage other people's emotions when they were struggling with their own.

> *'Other people, you know. People that you don't know, and I didn't know who they were, what they did, and how they were coping with this day and that day, you know – did I want to know what their life was like? When you're coping with your own, you don't want to know anybody else and what they're doing.'* (Participant 5)
>
> *'But she said it was a shame, because of course, if someone like me sat in the room and gave the flipside of how to manage it, it would help. But, I said, 'I can't take on ten people, I'm not… I don't...', and you know, some people would say, I don't know, 'she's not got Fibro because she doesn't feel like we do', but I know that's not the case with such a wide range of symptoms and it's all about, we can all have different thresholds can't we, and resolve of how to manage life?'* (Participant 7)

Another participant thought that the 'negative' participants were less likely to try coping methods described in the group.

> *'and even sort of talking to them and trying to (pause) say to them that actually doing some exercise does help but just find what's right for you…you know (pause) um it was quite hard I found that people- some people were very reluctant to, to do that.'* (Participant 3)

4.2.3.2 Subordinate theme 2.3.2: 'I'm not like them'

Half of the participants commented on how they felt different from their cohorts. For some this was because they were coping better.

> *'I think some people needed to (pause) talk about how they felt about their fibromyalgia and to perhaps let go of some of that, which I'd probably had a little bit more time to do…because I'd had it for longer.'* (Participant 3)
>
> *'Not one of them came up with a positive side. And every time I put my hand up or whatever, to say something positive, I'd kind of get… they'd all look at me as if to say,*

> *'how dare you come in with that kind of mentality, don't you know how it feels?', or I don't know. It just… yeah, I was not comfortable at all.'* (Participant 7)

Others felt that they were suffering less from symptoms or were less disabled than others.

> *'I said, 'I must admit, when I did the Fibro pain management course, compared to some of the candidates', I said, 'I actually felt, almost fraudulent' because, I wasn't walking with a stick or a frame, I wasn't spending days and… what I class as… well, would class as days and days in bed.'* (Participant 6)
>
> *'although at the time because I worked I couldn't fit in the things that you know people I was with didn't work I don't think anyone else on the course worked so they do a bit of hoovering and then lie on the sofa didn't really (chuckles) fit with me at work.'* (Participant 3)

One participant felt that being younger meant that they were too different from their peers.

> *'…and when I went it was alright but no one was my age which I didn't like they were a lot older than me and I was the youngest and I didn't go to a lot of them because I had college and it (pause) clashed.'* (Participant 2)

4.3 Superordinate theme 3: Making sense of and reactions to psychological approaches to fibromyalgia

After their psychological treatment, all participants attempted to make sense of their experiences and of how they felt. Participants focused on the parts of the programme that had the greatest impact on them. All participants were able to describe the impact of their treatment or the changes they had made for the better. Many participants described poor practice, feeling let down and thinking that psychological treatment was a '*waste of time*'. Two participants felt that cognitive behavioural therapy (CBT) techniques they experienced on the PMP were negative because they felt they were being told that their symptoms were '*all in their head*'.

4.3.1 Ordinate theme 3.1: Psychological approaches are a waste of time

Some participants felt that the content of their psychological treatment was *'empty information'* as they did not learn anything that they did not know already.

> *'So, it was just a- the- when I say, 'empty information' it j- I just meant by a- they didn't teach us anything we didn't know because what they were saying we, we were we've been through it, going through it or it was a bridge we'd crossed or…nearly crossing so yeah it was just like hmm, like this is a bit like, you know (pause) it doesn't help at all'* (Participant 3)
>
> *'It's like you know whatever they're saying we already know what you're telling us we already know that we've done our research. Tell us something that we don't know (pause) why is, why is there out there that will help us to be normal?'* (Participant 8)

Some participants felt that they were expecting more from their treatment and that it was a box-ticking exercise.

> *'I thought "no disrespect but you've gone through how many years of university to sit there and listen to someone" …" I can talk to a friend or a family member" …that can sit there and listen" like you want a bit more interaction like you know.'* (Participant 4)
>
> *'So, I just found it very… I found it was a box ticking exercise, the first time around. I just thought, 'I'm here because you're going to tell me this, this, this and this. And, once you've done all that, that's it'. I was out on my own, and I didn't find that helpful at all.'* (Participant 6)

Finally, all participants including those that did not speak negatively about the course found it difficult to remember aspects of their psychological treatment good or bad.

> *'I can't really remember (pause) much about it really.'* (Participant 1)
>
> *'um (pause) gosh (long pause) there was quite a bit and I can't remember the rest (long pause) I can't remember the rest sorry.'* (Participant 3)
>
> *'they went through what pain is, how to manage it (pause) medication (pause) and we had a few tai chi light exercise (pause) that's all I can remember.'* (Participant 8)

4.3.2 Ordinate theme 3.2: Let down by professionals using psychological approaches

Most participants had experienced disappointment in the mental health professionals providing their psychological treatment. Due to the multidisciplinary nature of the PMP this included physiotherapists and anaesthetists, professionals not usually on the front line of mental health treatment. This may explain the participants feeling that their clinicians were not competent or knowledgeable enough.

> *'Cause sometimes when you have um (pause) people like that in uh (long pause) in a, in a counselling session (pause) they're not equipped to answer questions because they're a psychologist they don't know anything about fibromyalgia…cause they haven't studied it so yeah, you're not even going to be inclined to get any (pause) uh support back from that either so yeah it doesn't really, it doesn't really help.'* (Participant 4)
>
> *'Cause to be honest you know all of us who are either suffering with fibromyalgia or any other chronic pain we know better than the doctors to be honest!'* (Participant 8)

Two participants felt abandoned by the professionals providing their psychological treatment. Either because the professionals left their job or because they felt they were pushed away or discharged too early.

> *'Yeah so- I have had it like I've had different psychologists but like they just didn't want me like I've had four different ones and after four weeks I've got discharged (pause) but they don't understand that I'm not going to trust in four weeks' time (pause) that's the impact I have.'* (Participant 2)
>
> *'we did have a psychologist come in (pause) now the one that worked here I think had was just leaving cause she left part way through the course I think (pause) I'm sure she left part way through the course…and she just had- we just had one session with her I think because obviously there was nobody else at the come to come and take- she'd either just left or was just leaving I can't remember now.'* (Participant 3)

Participant 2 had particularly difficult experiences of mental health professionals finding some to be dishonest and unprofessional or showing prejudice towards them.

> *'I had a mental health assessment and the woman literally just lied on the discharge paper cause I told her stuff, she didn't write on it (pause) she just lied and then like she kept saying "you don't need it, you don't need it" then I said, "I don't want it then"'* (Participant 2)
>
> *'There was one negative with the [name of a hospital for children] psychologist…she, she just used to ask too many questions about my religion and like…and like you, you can tell when someone's racist… she kept on saying "are you oppressed?", "did someone force you to wear a scarf?", "did someone do that?" …this was at the end she started asking me.'* (Participant 2)

4.3.3 Ordinate theme 3.3: Psychological treatment ingredients

All participants were able to remember something of the content or method of their psychological treatment. Whilst all were able to remember positives of their treatment a significant minority felt that the psychological treatment was forced on them and reacted negatively because of this. The participants spoke most about the pleasure of talking about fibromyalgia and learning from the educational elements of the treatment they received.

4.3.3.1 Subordinate theme 3.3.1: Professionals trying to help

Despite the negative experiences described in Section 4.3.2 most of participants could identify positive practice from the professionals involved in their psychological treatment.

> *'it was a special group cause although you had your psychologist teaching you had nurses around you as well…and people from pain management there with you… who would step in and help and do certain things throughout uh the programme…'* (Participant 4)
>
> *'And, just asking you, and then speaking through how you can actually cope with your everyday bits and pieces. They were very good, very good to speak to and everything.'* (Participant 5)

Two of the participants spoke about having their treatment tailored for them and valued being treated as an individual.

> *[of CAMHS psychologist] 'And then like we used to talk through like writing and cards and stuff because like I never used to speak…and then because I don't want to speak because I was scared… and my confidence was always quite low so like she used to play games with me and cards just to show that she's not something to be afraid of.'* (Participant 2)
>
> *'But I've never felt like that. I think everybody that I've seen has seen it at face value, and not… I don't think I've ever… no-one's ever said to me, 'oh, just…', I don't know, 'that's your Fibro', or whatever. They always seem to treat me as an individual and look at the other alternatives.'* (Participant 7)

4.3.3.2 Subordinate theme 3.3.2: CBT 'rammed down your throat'

The term 'CBT' is not explicitly mentioned in PMPs (BPS, 2013) but nevertheless remains the backbone of psychological treatment. Some participants noticed the principles of CBT at work during the programme and reacted strongly against it. There was a feeling with two of the participants that professionals were attempting to get them to think more positively.

> *'there was an element of sort of like cognitive stuff so sort of being in the supermarket and you've got I can remember them saying you've got pain and trying to think of something different and…(inaudible) duh, duh, duh, duh.'* (Participant 3)
>
> *'It almost sent you on the course because they're trying to steer your thought process towards positive and you know, exercising and all the rest of it.'* (Participant 7)

When participants noticed the CBT technique of 'cognitive restructuring' they felt that they were being told that their experience of pain was '*all in my head'*

> *'But I think it's because – and I can only talk from a personal experience here – I decided I didn't like the way it was being put across, and that erm, I almost felt like I was being told it was all in my head. Which, I know it wasn't.'* (Participant 6)

> *'Because I know it's not only me with things, it's not in the head. That, that's another thing when doctors say it's in the head it really does (pause) bring you down cause we know it's not in the head.'* (Participant 8)

Finally, Participant 6 found the focus on cognitive and behavioural change very off-putting.

> *'But that's what did me for that first course. But it wasn't… it was very different when we did it with the Fibro. [what was different?] I don't know. Perhaps I took it… it wasn't so much… I don't want to say, 'rammed down your throat', because that's the wrong… but do you know what I mean? It wasn't pushed at you so much. And I think more because it was perhaps, a group, than when I did it before, it was individual.'* (Participant 6)

<u>4.3.3.3 Subordinate theme 3.3.3: Opening up and offloading</u>

Almost all participants spoke about their experiences of talking about their lives, relationships and symptoms with mental health professionals and peers. Participants identified two ways that talking supported their mental health while they were receiving treatment: opening up and offloading. Participants realised that they rarely spoke about their experience of fibromyalgia valued the opportunity to talk.

> *[of speaking to a counsellor at work] 'it was a good thing that I had something because I didn't have anything else so I had something um (pause) and for me to be very open and honest with them (pause) um has you know, has maintained me to still, to still be working there'* (Participant 1)
>
> *'so, I think uh feelings were discussed, and you know how we view things and how we perceive things, how we deal with things uh emotionally and physically and how it can have an impact on you so that really, really helped yeah.'* (Participant 4)

For two participants talking to other people was a chance to *'offload'* some of the emotions they had kept bottled up.

> *'the person that I was speaking to at work was just someone who was just sitting listening really…for me just to (pause) you know spout off about how much I hate fibromyalgia and all those kind of things really'* (Participant 1)
>
> *'so, you know swear as much as you want, say what you want they understand they won't give you the eye "oh she's in that mood" …they know because you're in that mood you're getting it out of your system (pause) it was good'* (Participant 8)

Two participants gave a clue as to why all participants valued being a member of a community or opening up and offloading: it is hard to talk with family or friends.

> *'They're outside the box. You've got your family, they cope with the everyday, but then you've got somebody outside that's looking in, and they can tell you, 'this is the way I cope'. And it's good that you've got somebody outside that box that can tell you a little bit more, and somebody else that you can speak to like that'* (Participant 5)
>
> *'So that does help, I think that group is helping me you know when I'm having one of those days and I go "I can't share it with the kids I don't to, let me share it with the group and get it out of my system" once you type it you do feel (chuckles) you do feel better.'* (Participant 8)

4.3.3.4 Subordinate theme 3.3.4: Learning about fibromyalgia and management techniques

Most participants discussed learning from the expertise of professionals during their psychological treatment. Participants found that psychological treatment provided them with up-to-date and reliable information about pain and fibromyalgia.

> *'that's quite useful cause then you keep up to date with what might help fibromyalgia and I think that's important for people, otherwise you're still left- if you don't have that continuity and people informing you about things that have come out…you get left with whatever you've got at that particular moment or that particular time.'* (Participant 1)
>
> *'I learnt a lot off that, and how to sort of, utilise the information I'd got. And, in some ways, how to just totally ignore the information I had.'* (Participant 6)

Participants learned specific methods of pain management such as cognitive therapy and pacing.

> *'I mean, they didn't just do the physical side, they did help with the mental side of it as well.'* (Participant 5)
>
> *'We had… we had sessions on learning to pace. Pace yourself with what you did, and how you go about doing things. So you know, if it's the simple thing that… as it was put, if I remember along the lines – you go around the house on a morning with the duster, it might have took you, you know, half an hour to do the whole house a while back, but you know, one room can be… or a couple of rooms, is enough. If you're starting to feel you're flagging a bit, then stop, have a break, or change the job or the role that you're doing.'* (Participant 6)

A significant minority of the participants found learning about relaxation breathing, mindfulness and meditation to be beneficial to coping with their symptoms.

> *'then the one big thing that [name of psychologist] did was say "it doesn't matter" she said, "it really doesn't matter… if my mind wanders it doesn't matter, I can just bring it back to the tape and that's it" and that really helped just that one thing really helped, and I found the mindfulness very useful (pause), so I still do that…'* (Participant 3)
>
> *'We'll sit in, we'll do exercises, but you can sit and do them, sitting down. You haven't got to get up. We'll do these breathing exercises, but you know, as you're doing some of these exercises, we'll talk to you and see how you're feeling and that', and that really did help.* (Participant 5)

Finally, most participants remembered their experiences of being invited to try different exercises during the PMP though the participants experienced the exercise differently.

> *'They obviously a- you know, advised me possibly to take up, you know, maybe yoga, tai chi…all those kind of things, which is what I tried but for whatever reason my body just didn't accept it um and that actually while I was doing the tai chi (pause) um the pain was just…intense and I thought I can't, I can't go through it cos I need to enjoy it'* (Participant 1)

> *'You know, they did used to bring people in to have a talk. I think… so the last person that came in, she did something for… just sitting there and doing a laughter yoga. And it's so weird. You don't expect to sit there, and just sit there laughing at each other, but when somebody starts and you listen to them laugh, then you start, you think, 'how stupid are people?'. But it does help, actually.'* (Participant 5)

4.3.4 Ordinate theme 3.4: Outcomes

All the participants spoke about how their psychological treatment had impacted on their lives, symptoms, and mental health. Each participant took something positive away from the programme and no participant was entirely negative about their experience. Participants spoke about the changes they had made to help improve their self-care and they appeared to have a developed confidence about managing their fibromyalgia. As with the theme of ambivalence in Section 4.2 participants experienced contradictory feelings about the outcome of their psychological treatment, such that participants discussing positive outcomes also spoke about the negative impacts of treatment. Five of the participants felt that the PMP would be beneficial for the mental health of people with fibromyalgia.

> *'but I guess out of- out of all of it, it would be something that would be beneficial for people in the future, from my own experience'* (Participant 1)
>
> *'I'd say anyone who's got Fibro, can get on the Fibro pain management course, then they should. Because it was just so informative if it's something you don't know about, and you can take so much away with you, to either store until you need to use it, or to use it.'* (Participant 5)

Several participants felt that the treatment had made a difference to their pain, either by reducing it or allowing them to think more clearly when it worsened.

> *[has the course made any difference to your fibromyalgia?] 'Yes, I'm not in so much pain as I was, other things happen but I'm not in so much pain. I learn now how to ah (pause) use my body itself……to ease certain pain um and even with an ordinary person I'm like- they'll say "oh this hurts" I'm like "oh well do this" and they're like "oh yeah that helps!"'* (Participant 3)

> *'Mental health has been, against my fibro, has been a lot better. I admit that. Whereas my Fibro is concerned, it's… because, I try to be positive, and because I know the answers – she says – and I know how to deal with them better, then I've found that has been a lot easier.'* (Participant 6)

4.3.4.1 Subordinate theme 3.4.1: 'A positive mindset'

Most participants spoke about a change in their thinking after receiving psychological treatment. This change expressed itself in different ways from becoming more *'positive'* or *'confident'* to increases in self-compassion and kindness.

> *[has the PMP changed your views on yourself or fibromyalgia?] 'It gives you a different mindset altogether, doesn't it, really? You know that if you're… you know that you're going to be in a certain amount of pain, so you… it's trying to get into that mindset, 'I'm not going to let it get to me, I'm going to go and I'm going to do what I need to do, every day'* (Participant 5)
>
> *'But um family been saying you know "you find it hard sit down and do it" cause you can sit down and do it I go "no I ain't going to do it- sit down no" …" I'm going to still try; I'm not going to give up"* (Participant 8)

Participant 7 explained their new positive mental attitude in a particularly evocative way.

> *'you could look at it that your brain is, I don't know, it's like the archives of a giant library or something. And, I have all my little drawers where there is all the stuff about Fibro, I know that they exist and I know it's rubbish, and I know it makes me feel like crap. But what I do is, I try and shut those drawers, and then open the positivity drawers [laughs], and go, 'I can do this.'* (Participant 7)

Two participants experienced positive changes in their attitude through increases in confidence and being able to assert their needs.

> *[of the teaching about assertiveness] 'I liked that bit because like (pause) I used to do everything for everyone so now like I pace it at my own pace and I go "if I can't do it I'm not going to do it and I'll do it when I can"* (Participant 2)

> *[What was helpful about it (a third sector MH group)?] 'Ah just (pause) it was helping you to become a better person, like if you know you can't do something but you're such a kind person you always say "yes" you don't learn to say "no" so they teach you, you know "if you can't do x, y, z don't push yourself because you're just going to put pressure on yourself knowing that you can't do it having to cancel or say "actually no I can't actually do this"" you know… yeah it was positive in those aspects, so yeah again things like that you remember.'* (Participant 3)

Finally, several of the participants noticed that their self-perception had changed. This new view of themselves allowed them to be kinder to themselves and experience self-compassion.

> *[have you noticed any changes in the way you view yourself or fibromyalgia?] 'Yeah… not beating myself up so much. Stop and give myself time, don't beat myself up uh stop trying to push through things uh trying to get things done…you know.'* (Participant 4)
>
> *[have there been any changes in how you view yourself or Fibromyalgia] 'Yes. I certainly view Fibromyalgia very different, because I have a better understanding of it. What it is, and sort of, what it does. I know with… I listen to myself more. I listen to what my body says, 'look, you've done this for a bit now. Enough, have a rest', or… do you know what I mean?'* (Participant 6)
>
> *'Other people can do as much as they can and give you medication and send you on these courses, but the main person who can help you, is yourself.'* (Participant 8)
>
> *'I- the only thing I'd say (pause) since the group when I have those days where I feel like crying and screaming and yelling (long pause) I'd say I tell myself "I'm not useless, I can get through this"* (Participant 8)

4.3.4.2 Subordinate theme 3.4.2: 'I just take it at my own pace'

Following psychological treatment most participants found that they changed how they managed their fibromyalgia. Some of these changes were based on pain management strategies taught in the PMP (see Section 4.3.3.4) for example pacing or relaxation.

> *'Like with fibromyalgia like you can't do everything in one go, you have to take breaks and sometimes you have to say no even if someone's giving you too much jobs to do in one go…that's what I learnt… because I used to do everything in one go and now I don't…'* (Participant 2)
>
> *'It's like when I feel the uh the pain is really too much (pause) I tell myself "I remember being in the group when he says body tells you to rest you rest" I do no matter I'll just give up and I'll go, go to my bed and I'll rest. Cause the old me is "something needs to be done it needs to be done"* (Participant 8)

Most participants found that they had become calmer post-treatment and enthused about the relaxation and meditation skills they had been taught.

> *[on what supports her fibromyalgia] 'yeah um (long pause) and relaxation…meditation big, big one meditation yeah…amazing, it really, really helps.'* (Participant 4)
>
> *'So, doing them breathing exercises, showed that everything can relax, and you feel everything going… it's just brilliant for anybody that's got any sort of pain or anything else, it takes you away from it all.'* (Participant 5)

Two participants' treatment included a focus on their sleep, and both commented on the changes they had made post-treatment.

> *'the biggest one for me I would say would be the mindfulness with [name of psychologist] and that was a huge thing for me being able to come off the sleeping tables and at least get some quality sleep.'* (Participant 3)
>
> *'Yeah, I think stuff like, I probably changed my sleep environment, like I say, I started wearing ear plugs, I made sure that my… I think I doubled up my curtains to make it more blacked out in my bedroom. Erm, definitely took heed of the whole, 'not having caffeine' … little changes like that helped.'* (Participant 7)

4.3.4.3 Subordinate theme 3.4.3: 'I didn't really get much from it'

Most participants experienced an aspect of their psychological treatment as negative and one participant felt that the treatment had actually worsened their fibromyalgia. The biggest difficulty experienced by participants was simply that they felt that there had been no change.

> *[did psychological treatment change the way you view yourself?] 'That- no because I still don't have the confidence or belief in myself…it's taking time because I haven't had that mental health support yet.'* (Participant 2)
>
> *[on seeing a CBT therapist] Yeah (pause) 'I didn't really get much from it so there was nothing to miss…it's not like I thought "oh this is really great I can't believe I'm not going to have it anymore"* (Participant 3)
>
> *'Have I found myself changed? Um (long pause) to be honest no (pause) apart from in the back of my head if I need to let it out, I let it out in the group (pause) other than that.'* (Participant 8)

Participant 7 found peers on the PMP to be excessively negative and contributed considerably to Section 4.2.3.1 on negativity. They also spoke about the deleterious effect of the PMP on their mental and fibromyalgia symptoms and how they had left treatment early.

'*But they allowed me to bow out. I met the Psychologist that was running it and just said to her, 'look, my mental state is so positive, but that doesn't mean it's not fragile, so if I sit in a room with 10 people who are literally just moaning and whinging and don't want to look for a solution…', which is what I felt, which is why they were on the course.'* (Participant 7)

> *'But they were all just arguing with it constantly, and I just said, 'look, it's no good for me sitting in there'. It was a bit like you know, I felt like, 'we should all just make a suicide pact' [laughs], 'just leave because we can't cope, because we've got Fibro', and I didn't want to be part of it.'* (Participant 7)

Finally, Participant 1 tempered praise with a reminder that they had not received psychological treatment when they needed it (see Section 4.1.1).

‘Yeah, but it would have been (pause) yeah it would have been very, very useful, pretty much straight away or certainly within six months (pause) and I think that would have helped because it helped when I was there.’ (Participant 1)

5. Discussion

5.1 Summary

The aim of this research study was to describe and explore the experiences of psychological treatment of people with fibromyalgia. The participants contributing to this research described the psychological treatment they received. Most treatments were provided by the NHS in pain management clinics via pain management programmes (PMP) and through one-to-one appointments with psychologists. Additional psychological treatments were provided by workplace counsellors, college mentors, cognitive behavioural therapists and third sector groups. The experiences of all psychological treatments were analysed together to provide themes across the topic of 'psychological intervention' rather than group delivered PMPs only.

The analysis of participant interviews produced three superordinate themes:

Frustration and uncertainty about psychological approaches
Ambivalence about the group setting
Making sense of and reactions to psychological approaches to fibromyalgia

Participants greatly valued the opportunity to meet and speak with peers with the same diagnosis and symptoms as them with all participants adding to this theme. However, participants did not respond uniformly to any other aspects of their psychological treatment, including the necessity of receiving treatment for their mental health. This ambivalence was present in multiple strands of the analysis e.g., 'doing what I'm told vs. choosing my treatment', 'high functioning vs. doom and gloom', 'let down by professionals vs. professionals trying to help'. This was also true of the outcomes of treatment with some participants reporting their dislike for PMPs whilst also speaking of the improvements they have seen in their mental health and symptomatology.

5.2 Where this research fits within the existing literature

This study provides information about the experiences of people with fibromyalgia that have not previously been investigated. Whilst qualitative studies have previously explored the experiences of people with fibromyalgia in health services in general, this is the first study to focus specifically on experiences of psychological treatment. As psychological treatment for fibromyalgia is one of the evidence-based interventions for fibromyalgia, it is important that this group of services users describe how they experienced this treatment. This study will help to inform the clinical work of mental health professionals working with people with fibromyalgia and may allow for potential developments for services designed for this client group. It may also provide support for clinicians providing evidence-based treatments such as cognitive behavioural therapy (CBT), about which participants expressed a dislike.

5.2.1 Fibromyalgia and peer support

One of the strongest emergent themes from the analysis was the relief participants experienced at meeting people that shared their symptoms and diagnosis. This finding tallies with previous qualitative research looking at the experiences of people with fibromyalgia. Sallinen et al. (2011) found that after receiving a diagnosis of fibromyalgia people struggle to share their experiences with their loved ones and are forced to rebuild supportive relationships with people experiencing the same symptoms. Ashe et al. (2017) reported that people with fibromyalgia value the support of their ‘fibro-family’ as this group of peers understand their needs and are not judgemental. Male participants also reported that the expectations and cultural norms of support group attendance presented a barrier to their attendance (Ashe et al., 2017), an important finding considering the lack of male participants in this study. Literature on the effectiveness of peer support interventions for people with long-term health conditions on psychosocial adjustment and morbidity present a mixed picture. There is weak evidence to suggest that people with long-term health conditions receive some benefit from peer support interventions, but a lack of methodological rigour prevents further conclusions being made (e.g., Dale et al., 2012; Hoey et al., 2008; Parry & Watt-Watson, 2010).

5.2.2 Fibromyalgia and ambivalence

The experience of ambiguity, of conflicting emotions and symptoms is a feature of existing research reporting the accounts of people with fibromyalgia (e.g., Mengshoel et al., 2018; Sim & Madden, 2008; Toye et al., 2013). Mengshoel et al. (2018) posit that the ambiguous nature of fibromyalgia as a diagnosis, coupled with the ambivalent attitudes of health professionals towards people with the condition creates ambivalence in people with the condition. Miller and Rollnick (1991) assert that ambivalence can translate into a lack of motivation towards treatment and therefore increased non-completion of treatment. Merton and Barber (1963, p. 6) suggested that ambivalence, in a sociological sense, refers to '*incompatible normative expectations of attitudes, beliefs, and behaviour assigned to a status or to a set of statuses in society'.* Their suggestion is that when individuals have conflicting sets of normative behaviours, they experience ambivalence. In people with fibromyalgia, this could be expressed in terms of societal norms of seeking treatment when sick versus norms advocating fulfilling responsibilities. Weingardt (2000) applied the sociological theory of ambivalence to psychotherapeutic practice, suggesting that '*structural*' attributes of health treatment such as expectation of continuity, dependence on healthcare providers and questioning the motivation of healthcare providers promote ambivalence and stifle therapy. The sociological theory of ambivalence dovetails with psychological models of shame, particularly that of Gilbert (e.g., 2017) who suggested that shame consists of 'external shame' based on negative beliefs of how others view a person and 'internal shame' where the person believes themselves to be deficient. For people with fibromyalgia this could present itself as shame generated by the belief that others believe them to behave in contradiction to societal norms (by not recovering after seeking medical advice) or through beliefs from the individual that they should have recovered. The cognitive dissonance (Festinger, 1957) provoked by this shame and the individuals' positive feelings about themselves may begin to account for the ambivalence in the accounts of people with fibromyalgia.

5.2.3 Social comparison theory

The finding that participants considered themselves to be better off than their peers on the PMP can be understood through Festinger's Social Comparison Theory (1954). Festinger's theory asserts that humans compare themselves to their peers to evaluate their social position and relieve uncertainty. Buunk and Ybema (1997) expanded social comparison theory by categorising directions of social comparison. They suggest that in addition to upward/downward comparisons there is also a process of upward/downward *identification*, that is likening themselves with peers who are coping better or worse. Affleck et al. (2000) examined social comparison amongst people with fibromyalgia and found that those that compared themselves positively to their peers experienced less pain and improvements to mood. These studies suggest that positive downward social comparison helps alleviate the impact of pain in people with fibromyalgia.

5.2.4 Qualitative research on group programmes for long term health conditions

There is a wealth of qualitative research on the experiences of people with long-term health conditions (LTCs) of group interventions that can be compared to this study. Many studies (e.g., Barlow et al., 2009; Brandão et al., 2018; Dwarswaard et al., 2016; Esbitt et al., 2015; Finlay & Elander, 2016; Johnston et al., 2012; Larsen et al., 2015; Maheu et al., 2015; Wright, 2013) found that group participants valued the opportunity to compare their experiences to those of their peers. This was both in terms of providing practical advice and knowledge along with the development of relationships and a community around their condition. This finding appears to suggest that people with LTCs (including fibromyalgia) value the opportunity to meet peers regardless of the health condition with which they are diagnosed. The literature suggests that people with diabetes (Esbitt et al., 2015) and chronic pain (Larsen et al., 2015; Moore & Martin, 2015) experience similar feelings of ambivalence towards their fellow group members as found in this study; for example, some participants felt that their peers were coping worse than them as they did not take responsibility for managing their health. In terms of the experience of the psychotherapeutic elements of the programmes several studies (Dwarswaard et al., 2016; Johnston et al., 2012; Moore & Martin, 2015) found similar results to this research, with participants feeling empowered and that they had learned ways to change their perspective for the positive. In their research on the experiences of people with breast cancer of group psychotherapy Brandão et al. (2018) found that participants noticed the positive attributes of their therapists (as in subtheme 3.3.1: ‘professionals trying to help’), however, participants did not mention negative experiences of psychotherapy (e.g., ‘CBT rammed down your throat’).

5.3 Contribution of findings to the literature

For psychologists and mental health professionals working with people with fibromyalgia there are several findings from the analysis that could be applied in clinical practice and to service improvement.

5.3.1 Clinical relevance

5.3.1.1 Clarify the aims of psychological treatment

Participants found the purpose of psychological treatment to be confusing and went along with treatment without understanding the reasons for their attendance. It would be useful for clinicians to explain the role of mental health professionals and the skills they can use to help. The therapeutic relationship could be improved if clinicians were to clearly discuss the purpose of psychological therapy for fibromyalgia. This strategy could be further enhanced with the provision of clear information handouts, to mitigate the memory issues associated with fibromyalgia and because several participants appreciated the resources, they received during treatment.

5.3.1.2 Addressing ambivalence

The results of the analysis appear to show that people with fibromyalgia are ambivalent about psychological treatment, and previous research (e.g., Rodham et al., 2010) has shown that this service user group is wary of the implication that their condition is 'all in their head'. Mental health professionals involved with the treatment of people with fibromyalgia would do well to address these concerns immediately, as they are likely to emerge at some point during therapy. Creating a consensus for the benefits of psychological treatment with the physical health clinicians involved in the client's care would help to support this conversation. Weingardt (2000) suggests adapting sociological approaches of ambivalence to ensure attendance at future appointments and enhance therapeutic work.

5.3.1.3 Pain psychoeducation

One finding of this study was that participants appeared to value learning more about their condition. People with fibromyalgia experience long delays in receiving a diagnosis and this study suggests that during this time they research their condition and come to their own conclusions. This necessarily gives rise to misconceptions and confusion about the experience and neurobiology of pain. Participants in this research commented on mental health professionals lack of knowledge regarding pain and their lack of faith in them because to this. Refresher training in the neurobiology of pain for mental health professionals, potentially involving experts by experience, would help to demonstrate this competence during psychoeducation interventions. The provision of psychoeducation about pain has some support as a strategy for managing fibromyalgia (Arnold et al., 2016). This psychoeducation would help to alleviate the uncertainty of people with fibromyalgia about the nature of their pain and increase their faith in the competence of mental health professionals.

5.3.2 Service improvement

5.3.2.1 Faster access to psychological treatment

Participants within this study felt that they did not receive psychological treatment when they needed it. Research suggests that longer durations of untreated mental health issues (such as anxiety or depression) worsen outcome for clients (e.g., Ghio et al., 2014; Kisely et al., 2006). Not knowing when psychological treatment will be initiated could also affect people with fibromyalgia adversely as studies have shown that they do not cope well with uncertainty (Reich et al., 2006). This would seem to suggest that people with fibromyalgia should be offered psychological treatment for their condition as soon as they receive a diagnosis, or access to a peer support group, as this was the aspect of treatment the participants most valued.

5.3.2.2 Choice of treatment

The results of this study also showed participants questioning the practice of pain management clinics prioritising medication-based treatments before psychological ones. To address this issue people with fibromyalgia accessing pain management clinics could be offered PMPs when they start treatment. Offering choice and personalised care is one of the principles of the NHS and has been shown to promote health outcomes in people with long-term health conditions (Coulter et al., 2015).

5.3.2.3 Individual psychotherapy

This study provides an unclear picture on people with fibromyalgia accessing individual psychotherapy for their condition. Whilst many participants spoke about their happiness with meeting other people with fibromyalgia, many more spoke about their anxiety about group psychotherapy. Several participants spoke about their preference for one-to-one psychotherapy. The findings of this research suggest that further research on the views and experiences of people with fibromyalgia attending individual psychotherapy is necessary to determine its acceptability.

5.4 Alternative interpretations

It was clear from the number, and speed of responses to the email promoting the study that people with fibromyalgia are interested in having their views heard. It is conceivable that this self-selecting cohort of participants represented an atypical group of people with fibromyalgia. If this view is correct it is possible that this group possessed a bias for/against psychological treatment or had their reasons to discuss the services they received. For this study it is difficult to disprove this notion, however the results of the analysis do correspond with previous qualitative research with this service user group.

5.5 Strengths and limitations

5.5.1 Strengths

The strengths of this study include the use of Template Analysis as a method of exploring the experiences of people with fibromyalgia within the context of the healthcare services they access. This helped to ground the research in the ‘real world’ allowing for attention to be focused on using the research findings to improve services for this client group. Great effort was spent in increasing the plausibility and validity of this research by using research journals, a qualitative research group and iterative creation of templates.

5.5.2 Limitations

None of the participants of this research had received psychological treatment within the last year and the length of time since the end of their treatment was not recorded. This coupled with the memory difficulties associated with fibromyalgia means that participants may have struggled to recall information and experiences from their treatment. As people are more likely to recall negative experiences (Thomas & Diener, 1990), participants’ recollections (and therefore the themes arising from them) may have been biased towards the negative. The research recruited fewer participants than planned which reduces the amount that can be learned about the services participants experienced.

Due to the short timeframe for recruitment and analysis there was no opportunity to present themes or templates to the participants to review. Participants were not asked how long they had been experiencing their symptoms or when they received their diagnosis. These details may have helped to distinguish between the experiences of the participants, for example people with a longer history of symptoms may show a greater tendency to be ‘doom and gloom’. The data primarily focused on participants’ experiences of PMPs, with experiences of individual therapy folded into the analysis. This means that the themes generated from the data describe only a small aspect of psychological treatment and that experiences pertaining to individual therapy are subsumed into the main themes are difficult to tease apart.

As the sample of this research was entirely female the experiences of men with fibromyalgia were not considered and the results can therefore not be applied to them. This is important as previous research suggests that the men with fibromyalgia have differing experiences to women with the condition (Muraleetharan et al., 2018; Sallinen & Mengshoel, 2019). In a survey of 1,163 men with fibromyalgia, Muraleetharan et al. (2018) found that respondents felt stigmatised as fibromyalgia is a condition that primarily affects women, that men were less likely to talk about their symptoms and were more likely to face barriers to treatment because of employment. The previous research suggests that the analysis in this study might have been affected by neglecting the experiences of male participants and that the findings would be skewed towards the experiences of the female sample. For example, Barlow et al. (2009), in their research with people with long-term health conditions, were more critical of group content and less willing to share their emotional experiences with other group members. Finally, the generalisability of this research because the findings refer primarily to psychological treatment provided within pain management clinics.

5.6 Directions for future research

This research could be improved upon in future studies by interviewing participants immediately after psychological intervention, to help improve recall of their experiences. Furthermore, duration of time since diagnosed should be recorded so that participants’ experiences can be analysed in the context of their fibromyalgia treatment journey. Male participants should be sought to develop research around the male experience of psychological interventions. Future research could focus on the experiences of people with fibromyalgia receiving psychological treatment in primary care, particularly within the Improving Access to Psychological Therapies (IAPT) services for people with long-term health conditions. Further work could focus on the interactions between the ambivalent attitudes of healthcare professionals towards fibromyalgia and the impact this has on those with the condition.

6. Conclusions

This research aims of this research were met with a caveat that the results may not be as transferable to other mental health settings as originally hoped. People with fibromyalgia face a multitude of challenges and it seems apparent that receiving appropriate psychological support is one of their issues. Their frustration and uncertainty about psychological approaches, ambivalence towards treatment and group work present barriers to the efficacious treatment of fibromyalgia. These barriers need to be addressed to improve the treatment and quality of life of people with fibromyalgia.

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Press Releases

New research offers insights into for pain management for people with fibromyalgia

Specialised pain management groups for people with fibromyalgia are no better than generic psychotherapy new research has found. Fibromyalgia is a long-term health condition characterised by chronic overall body pain, tiredness, and sleeplessness. Due to the long-term nature of the condition, people with fibromyalgia often develop mental health difficulties as they wait for treatment.

Fibromyalgia and similar conditions are estimated to cost the NHS approximately £3 billion a year due to the disabling nature of the condition. Fibromyalgia is estimated to affect 40 per 100,000 people in the UK. The best treatment for people with fibromyalgia is still being sought with the current best practice guidelines providing variable results.

Currently, the physical symptoms of fibromyalgia are treated in specialist pain services with both medication and physiotherapy. The mental health of people with fibromyalgia is supported through specialised groups based on cognitive behavioural therapy (CBT). Although these groups are offered nationwide there is little evidence on the effectiveness of these groups. This new research compares the difference between specialised and generic psychotherapy groups in terms of patient outcomes.

Researchers at the University of Birmingham combined the results of 17 existing research studies, to see if the specialised pain management groups offered to those with fibromyalgia are effective. All the studies focused on group psychotherapy as an approach to treat the symptoms of fibromyalgia. Each group was rated to see how close it was to the current standards.

The new research showed that the specialist pain management groups were no better at reducing fibromyalgia symptoms than ones using basic CBT. This result implies that people with fibromyalgia could be waiting longer to access specialised pain management groups when they could be accessing basic CBT groups instead.

People with fibromyalgia often struggle to receive treatment and have long waiting times for treatment, which can worsen their condition. Whilst this research confirms earlier findings that CBT is effective in treating fibromyalgia, it is the first to compare specialised pain management groups and show that they are just as effective.

The research offers important findings which will help to improve the provision of treatment and mental health services for this under-served population. Potential improvements could include supporting people with fibromyalgia to access existing mental health services or simplifying groups inside pain management clinics so that they can be run by junior clinicians. It is hoped that the research will be used by policy makers, commissioners, and mental health providers to create better services for people with fibromyalgia and improve the lives of those 1.5 million people in the UK with this debilitating condition.

Worse symptoms for fibromyalgia patients due to long/18 month wait for psychotherapy

In a study carried out by researchers at the University of Birmingham, fibromyalgia patients have described long waiting times for psychotherapy, which worsened their symptoms, leaving them anxious and depressed. Some participants reported waiting over 18 months to receive mental health support, where others received ineffective brief therapy lasting four weeks or less. Participants were particularly enthusiastic about the opportunity to meet and learn from other people with the same condition.

Fibromyalgia is a long-term health condition characterised by chronic overall body pain, fatigue, and insomnia. People with fibromyalgia report both psychical and mental symptoms due to the debilitating nature of the disease. Physical symptoms are treated in specialist pain services with medication and physiotherapy. However, the mental health of people with fibromyalgia is supported only through group pain management programmes based on cognitive behavioural therapy (CBT).

The research, undertaken by a doctoral student at the University of Birmingham, is aimed at improving the provision of mental health services for this under-served population. The lead researcher worked with a specialist pain management clinic and interviewed eight women with fibromyalgia to understand their views on the mental health treatment they had received to help with the condition. Participants had waited up to 18 months to access psychological treatment and were only referred after medication for their pain proved unsuccessful. Lead researcher Alexander Smith explained

> *"People experiencing fibromyalgia have often spend years in the NHS looking for a diagnosis. This has a detrimental effect on their mental health with many developing depression"*

Analysis of these interviews showed that there were recurring themes of ambivalence about psychological approaches, feeling understood and developing a new confidence in managing their symptoms. Whilst participants valued their psychological treatment, they also felt strongly that they were being told that their condition was 'all in their head'. Fibromyalgia is commonly misinterpreted as a psychological condition and this is a real concern for those that living with the condition.

In 2014 The NHS 'Five Years Forward' White Paper extended the provision of the Improving Access to Psychological Therapies (IAPT) initiative to people with fibromyalgia, but the researchers argue that this service is not specialised enough.

> *"This basic level of mental health support has proven effective for people with long-term health conditions in the past but people with fibromyalgia have needs not covered by IAPT,"* says Smith. *"We found that what fibromyalgia patients particularly value is being able to meet other people who are living with the condition. This is something that would be completely lacking from the NHS's proposed treatment strategy."*

The results provide key information on the unique needs of people with fibromyalgia and provides an insight into the experiences of this underserved population. This research will support policy makers and commissioners to provide appropriate and acceptable psychological treatment for people with fibromyalgia. It will also allow mental health professionals to tailor their psychological treatment to get the best results for people with fibromyalgia.

Future research in this area could focus on the experiences of people with fibromyalgia receiving psychological treatment in mental health services. Alternative topics could include exploring how participants’ ambivalence about psychological therapy impacts on the psychotherapy they receive.

Appendices

Meta-Analysis

Appendix 1: Summary of the British Pain Society Recommendations for Pain Management Programmes

1. *Graded activation guided by participant goals*: Consisting of goal setting, identification, and management of barriers to activity, and the practice of specific practical and psychological skills to produce integrated and sustainable patterns of healthy activity. (p.13)

2. *Cognitive therapy method*s: These methods are used to identify, examine, and change the impact of distressing, misleading, or restricting thoughts and beliefs. These methods are sometimes called "cognitive restructuring" and includes "behavioural experiments. (p.13)

3. *Graded exposure:* Structuring a series of practice activities in ways that are specifically designed to reduce fear and avoidance. (p.13)

4. *Methods to enhance acceptance, mindfulness and psychological flexibility*: There are a range of methods designed to enhance participant openness and willingness to experience undesirable feelings, and to loosen the influence of judgemental, evaluative and analytic thought content (p.13).

5. *Skills training and activity management:* Typical skills include relaxation, attention management methods, cognitive restructuring, mindfulness, acceptance and awareness exercises, methods for identifying, setting, planning and pursuing goals strategies for co-ordinating, scheduling and managing the rate and pattern of goal-

directed activity, skills for communication and social interaction, sleep management methods (p. 13-14).

6. *Physical exercise:* Physical exercise is helpful to increase movement, to enable increased goal-directed activity and to improve fitness and physical health. The long-term aim is to improve quality of life through changes in physical fitness, strength, endurance, and flexibility (p. 14).

7. *Education:* Education should be considered as a relatively low-intensity method that can improve knowledge and could include pain mechanisms, anatomy and physiology of pain, psychology and pain, safety and risk in relation to increased activity, advantages and disadvantages of treatments, self-management approaches & lifestyle change issues for maintaining general health (p.15).

8. *≥ 36 hours in total*: A standard PMP should be the equivalent of twelve half day sessions (e.g.12x3 = 36 hours) delivered as outpatient programmes (p. 15).

9. *Group size 8-12*: Group size varies, but most groups aim to have 8 to 12 participants (p. 16).

10. *Multi-Disciplinary Facilitators:* As part of a PMP education should be provided by all members of the multidisciplinary team using an interactive style to enable participants to raise and resolve difficulties in understanding material or in applying it to their particular situations or problems (p. 15).

British Pain Society. (2013). Guidelines for pain management programmes for adults. *An evidence-based review prepared on behalf of the British Pain Society*.

Research Study

Appendix 1: Promotional Email

Dear Sir/Madam,

You are being contacted because you recently completed a Pain Management Programme. My name is Alex Smith and I am hoping to interview volunteer participants about their lived experiences of treatment for fibromyalgia in the NHS. I am particularly interested in learning about treatments that have been helpful and unhelpful, with a focus on treatments involving mental health.

People with fibromyalgia are not often asked about their experiences of healthcare services and few are asked about what made their treatment successful or not. I am keen to find out about your experience of pain management programmes focusing on what you found helpful and unhelpful during the treatment you received. My hope is that this project will enable people with fibromyalgia to have their views heard and that this will help to improve services in the future.

Interviews are expected to last around 90 minutes but can be shortened, split or include breaks depending on your current level of pain and fatigue. To get involved with the research or if you have any questions please email me at: [redacted]. If you are interested, please read the attached information sheet which provides greater detail about the research and how your interview will be used.

Yours faithfully,

Alex Smith

Trainee Clinical Psychologist

University of Birmingham

Appendix 2: Participant Information Sheet

Participant Information Sheet

IRAS ID: **257808**

Study Title: What are people with fibromyalgia's experiences of psychological treatments for their condition?

Introduction

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement would include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask about anything that is unclear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part.

Who is carrying out the study?

The lead researcher is Alex Smith who is carrying out this research as part of a doctorate in Clinical Psychology. Supervision is provided by Dr Ruth Howard (Senior Academic Tutor at the University of Birmingham), Dr Andrew Fox (Lecturer in Psychology at the University of Birmingham) and Dr Alice Kennedy (Lecturer at York St. John University).

The study is sponsored by The University of Birmingham and has received full ethical approval from the NHS Research Ethics Committee.

What is the purpose of this study?

The aim of this research project is to explore the lived experiences of people with fibromyalgia in the NHS. We are particularly interested in learning about the treatments that have been helpful and unhelpful, with a focus on treatments involving mental health. People with fibromyalgia are not often asked about their experiences of healthcare services and few are asked about what made their treatment successful or not. We are keen to find out about your experience of pain management programmes focusing on what you found helpful and unhelpful during the treatment you received. Our hope is that this project will enable people with fibromyalgia to have their views heard and that this will help to improve services in the future.

Do I have to take part?

It is up to you whether you decide to take part in this study and deciding not to take part will not affect any treatment you may be receiving. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form to confirm that you understand what the research entails. Agreeing to join the study does not mean that you must complete it. If you change your mind during the study you can withdraw without giving

giving a reason. If you decide to leave the study up to two weeks after your interview you can ask for your interview data to be destroyed. Your decision to join or leave from the study will not be communicated to your doctor or any other healthcare professional you may be working with.

Are there any restrictions that may prevent me from participating?

You are eligible to participate in this research if you have a diagnosis of fibromyalgia, are currently attending a pain management clinic and a pain management programme (or have done so in the past). As the research will involve an interview you must be able to understand and communicate in English and be able to sit to be interviewed for 30 minutes. You must also be over the age of 18 years.

How long will my part in the study take?

If you decide to take part you will be invited to attend an interview, which will last approximately 90 minutes. If you feel that your current level of pain and fatigue will prevent you from being interviewed for this long we can include breaks, which may increase the interview time. You will be sent a copy of the transcript of your interview to check for accuracy, which may take a short while.

What happens if I am interested in taking part?

If you are interested in taking part, you can contact us by email or by phone and we can discuss any questions you may have. Contact details are provided on page 4 of this information sheet. If you decide to participate we will arrange a convenient time for us to meet for the interview. This meeting take place on NHS premises at the clinic you attend(ed). At this meeting you can ask any additional questions you have and you will be asked to sign a consent form to confirm that you have agreed to participate.

Once you have signed the consent form we will begin the interview, which will be audio recorded on an encrypted Dictaphone to ensure data protection. The interview will last approximately 90 minutes and will consist of questions about your journey through the NHS to get treatment for your condition, your experience of living with fibromyalgia and the treatment you have received. You do not have to answer any question you do not want to and do not have to give a reason. Your interview recording will then be transcribed by Alex Smith or the company *University Transcription* and any personal identifiable information will be removed. You will be sent a copy of the transcript via email in order to check that it is accurate. The audio recording will be deleted once any corrections have been made.

What are the possible disadvantages, risks or side effects of taking part?

The possible disadvantages, risks or side effects to all participants have been considered. It is unlikely, but it may be possible, that you find the interview process distressing, for example, you may remember difficulties you have experienced during treatment. If you disclose medical treatments that could be considered bad or malpractice this information will be shared with NHS Trust where the treatment took place.

The interview will also last up to 90 minutes so fatigue and pain may become issues if you are not used to sitting in one place for that long. To reduce this risk you can ask to take a break whenever you want and we can arrange a two-part interview with shorter times if you need.

It is possible that you will need to pay for travel to attend the interview(s); if this is the case for you bring a receipt or ticket to your appointment and you will be reimbursed.

What are the possible benefits of taking part?

There are no guaranteed benefits from taking part in this study but it is hoped that this research project will contribute to the literature around the treatment of fibromyalgia. It is possible that themes emerging from your interview may be used to improve NHS services in the future. It may also be potentially beneficial for you to discuss issues that you have found positive or negative, though this is not the aim of the interview.

How will my taking part in this study be kept confidential?

You will be assigned an anonymous identification number which will be attached to the transcription of your interview and your identity will be known only to members of the research team (Alex Smith and Research Supervisors). Healthcare providers currently involved in your care will not receive any information about your participation or have access to your data. The findings of the project may be published in an academic journal; to protect your identity all data will be anonymised by changing your name and other details that could identify you.

What will happen to the data collected within this study?

Information that identifies you will be securely stored for the length of the study and deleted within three months of its end. All data arising from interviews will be anonymised and stored electronically, on a password-protected computer, for a period of ten years, after which time it will be destroyed under secure conditions. Data will also be stored in hard copy format and destroyed under secure conditions after ten years. It is possible that data may be re-used or further analysed in future ethically approved studies.

The study findings will be written in a thesis for the qualification of Clinical Psychology Doctorate (ClinPsyD). Papers reporting the results of the study may be submitted to relevant academic and professional journals for publication. There will be no identifying information contained within these publications. The findings of the research may also be used for presentations or internal reports within the NHS. If you would like to receive a copy of the Final Report, please leave an email address on your consent form so a copy can be sent to you.

Who has reviewed this study?

This study has been reviewed by Research Governance at the University of Birmingham and the East Midlands NHS Research Ethics Committee. All documentation to be used by participants, including the interview questions, have been reviewed by a person with fibromyalgia.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details, please contact the research team, in writing, by phone or by email:

Alex Smith
Address: Doctorate in Clinical Psychology, School of Psychology, 52 Prichatts Road, University of Birmingham, B15 2TT
Email: [redacted]
Phone: [redacted]

If you have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Patients' Advice and Liaison (PALS) at:

E-mail: PALS@uhb.nhs.uk
Tel: 0121 371 3280
Website: https://www.uhb.nhs.uk/pals.htm

It is not expected that the interviews will cause you any emotional difficulty or distress, however if any of the issues arising from this research project are distressing you can contact your GP or other healthcare provider. Additional support can be found from the providers below:

Fibromyalgia UK support group
Website: http://www.fmauk.org/

NHS non-urgent services
Tel: 111
Website: https://111.nhs.uk/

Samaritans UK
Tel: 116 123
Email: jo@samaritans.org
Website:https://www.samaritans.org/how-we-can-help-you/contact-us

University's regulations governing the conduct of studies involving human participants can accessed via this link: s://www.birmingham.ac.uk/Documents/university/legal/research.pdf

Thank you very much for reading this information.

General Data Protection Regulations (GDPR)

The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Birmingham will keep identifiable information about you for ten years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by contacting dataprotection@contacts.bham.ac.uk.

City Hospital Pain Management Clinic will collect information from you for this research study in accordance with our instructions and keep identifiable information about you from this study until the study has finished.

City Hospital Pain Management Clinic will keep your name and contact details confidential and will not pass this information to the University of Birmingham. City Hospital Pain Management Clinic will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from the University of Birmingham and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people at the University of Birmingham who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in the University of Birmingham. Your information will only be used by University of Birmingham researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Appendix 3: Participant Informed Consent Form

CONSENT FORM

Title of Project: **What are people with fibromyalgia's' experiences of psychological treatments for their condition?**

Name of Researcher: **Alexander Smith**

IRAS ID: **257808**

Centre Number:

Participant Identification Number for this trial:

Please initial box

1. I confirm that I have read the information sheet dated .... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and will not be identified or identifiable in the report or reports that result from the research. ☐

4. I agree for this interview to be recorded using an encrypted digital audio recorder and I understand that the data will be stored on a password protected computer. ☐

Appendix 4: Interview Schedule

Interview Schedule for Participants

Structure

Following the brief with the participant information sheet and the participant signing the informed consent form the interview will proceed. It will begin with an introduction, reminding participants that they are entitled to breaks, can stop at any time and that the interview will be recorded. At 30-minute intervals the participant will be asked if they would like a short break. At the 45 minute halfway point participants will be asked if they would prefer to continue the interview or meet for a second interview at a later point. At the end of the interview participants will be reminded about the confidentiality of their recording and how to request their data be withdrawn from the study if they choose. They will also be reminded of avenues of support they can access if the interview has been emotive.

Introduction

This interview is intended to last 90 minutes in total, however it's important that you are comfortable and feel able to complete the interview. For this reason there will be opportunity for breaks throughout the interview and the interview can be divided into two parts if you require this. I will check with you throughout the interview to ensure that you are comfortable to continue, and you should let me know if you require a break sooner. As discussed in the participant information sheet this interview will be recorded. Please remember that your participation is voluntary so you can withdraw from this research at any point, without giving an explanation.

Questions

1. *What do you* understand by fibromyalgia?
2. How has fibromyalgia affected you as a person?
3. Please describe your journey through the NHS for help with your fibromyalgia? What do you understand by fibromyalgia?

4. Can you tell me about your experience of fibromyalgia treatment in the NHS? Prompt: things gone well, not so well.
5. How did you come to be in the pain management programme? (route into PMP, what they thought about it, who told them, what did they feel?)
6. Can you tell about the pain management programme? (content)
7. (What was it like for you) What were your experiences of the pain management programme?
8. How does the pain management programme fit with your understanding of fibromyalgia? (acceptability, tolerance, acceptance, confusion, contradiction)
9. Since you've been doing the group have you noticed any differences in the way you've managed fibromyalgia?
10. (Prompt about mood if they mention mood, sleep, pain, functioning, activities, socialising?)
11. Having been through the pain management programme have you noticed any changes on how you view yourself or fibromyalgia?
12. Is there anything else that you want to say?

Prompt

Can you tell me more about that?

Conclusion

Thank you for your participation in this research. As discussed in the participant information sheet the interview you participated in has been recorded and will be transcribed by myself or a transcription company with a confidentiality agreement. Should you want your data to be removed from the study you can request that your interview, and any transcription resulting from it, be destroyed up to two weeks from today. You can request for your data to be destroyed by contacting me via the contact details included on the participant information sheet. Your transcript will be provided to you to read to ensure its accuracy as soon as it has bene transcribed. If for any reason you feel that you need support after this interview you can contact any of the agencies included on the participant information sheet.

Thank you very much for your participation.

Potential Themes Arising from Interviews

- Experience of symptoms
- Seeking a diagnosis pre-diagnosis, receiving a diagnosis, post diagnosis
- Pain features Pain communication, pain language, describing pain, and fatigue.
- Coping strategies self-initiated activity, professional treatments, passivity, escape behaviours, and resignation. Bodily constraint, activity constraint and identity constraint. Pacing. Struggling, adapting, giving-up.
- Psychological problems
- Legitimacy – being believed
- Re-evaluation of life
- Peers
- Pain Management Group
- Pharmacology
- Recreation/relaxation
- Community/citizenship
- Physical health/wellbeing
- Identity Pain, long-term condition, legitimacy
- Family
- Spirituality
- Work/career/education
- Friendships/social relationships
- Marriage/Intimate relationships
- Parenting

Appendix 5a: Templates used for Analysis – Template 1

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
Legitimacy	Process of legitimising	Who legitimises Who doesn’t	
	Challenges to legitimacy		
	Authenticity		
Story of the illness	Unexplained symptoms	Not knowing	
	Diagnosis journey	Complex journey through the NHS	
	Fight against it, accept it or come to some kind of accommodation		
	Biographical disruption (when taking a more narrative approach) how do you rewrite your own history, before and after fibro.	Temporal element to themes. Start with fight, defeatist, maturing into a sense of accommodation.	

Identity	Challenge to identity	Sense that people have identities imposed upon them ‘belligerent patient’, ‘problematic patient’ ‘heartsink patients’	
	Loss and adjustment.		
	Functional & role changes		
Family	Threatening family dynamics		
Culture			
Responses	Emotional response	Frustration Confusion Anger	

	Change in activity		
	Isolation		
	Coping	Struggling Adapting Giving up	
Symptoms	Psychological impact	Mood Cognitive impact	
	Pain		
	Physical co-ordination		
	Fatigue		
	Gastric symptoms		
Treatment	Mental health	Counselling	

		Peer support Psychological Medical	
	Medication	Tablets Injections	
	Acceptability		
	Pain management groups		
	Acupuncture		
Other	Understanding of fibromyalgia		
	Conflicting information		

Appendix 5b: Templates used for Analysis – Template 2

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
What psych treatment was like	Acceptability	Ambivalence about the group setting	
	Learning techniques		
	Unmemorable		
	'I'm not the only one'	Access to community/peer support	
		Developing friendships	
		Diversity	
Impact of fibromyalgia	Mental Health	Coping	
		Giving up	
		Hopelessness/suicidal thoughts	
		Needing support	
		Not wanting support	
		Other people notice you need support	

	Emotional response	Hatred	
		Sadness/depression	
		Anger/frustration	
	Relationships	Changing roles	
		Dependency	
		Support	
		Isolation	
	Biographical	Lack of independence	
		Loss/adjustment	
		Challenge to identity	
	Activity	Work	
		Education	
		Leisure/hobbies	
	Physical	Debilitating	
Inadequacy of NHS Treatment	Complicated journey to treatment	Delays	
		Waiting/In limbo	
		Re-referrals	
		Discharge	

		No choice on which treatment you receive	
		Not a priority	
	Professionals	Leaving unexpectedly	
		Prejudiced	
		Giving up	
		Trying	
		Let down	
	Side effects	Iatrogenic harm	

Appendix 5c: Templates used for Analysis – Template 2.5

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
Psychological Treatment	Acceptability	Ambivalence about the group setting/confidentiality?	
		No one like me	
	Learning techniques	Talking/opening up/spouting off/offloading	
		Exercise	
		Psychotherapeutic/CBT/Pacing	
	What psych treatment was like	Beneficial	
		Unhelpful	
		Unmemorable	
	‘I’m not the only one’	Access to community/peer support	
		Developing friendships	
		Diversity	

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
Impact of fibromyalgia	Mental Health	Coping	
		Enduring	
		Giving up	
		Hopelessness/suicidal thoughts	
		Needing support	
		Not wanting support	
		Other people notice you need support	
	Emotional response	Hatred	
		Confusion	
		Sadness/depression	
		Anger/frustration	
		Shock	
	Relationships	Changing roles	
		Support	
		Isolation	
	Biographical	Lack of independence/dependency	
		Loss/adjustment	

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
		Challenge to identity	
	Activity	Work	
		Education	
		Leisure/hobbies	
	Physical	Debilitating	
		The ‘next problem’	
		Flare ups	
Inadequacy of NHS Treatment	Complicated journey to treatment	Delays	
		Waiting/In limbo	
		Re-referrals	
		Discharge	
		No choice on which treatment you receive	
		Not a priority	
	Some good		
	Professionals	Leaving unexpectedly	
		Not there when needed	
		Unprofessional/Prejudiced/lying	

Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
		Giving up	
		Trying	
		Let down	
	Side effects	Iatrogenic harm	
Non NHS Treatment (support)	Pets		
	Talking/opening up		

Appendix 5d: Templates used for Analysis – Template 3

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
Psychological Treatment	Ambivalence about group setting	When you're struggling it's hard to be there for others		
		Treatment is a waste of time ('Why are we here?')		
		Information given is repetitive		
		Anxious in groups	People not voicing how they feel	
			Participating vs observing/listening	
			Confidentiality/trust	
		'I'm not the only one'	Access to community/peer support	

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
			People with fibromyalgia understand	
			Developing friendships	
			Diversity	
		No one like me		
	Methods of treatment	Psychotherapeutic/CBT	Talking/opening up	
			Spouting off/offloading	
		Exercise		
		Education about pain & fibromyalgia		
		Learning techniques	Pain management/pacing	
			Relaxation/mindfulness	
	What psychological treatment was like	Beneficial	Speaking to someone outside of the family	
		Unhelpful		
		Unmemorable		

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
	Outcomes	Confidence		
		Self-care		
		Assertiveness		
Fibromyalgia	Knowledge of fibromyalgia	Not knowing	Uncertainty	
			Questions	
			Doing own research	
		Public recognition of fibromyalgia	People not understanding/not being understood Family not understanding?	
			Increased recognition	
	Impact of fibromyalgia on…	Mental Health	Coping	
			Enduring	
			Giving up/hopelessness/suicidal thoughts	

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
			Needing support	
			Other people notice you need support	
			Not wanting support	
			Fibromyalgia strengthens you (resolve)	
			Getting used to fibromyalgia	
		Emotional	Sadness/depression	
			Anger/frustration	
			Hatred	
			Confusion	
			Shock	
			Stress	
			Guilt	
		Cognition	Memory problems	

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
			Pain affects thoughts/off in a different world	
		Relationships	Changing roles	
			People are supportive	
			Isolation	
			Family is Judgemental	
			Negative impact on children	
		Physical	Debilitating	
			Paying a price later	
			The next problem	
			Flare-ups	
		Biographical	Lack of independence/dependency	
			Loss/adjustment/ compelled to make changes	
			Challenge to identity	
		Activity	Employment/work/education	

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
			Hobbies/leisure	
Treatment	Complex journey to treatment	Delays		
		Waiting/In limbo		
		Re-referrals		
		Discharge		
		Misdiagnosis		
		Not a priority		
		Not there when needed		
		Immediate support		
	Professionals/gatekeepers	Unprofessional/Prejudiced/lying		
		Lack knowledge of fibro/teaching doctors		
		Reluctance to diagnose		
		Available to support		
		Trying to help		
		Giving up		

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
		Let down		
	As a patient	Trying things		
		Limited choice/no choice of treatment		
		Being in control		
		Self-management		
		Not prioritising own health/treatment (missing sessions)		
		Don't understand why offered treatment/know it already		
		Doing what you're told/asked to do		
		Left to manage on your own		
	Impact of Treatment	Side effects		
		Iatrogenic harm		

Macro themes	Superordinate Themes	Ordinate themes	Subordinate themes	Quotes to support
	Good NHS treatment	Diagnosis	Relief	
		Practical support		
	Non-NHS Treatment	Talking/opening up		
		Resorting to private healthcare		

Appendix 5e: Templates used for Analysis – Template 3.5

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
Psychological Treatment	Journey to treatment	Re-referrals/waiting/in limbo Not there when needed/ Left to manage on your own/needing support		
		Don't understand why offered treatment/give it a go (trying things)/ Other people notice you need support/ *Not wanting support*		
		Control (Limited choice/no choice of treatment Being in control/ Doing what you're told/asked to do)		
		Self-sabotage (Not prioritising own health/treatment missing sessions)		

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
	Ambivalence about group setting (Feelings about the group setting)	Anxious in groups People not voicing how they feel Participating vs observing/listening Confidentiality/trust		
		When you’re struggling it’s hard to be there for others		
		Access to community/peer support/ Developing friendships/Speaking to someone outside of the family /People with fibromyalgia understand/‘I’m not the only one’ Talking/opening up Spouting off/offloading		
		No one like me		

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
		Diversity		
	What psychological treatment was like	Treatment is a waste of time (‘Why are we here?’)	Information given is repetitive/know it already	
			Unhelpful/Forgettable (Uninteresting)	
		Professionals	Let down/ Unprofessional/Prejudiced/lying	
			People not understanding/not being understood /Lack knowledge of fibro/teaching doctors	
			Trying to help/ Practical support/ Available to support	
		Beneficial	Confidence & Assertiveness	
			Self-care	
			Learning techniques - Pain management/pacing	

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
			Relaxation/mindfulness Learning techniques Exercise	
		Detrimental	Iatrogenic harm	

Appendix 5f: Templates used for Analysis – Template 4

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
Psychological Treatment	Journey to treatment	Waiting/in limbo Not there when needed/ Left to manage on your own/needing support		
		Don’t understand why offered treatment/give it a go (trying things)/ Other people notice you need support/ *Not wanting support*		
		Control (Limited choice/no choice of treatment Being in control/ Doing what you’re told/asked to do)		
		Unhelpful coping		

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
		(Not prioritising own health/treatment missing sessions)		
		Excitement/interest in attending the PMP/ Expectations (what the course was going to be like)		
	Ambivalence about group setting (Feelings about the group setting)	Anxious in groups People not voicing how they feel Participating vs observing/listening Confidentiality/trust Different feeling working in a group compared to individually		
		When you're struggling it's hard to be there for others		

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
		Access to community/peer support/ Developing friendships/Speaking to someone outside of the family /People with fibromyalgia understand/'I'm not the only one' Talking/opening up Spouting off/offloading Diversity Wide range of symptoms		
		People with fibromyalgia have different needs	Doom & gloom/groups are depressing (online?)/moaning and whinging/being brought down/suicide pact/most people with fibro are hopeless negative spiral/talking about it makes it worse when people are negative/negative camaraderie/ Generic vs specific pain management course (people with fibro need specific)	

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
			people choose to be positive (being fed to the lions)/ Arguing with other course members/Leaving the course earlier/for my own good/They don't want to hear it but need to hear it/ , *No one like me*/I'm not like them/ Different types of people with fibro e.g. pill popping, elite high functioning/ /Feeling a fraud/fool on the PMP	
	What psychological treatment was like	Treatment is a waste of time ('Why are we here?')	Information given is repetitive/know it already	
			Unhelpful/Forgettable (Uninteresting)/ Box ticking exercise	
		Professionals	Let down/ Unprofessional/Prejudiced/lying	
			People not understanding/not being understood /Lack knowledge of fibro/teaching doctors	
		CBT	Trying to help/ Practical support/ Available to support/ Aims of the course: Trying to make you think positively/training your brain	
			Didn't like CBT/being told it's in your head/CBT rammed down your throat/making it up	

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
			CBT is wallowing I'd rather get on with it/confronting/ Shut off/ didn't want to engage Ignore fibro vs draw attention to it/don't want to talk about it/	
		Beneficial	Confidence & Assertiveness Everyone should have it	
			Self-care Taking control of managing your condition/taught me to do this	
			Learning techniques - Pain management/pacing Relaxation/mindfulness Learning techniques Exercise Accurate/up to date information provided/Prefer to learn practical skills rather than information (lecture style) Strategies for dealing with fibro	

Superordinate Theme	Ordinate themes	Subordinate themes	Themes	Quotes
		Unbeneficial	Iatrogenic harm No change	

Appendix 5g: Templates used for Analysis – Template 4.5

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
Psychological Treatment	1. Journey to treatment	1.1 Waiting/in limbo/ Not there when needed/ Left to manage on your own/needing support		
		1.2 Don't understand why offered treatment/Other people notice you need support/ *Not wanting support*		
		1.3 Control (Limited choice/no choice of treatment Being in control/ Doing what you're told/asked to do) (?have to do the treatments as there may be a treatment breakthrough?)		
		1.4 Unhelpful coping		

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
		(Not prioritising own health/treatment missing sessions)		
		1.5 Excitement/interest in attending the PMP/ Expectations (what the course was going to be like)/ give it a go (trying things)/		
	2. Ambivalence about group setting (Feelings about the group setting)	2.1 Anxious in groups People not voicing how they feel Participating vs observing/listening Confidentiality/trust Different feeling working in a group compared to individually		
		2.2 When you're struggling it's hard to be there for others		

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
		2.3 Access to community/peer support/ Developing friendships/	2.3.1 People with fibromyalgia understand/ Speaking to someone outside of the family/'I'm not the only one' Generic vs specific pain management course (people with fibro need specific)	
			2.3.2 Diversity/Wide range of symptoms People with fibromyalgia have different needs	
		2.4 High functioning vs Doom & Gloom	2.4.1 Negativity Doom & gloom/groups are depressing (online?)/moaning and whinging/most people with fibro are hopeless/negative camaraderie	
			2.4.2 I'm not like them People choose to be positive/*No one like me*/I'm not like them/ Different types of people with fibro e.g. pill popping, elite high functioning/ /Feeling a fraud/fool on the PMP	

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
			2.4.3. Conflict between group members Being fed to the lions/Arguing with other course members/They don't want to hear it but need to hear it	
	3. What psychological treatment was like	3.1 Treatment is a waste of time ('Why are we here?')	3.1.1 Information given is repetitive/know it already	
			3.1.2 Unhelpful/Forgettable (Uninteresting)/ Box ticking exercise	
		3.2 Professionals	3.2.1 Let down/ Unprofessional/Prejudiced/lying	
			3.2.2 People not understanding/not being understood /Lack knowledge of fibro/teaching doctors	
		3.3 Psychotherapy/CBT	3.3.1 Trying to help/ Practical support/ Available to support/ Aims of the course: Trying to make you think positively/training your brain	
			3.3.2 Didn't like CBT/being told it's in your head/CBT rammed down your throat/making it up CBT is wallowing I'd rather get on with it/confronting/ Shut off/ didn't want to engage	

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
			Ignore fibro vs draw attention to it/don’t want to talk about it/	
			3.3.3 Talking/opening up Spouting off/offloading	
		3.4 Beneficial	3.4.1 Confidence & Assertiveness (?different mindset?) Everyone should have it	
			3.4.2 Self-care Taking control of managing your condition/taught me to do this	
			3.4.3 Learning techniques - Pain management/pacing Relaxation/mindfulness Learning techniques Exercise Accurate/up to date information provided/Prefer to learn practical skills rather than information (lecture style)	

	Superordinate Theme	Ordinate themes	Subordinate themes	Quotes
			Strategies for dealing with fibro	
		3.5 Unbeneficial	3.5.1 Iatrogenic harm/ being brought down/suicide pact/negative spiral/talking about it makes it worse when people are negative/Leaving the course earlier or my own good	
			3.5.2 No change	

Appendix 5h: Templates used for Analysis – Template 5

Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
Psychological Treatment	1. Confusion & uncertainty about psychological approaches	1.1 I needed support for my mental health	
		1.2 Don't know why I was offered mental health support	
		1.3 Doing what I'm told vs choosing my treatment	
		1.4 Interested in attending	
	2. Ambivalence about group setting	2.1 Anxious in groups	
		2.2 Access to community & peer support	2.2.1 People with fibromyalgia understand
			2.2.2 Wide range of participants
			2.3.1 Negativity

Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
		2.3 High functioning vs Doom & Gloom	
			2.3.2 I’m not like them
	3. Making sense of & reactions to psychological approaches to fibromyalgia	3.1 Psychological approaches are a waste of time	
		3.2 Let down by professionals using psychological approaches	
		3.3 Psychological treatment ingredients	3.3.1 Professionals trying to help
			3.3.2 CBT ‘rammed down your throat’
			3.3.3 Talking & offloading
			3.3.4 Learning about fibromyalgia & management techniques

Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
		3.4 Outcomes	3.4.1 Everyone should have it
			3.4.2 Self-care
			3.4.3 Unbeneficial

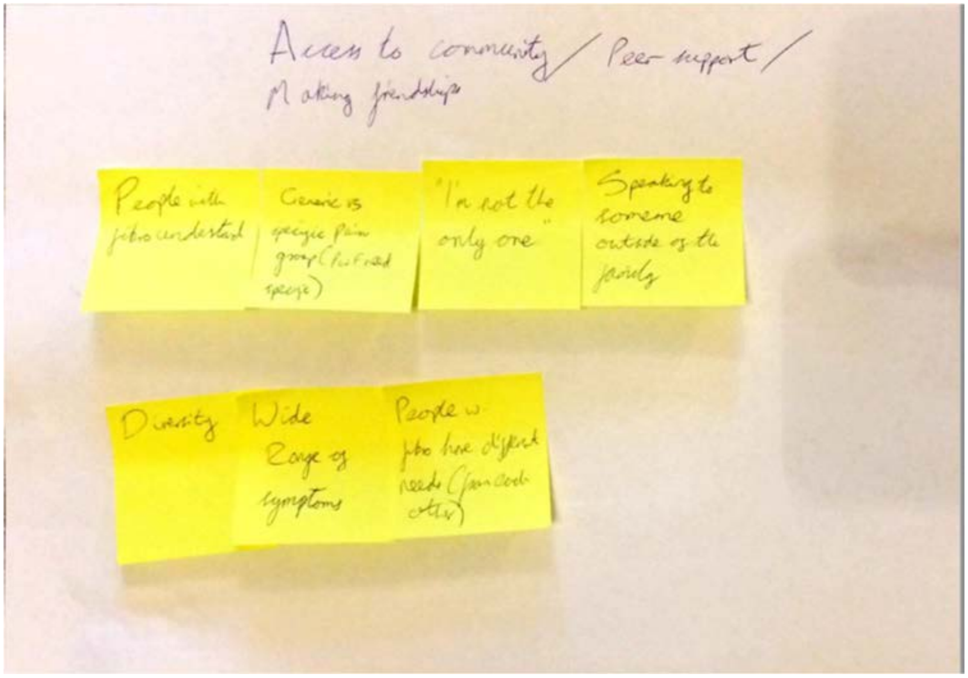
Appendix 5i: Templates used for Analysis – Template 5.5 (Final Template)

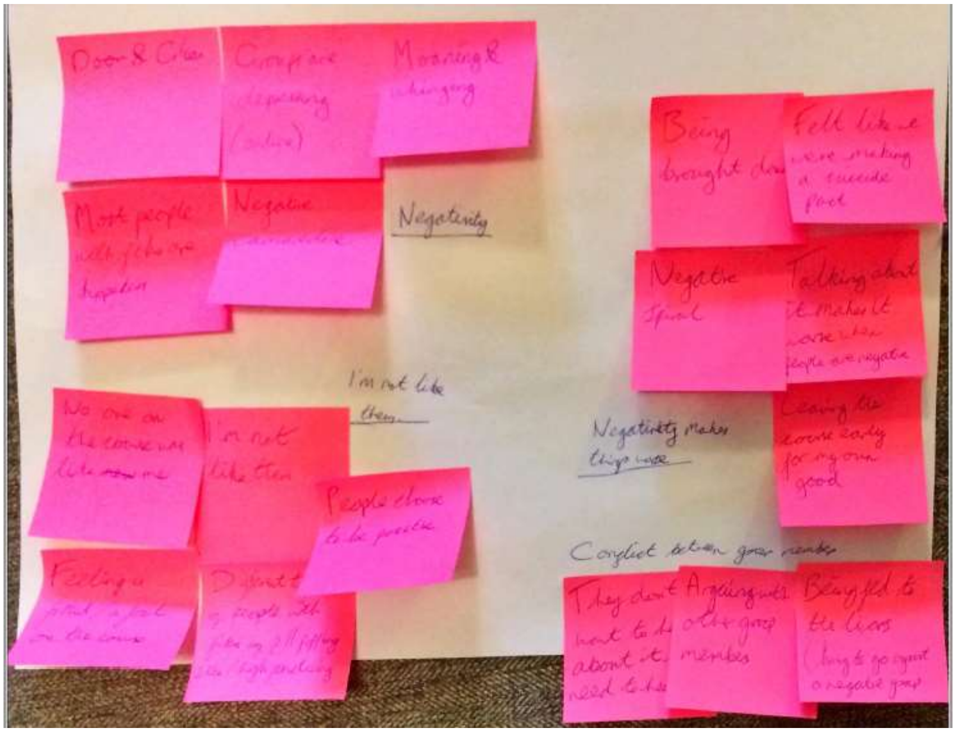
Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
Psychological Treatment	1. Frustration & uncertainty about psychological approaches	1.1 I needed support for my mental health	
		1.2 Interested in attending	
		1.3 Doing what I'm told vs choosing my treatment	
	2. Ambivalence about group setting	2.1 Anxious in groups	
		2.2 People with fibromyalgia understand	
		2.3 High functioning vs Doom & Gloom	2.3.1 Negativity
			2.3.2 'I'm not like them'

Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
	3. Making sense of & reactions to psychological approaches to fibromyalgia	3.1 Psychological approaches are a waste of time	
		3.2 Let down by professionals using psychological approaches	
		3.3 Psychological treatment ingredients	3.3.1 Professionals trying to help
			3.3.2 CBT ‘rammed down your throat’
			3.3.3 Talking & offloading
			3.3.4 Learning about fibromyalgia & management techniques
		3.4 Outcomes	3.4.1 ‘A positive mindset’

Macro Theme	Superordinate Theme	Ordinate themes	Subordinate themes
			3.4.2 ‘I just take it at my own pace’
			3.4.3 ‘A waste of time’

Appendix 6: Developing Themes Work-pad





Appendix 7: Sample of Research Journal

16/06/2020

Theme 2.3 = this has a lot of quotes. Maybe split into 'diverse people' & people with fibro understand as 2.3.1 & 2.3.2 respectively. Also, I'm not so sure about this one:

'2.4.1 Doom & gloom/groups are depressing (online?)/moaning and whinging/being brought down/suicide pact/most people with fibro are hopeless negative spiral/talking about it makes it worse when people are negative/negative camaraderie/

Generic vs specific pain management course (people with fibro need specific)'

Surely they're different? And the larger theme is 'people with fibro have different needs' that can't be right for the subtheme can it?

Also I think this one should be collapsed into people with fibro understand/people with fibro have special needs:

3.2.2 People not understanding/not being understood /Lack knowledge of fibro/teaching doctors

Does 3.4. need a 3.4.4 – spouting off, talking etc (P1 spoke about this in terms of her work counselling NOT being in a group which is where it is now

17/06/20

Did the theme of choice, preferring the group first make it through?

1459. …I would- I would rather have pain management than straight away going on treatment because if I felt on my own by me going to the pain management programme I've got the support group now and now I've found a wider range of community on Facebook. If I didn't go to the pain management programme I wouldn’t have the larger community group today that I follow on Facebook.

Appendix 8a: Participant quotations to support theme 1

1. Frustration & uncertainty about psychological approaches

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
1.1 I needed support for my mental health	-	292. [about needing MH support] …but I guess out of- out of all of it, it would be something that would be beneficial for people in the future, from my own experience not to be left um it's all well and good having something physical but there's also the, the emotional side of it um and if you're, I, I suppose, if you're, kind of weak emotionally I suppose, which I was at that point,	1058. Yeah so, I currently have no support apart from my mentor and my mentor I only see her once a week for half an hour and I don't think that's enough because obviously I've had- because um of all of my health I've been having a lot of thoughts…and I asked them for support and they helped me and they go "you've got severe depression so we don't understand why you don't get help"	526. I recognised that I did need to sleep to- cause I was still working at the time this was happening and um (pause) and I said uh you know "I'd like to but I need something else in place" so she referred me [name of physiotherapist] um for sleep management. 549. [did you ever have any other kind of mental health support] Um, no not really I can remember seeing the team and they would have- I think there was [name of doctor] the	331. [were you offered support for your mental health?] No (pause) I had to ask for it. 342. I think my last uh counselling session was probably about maybe eighteen months ago roughly something like that um (long pause) yeah so it's intermittent with myself… …um when it comes to uh mental health		883. [Did you receive MH support when waiting for the PMP?] No. Only really as part of the pain management programmes. Either… the previous one was for when I had the problem with my neck, and then on the Fibro. 843. But, I do feel that since then, nobody's really said to me, 'do you need anything else?' [laughs]. I've just been		282. I: Have you had anyone to talk to about this? P: To be honest no (pause) I used to cry myself to sleep (chuckles; long pause) which doesn't help 201. I: Mmm, did anyone offer you any support for the kind of, like you said, the

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		then it would be difficult to, to grasp what the actual rest of your life was gonna be like. 406. So I got re-referred to the pain management here and what was really annoying was the fact that I had an appointment, they cancelled it because they didn't have any consultants they, they'd- they just, they were closing it because there wasn't enough staff and then they gave me another appointment three or four weeks later ah, and they, they rang me to say that they'd double	1067. Yeah so, I mean I told my GP I've had thoughts, I've tried to end it here and there I've been admitted to A and E hospital some- and for some reason I still don't get mental health service help. 1071. [They're not paying attention] No (pause) and there's so many youngsters out there who have mental health like me and we've heard stuff because people don't get support one of our family friends he committed suicide from the top of the school	consultant and at the time it was [name of psychologist] who was the psychologist here and I saw all of them together. That would be about the only other (pause) psychological input.	support whether it's just coping and things like that, just managing things and you know it, it, it can be hard…so yeah it's been intermittent with myself but I've always had to reach out yeah.		left. But, maybe because I'm happy to be left, that's what I want [laughs]. I want to just get on with it.		breakdown days? P: No, nothing.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		booked so missed that appointment, so the first appointment I had was when I was here on Monday…and I said- the first thing I said to the person that I saw was "I don't" "I feel like a fraud being here because I'm actually not too bad" but I needed you last year", "I needed to be…" (pause), yeah "I needed you to help with the pain and help me with the coping and all those kind of things but you let me down twice and now I'm here and I'm just like okay" 426. they are going to send me	because he got no support in school (pause) and there's more suicidal in youngsters than adults because there's no current support for us. 994. No but recently my mental health has been getting worse because I have been waiting for [name of mental health team] for about a year now…my first mentor has left and now I'm on my second mentor and she goes "you've been waiting for quite a long time" and then she goes "I don't know why you're not getting						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		another appointment in three to six months because they know, that obviously with my Mum and stuff that I'm going to need some extra support but that was very disappointing. Really disappointing. 622. is there is there a positive to be told that you've got a condition that's for the rest of your life um (pause) not had any support emotionally from the NHS… 748. [on being offered the PMP] it was something that I'd, that I, that I needed 771. '- in that period of 18	support, because" she goes "a- I've seen other people who have got support and your- your mood is lower than them". 264. yes so (pause) they referred me to the mental health team…and the mental health team go "you don't need it" and then I get discharged. I've been waiting for the mental health team for about two years now. 293. at the [name of a hospital for children] I had a psychologist for about three years. [so you had the help you						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		months to two years when I said that it would be beneficial if I'd have had someone to speak to then that would have been (pause) a useful tool to have had um (pause) to have been seen or, you know, participated in something…um (pause) pretty much straight after diagnosis, but obviously that didn't happen…' 919. [of the MH group] 'It was a very good experience and that and you know I can't speak highly of it I just wish it had come twelve months, eighteen months earlier rather than two years down the	needed?] In the [name of a hospital for children] but as an adult I haven't got there yet. 325. I think the waiting list should be shorter. 339. But as I said the NHS has been draining down as the years have gone down. The waiting list have just been going longer and longer. 342. So, for my psychiatrists' team I waited for one and half years. For pain management probably was about four-five months. Yeah and then I'd got the consultants and did all the						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		line and then “oh we’ve got this group that’s running we can put you for that” 1014. only until I obviously went to the doctors last year to re-refer me because of obviously the um how I was um (pause) but then when the appointment never came through, the you know, they said that the next appointment that’s available is in February and I’m like … “but I need it now”, “yeah but you, you’re a new patient again” and, and I’m like “ yeah but I’ve already been a part of the (pause)	treatments and then for the pain management programme that was about three to four months as well. 424. Because like I waited for the mental health team for so long that my diabetic nurse she goes “I’m going to tell you this now that you’re going to be waiting for a very, very long time so ask college for help” so then I went to college and asked for help and then I’ve been having them for a year. 227. It was a bit scary cause I’ve always been in children’s wards so I didn’t know what the						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		the actual clinic itself why do I have to be re-referred?", "cause that's how it is", which I thought was very (pause) annoying… 1025. 'I suppose I thought once you're on the books, so to speak…you're on the books but (pause) clearly you're not on the books cause you have to go back to (pause) the GP and back to square one and then (pause) start the whole process again and we know how long the process is.' 1055. 'so that's why I'm glad that, you know, they've made this appointment for me because at	difference was cause I've been in hospital since I was 12 years old (pause) yeah so from 12 til 16 having them for that many years I didn't really like going adult because I can see the difference between children's and adult's team now. [what were the differences?] Children's are more supportive and they give you more intensive care compared to an adults. 357. That's impacted on me in big way because like I'm not having no support I don't know what to do and then like						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		some point I'm gonna need some form of (pause) intervention I would have thought… I, because (pause) I just know that I'm not, not going to cope…' 1256. [positive outcome of the group] it's helped me because I've taken some of them onboard so yeah so it, so it helped um definitely the emotional side cause like I said um when I got diagnosed it was just like I was left in limbo for a couple of years not really (pause) knowing what was going on 1312. 'I: …what do you think you	sometimes I just feel like no one cares…so like that has a big impact as well. Then sometimes I get so fed up of NHS that I don't go to my GP no more and ask for help. 261. It was disappointing because I didn't get the care and then I got upset and then it had a massive impact on my mental health because I have not got mental health support at all… 996. No but recently my mental health has been getting worse because I have been waiting for [name of mental health						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		needed (pause) at the beginning? P: (pause) I (pause) needed probably the group' 1319. [about the group being offered at the point of diagnosis] for me personally that, that would have helped because I'd been living with it for two years (pause) not really understanding (pause) what it was, why it was, how did it happen, where did it come from	team] for about a year now…my first mentor has left and now I'm on my second mentor and she goes "you've been waiting for quite a long time" and then she goes "I don't know why you're not getting support, because" she goes "a- I've seen other people who have got support and your- your mood is lower than them". 1067. Yeah so, I mean I told my GP I've had thoughts, I've tried to end it here and there I've been admitted to A and E hospital						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			some- and for some reason I still don't get mental health service help. 287. I don't blame them because they don't have enough staffs and they just want people who are severe- severe affected.						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
1.2 Interested in attending	-	779. 'so it's two years down the line and it was, it was very welcome.' 1394. 'when the group came up it was like "oh I don't know if I want to go to that"…but		599. I would go with an open mind cause I always think that "okay maybe not everything will apply to me but I'll take away what I can use" so there's always going to be some value	464. You just don't know what to expect, you just go along with an open mind you know even the first the time you don't know what to expect and then you go again so you know um (pause) you just to have an open mind sometimes uh when you're dealing	687. I think before, you know, your head's not all with it, sort of thing, when you go into these groups. You don't expect to get anything out of it when you first go in, but I did.	601. [what was your reaction to being offered the PMP?] Intrigue. Erm, definitely. Because, I'd not had… nothing had been geared specifically at Fibro, to me, whereas that was. So, I'm very interested and I,		335. I felt, I was happy actually when I heard I was gonna go to (pause) a group how to

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		(pause) talking it over with you know with [wife's name] it's just like "actually this would probably do you real…", you know so I'm glad that I did it.' 1417. ', I wasn't really sure what (pause) what to expect I was a bit nervous when I came in, just thinking "oh…"'		in it (pause) I was uh pleasantly surprised that it had changed a lot from that first one I'd done which was nice	with some- certain things where you don't know what you're walking into. So yeah um it's a bit daunting. 489. It was okay because there were people from the twelve week group, the first group (pause) we had a, a, a group chat…so we all planned to attend but the other ladies didn't attend! (laughs) It was just me that went! So yeah um (pause) maybe it helped me to go, who knows! But yeah it was okay, it was okay yeah. 610. I think it's just important to know what you're walking into uh just to prepare yourself for…for something really yeah.	694. before, I didn't think that I would be able to go and do anything. And, thought process… you know, I couldn't… I didn't expect to get anything out of pain management programmes or anything. 698. That's the only way. You've got to go through the programmes and that, to learn how to cope with some of the things. You'll only grab a few little bits out of any of the programmes.	you know, really wanted to do it because I knew that it was something that would direct… it was directly about what… it was specific. It wasn't sort of, a general. 611. even if they only taught me, you know, five things and I took three of them away, do you know what I mean, and carried on? 435. I think you just get to a point that either, you let it beat you, or you will just proactively try anything that, you know, that they suggest for you. So, and I'm very much, you		manage the pain

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					614. [Would it have put you off if you had a letter saying there was exercise?] No (pause) cause they would have explained why they were doing it. It's for their benefit for their, you know their research understanding whatever…just to see how they are running the course, you know that if they do this it'll help them run the course better or whether it helps or whether it doesn't, to take it out or keep it in you know so yeah it would have it wou- it, it would have just helped me to prepare for it really yeah 1042. they were doing laughing yoga which I really wanted to try, so I just made		know, I'll give it a go, if it works, it works. 572. [what was your reaction to being offered a PMP] Oh, I liked that I would get to maybe know… get better ideas of how to manage it, that's what I wanted… I was interested in. 'Now I've got it, how do I deal with it?'		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					sure that they were going to do it again and I think they are so I'm actually quite looking forward to that 1018. [What's it like going to the peer support groups?] It's, it's good yeah, like I say I've been there three times and uh I'll keep doing something until I give it an actually chance you know so yeah it seems to be good,				

Ordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
1.3 Doing what I'm told vs choosing my treatment	70. [about treatment in general] 'I've done everything that the doctors have asked me'	626. And I said "I'd rather do it one to one with you and not have the group" So, I'm just waiting for that, it's been about three months now.		1196. "whatever you want to talk about you can speak about it" um (pause) and (long pause) you don't know what to expect unless you try something so um and you if don't turn up you lose your remaining	465. But, I knew that, you know, I'd got to go everything because I didn't want to miss a treatment as well. Because, it's like I said, if I didn't go to some of	53. So, when I had the option of doing erm, a pain management course here, erm, originally the put me on the pain management, or I could wait a few		399. so my first thought we were gonna have a one to one session so they talk to you particularly about you're, about what

Ordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		894. They don't put us on the pain management programme straight away…they first do the treatments and that's the last option. But one of the questions in the group was "why don't why have that first instead of straight away going to the medicine?" 904….because I'd- I'd rather have no medicine and do the pain management group first and if that doesn't work then go on medicine because I don't like relying on medicine too much. Yeah, I would rather first be offered the pain		appointments as well because…obviously someone else could have had them.	these, I'd miss knowing what some of the Fibro was. 856. if you don't do the treatments, you don't know if there's going to be a breakthrough with any of the treatments, that you know, does help complete it completely, or take the edge off completely, from six to eight months at a time 743. [on going for treatments in order to access the treatment after that] Yeah, that's what it felt like at the time, you know. You've got to do that to get to the next stage, to… it's as if you've got to meet each stage,	months to be able to go onto the Fibro pain management. So, because I'd been diagnosed with the Fibromyalgia, I decided to wait and do the specifics. 717. [did it make sense why you were referred onto the PMP?] RES: It does now. It did after, but before… at the time, I saw it that it was an option that was there for me, that I could take or not take, to learn about it and what you can do about it?		you're going through and them advising you "this is what you can do, try this or try that"

Ordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		management programme. 912. The consultant should have offered it cause he offered it to me last. [you would have preferred the choice?] Yes, instead of treatment straight away. 1489. But I wasn't offered that the first time around…they just said "pain management programme as a group"			to get where you needed to get. 715. [did it make sense why you were offered the programme?] Not at first. I just seemed to go through the, thinking that that was what I'd got to go through, to get anything done, sort of thing. 728. [did anyone explain why you were being referred to the PMP?] Not really, no. I think… I think I was just like… I was just told it was just one of the things that I've got to do, sort of thing. 733. I felt like, you know, if I didn't do it, I wasn't going to get further on to… well, it's not just knowing what was			

Ordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					going on and everything in the group and that, but you know, if I didn't do that, I wouldn't understand some of the bits and pieces of what you've got to go through to learn and cope every day. 738. And, to get, you know, to get onto the next part of the things we're being offered. Any more different strategies, and treatment-wise and everything else.			

Appendix 8b: Participant quotations to support theme 2

2. Ambivalence about group setting

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
2.1 Anxious in groups		1394. ‘when the group came up it was like “oh I don’t know if I want to go to that”…but (pause) talking it over with you know with [wife’s name] it’s just like “actually this would probably do you real…”, you know so I’m glad that I did it.’ 1401. ‘I’m not very good in um in group (pause) situations really I’m quite, a bi-	447. As I’m not a very big fan of groups I’ve got to try it out because I don’t like a big group… 462. [why try the group?] It was because I think there’s no harm in trying and I have to do it because when I’m older and I’m working I’m going to have groups like that so like try and build up my confidence by just trying to go to it. So, I went to it and I felt fine but I just didn’t like it because there was no one my age and	836. The only problem with a group discussion I suppose is you always get people who aren’t going to voice how they feel. 841. One or two who didn’t, sort of, say a lot (pause)…but um you know it that- if they don’t feel comfortable enough to then obviously there’s nothing you can do about	470. it’s a bit daunting…at first because you don’t know anyone you don’t even know the person who’s teaching you because you’ve never seen them before. 474. so you’re just walking into a big field and you know there’s no fence around you to help you feel secure and stuff.	490. [did you know it was a group?] Not at first, not at first. At first, I thought it was going to be a one-to-one. And then, we walked into the room and there was about seven or eight other people, it was like, ‘I just want to turn around and walk out’		694. It was only, as I say, only the first two sessions, and I think I completely shut off after the first one because I just didn’t want to engage. 669. So, there might be somebody who’s going, ‘oh, the sleep’s horrendous’, and then somebody would be like, ‘oh, but we don’t miss…’, whatever’s going on at	356. Not helped it would have been good cause we when you do it alone it’s different whereas if you do as a group it’s a different experience a different feeling emotionally as well. 336. it was okay but they could have done more better with more (pause) practical

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		a bit quiet I just kind of take everything in and just, that kind of thing but um from what I can remember I quite surprised myself I joined in with quite a few different conversations and it was just, just helpful' 1417. ', I wasn't really sure what (pause) what to expect I was a bit nervous when I came in, just thinking "oh..."'	no one really talk-spoke to me. 490. I was feeling nervous I didn't know how people would be like because I've never been in a focus group... yeah, so I didn't know what to expect but when I went I felt alright. 602. Everyone used to talk to each other but none used to like make an effort with me so I just used to go on my phone. Like I like my pain management support group that I go to every month...because people make an effort to talk to me and stuff and this was much of a bigger group	that...you can only offer like they did to go and speak to somebody if you want to.	476. so me after you know you're warming even now it's been (pause) um I'd been invited there back maybe a year ago (pause) 2018 yeah about a year ago and then I didn't go for about four or five months um (pause) but I suppose everybody's in the same boat... 991. sometimes you want to say something (pause) but when it comes to you something else has	493. [on the group] So, it's like any of the others, you know, in the first meet you sit on the edge and you don't want to get involved. 495. But, I'm glad I went in, I'm glad I did it. But, you know, I think if they'd have told me it was a group to start with, I probably wouldn't have set foot in the room. So, maybe it was for the best that I		2am, some particular show. We could all have a bit of a giggle. . So, it was quite... there was kind of, an easy side to it that I quite liked. But, that could have just been based on the people who were in that course. If I was given another 10 people, I may have not enjoyed it at all.	things rather than just sitting down and (pause) listening like lecture kind of thing. 390. Meeting other people going through the similar things, sharing your feelings and thoughts with them and staying within the room (long pause) I'd only say them, nothing else. 399. so my first thought we were gonna have a one to one session so they talk to you particularly

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			compared to last years. 612. [of the peer support group] So that's why I go to it every month but if I didn't feel comfortable I wouldn't go to it at all. 619 So, like because my pain became bad again last year I got referred here again and I saw one of the physiotherapists and he asked me "do you want to go to another pain management group or do it one to one?". And I said "I'd rather do it one to one with you and not have the group" 629. Yes. I mainly have everything one to one but I've		moved on so yeah but yeah it's um (pause) I'm warming to it more… 1025. I'm not really a secluded person but um I suppose other people are a bit reserved…as well yeah maybe they don't see you so much because their a bit kind of "oh who's that?"…	wasn't told that it was that… that, you know…. 502. [what put you off about the group?] I don't know. I think it was just, opening up to other people. 522. But, obviously if you go into the group and you're quiet to start with, there's that many loud people in there that want to speak out, that you do sit at the back and you do let			about you're, about what you're going through and them advising you "this is what you can do, try this or try that" but it was a big group thing I think they'd gave us individually somewhere and then maybe would have had a different experience, come out with something different. 356. Not helped it would have been good cause we when you do it alone it's

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			been trying to go to groups because even with my other healthcare team they tell me to try and go to groups. 640. And then like I preferred my diabetes group so it was my choice whether to go to the diabetes group or pain management and I preferred my diabetes group because I preferred them because they all spoke to me and stuff even though they were thirty-forty years older than me. 678. Everyone just spoke about their daily life, their feelings but with m- me um I don't like to talk about			them speak first. Because, you know, they like to rule. Some like to rule the group, and think that they know it all 527. and some, you know, will sit back on the side lines and take it all in. At that time, I was taking it all in and not doing anything. 519. I think it's more a sense of relief, that you know they're going through			different whereas if you do as a group it's a different experience a different feeling emotionally as well.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			my feelings… in public (pause) and like it- because I have severe trust issues the only people who I trust is professionals because I've seen them since I was young. Apart from them I won't tell anyone anything. 695. Yeah but I think the group were brave to do that but for me I wasn't able to because my trust has been broken in the past… 698. I did not know whether it was going to stay in the group or go outside the group. 702. [on concerns about confidentiality] Yeah (pause) because professionals have			similar things to you. And, you shouldn't be frightened of speaking out, because they're all in the same position as what you are			

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			broken my trust and it's like teachers and some- some of friends so that's why (pause) that's why I only trust people that I'm really, really close to. 1465. I: if they'd said at the beginning like "either we can give you uh a pain relief with medication, we can give you a pain management programme or we could give you pain management one on one", which one of those three do you think would have been best for you? P: Pain management programme one to one.						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			590. I: You've-you've mentioned there that there are (pause) the other people in the group and that they were a lot older than you… P: Yeah. I: …and it sounded like from what you saying that you, you didn't really (pause)… P: Communicate. I: Yeah, is that, is that fair? P: Yeah. I: Okay. P: I only used to communicate with the professionals.						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
2.2 People with fibromyalgia	-	751. 'you don't know (pause) how it is or what it's like	479. Yeah, I go to a pain management support	1079. Yeah okay, the first group I did was a more general one so	956. it was actually quite warming to	519. I think it's more a sense of relief, that	613. I took quite a lot, to the degree that	669. So, there might be somebody	174. Going to that group did help in the sense (pause) I

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
understand		until you've actually been through something sort of similar um and, you know' 802. 'the people there were (pause) were obviously speaking about how it had affected their lives' 951. 'I think if it had been brought forward a little bit it, it may have helped because there were likeminded people who were still going, who were going through (pause) similar (long pause)) experiences	group now, they're friendly they speak to me even though I'm still the youngest out of all of them but they speak to me. 752. It's just like, like I didn't know anyone else had fibromyalgia apart from myself but then like when I seen other people it's like I'm not the only person who's going through this there's other people out there who are going through this.	there were people with arthritis, all types of different reasons for their pain um there were (pause) there was no "you need to attend so many" which they did say this time (pause) we turned up and I think by the first lunchtime we'd probably lost about four people 441. So now they've got a specific, you know, pain management course for it which was… nice to know where people could learn from one another and from the staff that were now more	be honest cause I didn't know anyone, no one at all so yeah it was very nice uh and reassuring. 279. [what were the positives of the journey to treatment?] Um (pause) probably meeting people along the way…the strength that you get from people. 504. [what was useful about the PMP?] Just to know that there's	you know they're going through similar things to you. And, you shouldn't be frightened of speaking out, because they're all in the same position as what you are. 389. There's always a group of six or seven, at least. And, you get together and you know, you can tell each other	a lady I work with at the moment, her daughter has it, but she's never been offered anything like that. Trust different places, it's different. And, I says to her, 'well, if she's up for reading', I said, 'she can read through my one, because I found it really helped' 624. I said, 'do you know, I'm sat here and I almost feel	who's going, 'oh, the sleep's horrendous', and then somebody would be like, 'oh, but we don't miss…', whatever's going on at 2am, some particular show. We could all have a bit of a giggle. . So, it was quite… there was kind of, an easy side to it that I quite liked. But, that could have just been based on the people	met other people going through the similar things. 176. so we're still in contact… as a group so, you know if we- if you have one of those days you know even if you swear in the group "hey she's got a bad day (chuckles) let it out! 361. [on what it was like in the PMP] It was good (pause) cause we knew were safe whatever we say whatever we share it'd stay in that room (pause) cause everybody else was going

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		that, that I was going through… even though everybody's individual (pause) but like I said we all had that common factor.' 1151. 'so I was still having that when we were having the group so it was (pause) in a weird kind of way it's good to talk to someone who is actually also in pain as well' 1153. it's good to talk to someone who is actually also in pain as well (pause) with the same…conditi	758. [it sounds like that was quite important] Yeah, like I have other health conditions and I thought no one had it but when I go to groups I see there are other people it's just not shown people just hide it. 1451. It makes sense (pause) I would prefer pain management programme because there's other people there and you can	knowledgeable about what would help people so that was more positive. 446. partners were invited in as well so that they could learn and find out, you know, what the problems were…it was quite interesting actually cause my current partner's very understanding and came in and the partners went off in rooms to talk and afterwards they were saying it was quite interesting that there were quite a few people there who really didn't understand	someone who understood, listened and understood what you were going through um (pause) yeah and, and having people around you that actually wanted to try and help you get better or ease things…or help you understand certain things, teach you not to push yourself too much… I: Mmm. P: …take little steps	what you're actually suffering with. 397. I don't think you'd be in the same mind with any of it, if you didn't have somebody to speak to. 399. I think I'd be in a really dark place if I didn't have the… everybody around that I can speak to. 430. [in what way the group helpful?] I just think that they understand	a bit of a fool, because we'd built up quite a rapport as a group', and they went, 'you're joking, we think that you're doing so well because you're doing the voluntary stuff you do, you're working full time, and you've got…', and I didn't really look at it the other way around, so. 733. not just from what they taught us or what	who were in that course. If I was given another 10 people, I may have not enjoyed it at all. 547. we all came each week, and it wasn't for me, just about talking about what we can do about these things, it was about the social side of it. I really liked meeting… like especially the lady, I loved this	through the same thing, 390. Meeting other people going through the similar things 539. [on the purpose of the PMP] Mentality you know mentally to…acknowledge see other people and know how are other people are coping with the pain. 749. even if I don't speak to them for ages (pause) when we're logged into the group we know just by how (pause) everyone is typing how they're feeling.,

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		on (pause) um but there were people who obviously managing their pain and there's people that had just been diagnosed... 1250. 'I guess it, like I said, it just gave me more of an insight about how I need to (long pause)) how I- how I need to live…and to take onboard, you know, (pause) listening to other people about their (pause) you know, their, their stories and their kind of how they've	speak to them and it feels like you're not on your own… 1455. …I would- I would rather have pain management than straight away going on treatment because if I felt on my own by me going to the pain management programme I've got the support group now and now I've found a wider range of community on Facebook. If I didn't go	201. it was good to do the course and good to meet other people as well that everybody suffered from fibromyalgia so sort of understood what was going on for each other, so that that was useful 444. [of the PMP] where people could learn from one another and from the staff that were now more knowledgeable about what would help people so that was more positive. 589. as well um we sort of very much used ourselves as	and not big steps you know, so yeah that was, that was very positive. 934. I just, just remember just having the warmth and support from the people in the group, you know and the, the people around me helped… 962. Everyone, it was everyone yeah, yeah it was everyone yeah everyone there they	a lot more of what you're going through, than even my own husband, and Doctor do. Because, they're actually feeling the same sort of pain as what you are 712. it's good that you've got somebody outside that box that can tell you a little bit more, and somebody else that you can	we got to read, but from everybody's experiences. And, having somebody who, or people that knew what we were talking about. When we could say, 'oh you know, I really struggled to lift the duvet up this morning', you know, 'and people will go, 'I know where you're coming from' 851. It was different,	little old lady, getting her a cup of tea and sitting and having a chat beforehand , and in breaktimes.	365. so you know swear as much as you want, say what you want they understand they won't give you the eye "oh she's in that mood"…they know because you're in that mood you're getting it out of your system (pause) it was good… 688. I think we all feel the same (pause) but for them it's (unintelligible) children or other commitments. 784. It's a nice feeling knowing there's somebody

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		managed it then (pause) it's helped me because I've taken some of them onboard…' 1266. 'but actually seeing other people (pause) that actually people do (pause) do exist with the same condition and in the same local area as well…which (pause) I don't know is it's a bit (pause) I don't really a bit naïve I suppose to think that I was the only one' 1321. 'then suddenly going into a group, a roomful of	to the pain management programme I wouldn't have the larger community group today that I follow on Facebook. …on my own no-one understands it, like when you try to explain people just like compare it to arthritis or whatever people just don't understand it and then like when I went to those groups there's other people that- who are	support as well and discussed that, we discussed techniques for sort of um (pause) dealing with pain um (pause) sort of- oh trying to think what it's called sorry um (pause) hmm discuss various coping mechanisms… 604. it was nice to be with other people who also had fibromyalgia......and to make contact with them because it's not very often probably that you find other- come across other people with fibromyalgia and it was nice to- that other people	were all really nice and supportive 1054. Just getting to meet people, getting out of the house um other people inspiring you, giving you courage to do things that you probably um know that you should be doing and haven't done it yet 1057. I got a bit of inspiration off this um older lady I was sitting next to um	speak to like that. 443. [did the group members teach you relaxation?} They did, and… yeah, they did, and the pain management did as well. So, it was very helpful. 433. so they know what your coping strategies can be, and what different things you can do, to try and alleviate some of the pain each time. It's	because we were trying. And, as we were saying about, we try to put… a lot of people were saying they try to put a positive spin on things, and you know that if you, you know, this can make you feel this, and then having that can make you feel… you know. So, we were quite, we were all quite positive. There were a few that weren't, but		there who understands you, who actually understands you. 759. I think (unintelligible) that emotional support knowing somebody's there they understand what you're going through they know you're not making it up. 764. I think that apart from those ladies and apart from my kids and my husband nobody else actually understands the extent (pause) of pain I'm going

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		people have got the same thing, experiencing the same kind of (pause) difficulties that I was ex- that, you know that I was experiencing and it was just well actually, you know, it's not just me (pause) so (pause) that is probably the one thing that I could have needed at the very beginning…' 1328. 'which is, once it's there "okay lets, lets, lets get you in with some likeminded people	understanding this pain. 773. …but I was on my own then, so when I went to that group I'm not the only one. 789. …so, then when we were altogether I realised "I'm not the only one" so I had a different mindset…or like before it's just like "no one understands". 794. Yeah like "I'm not the only one there's other people" and like there's people like when I went	would understand. 673. whereas the second one you did it you were encouraged to (pause) um get to know people in your group and to talk um and then you were encouraged to attend the sessions afterwards um and the- one or two people went from the course I was on but it didn't bother me cause just go and meet other people and chat to them and get to know them so it's a I suppose it's a social support…as well as being a sort of um more practical support	where I just felt like I needed to go back to the hydrotherapy pool	like, you know, when they tell them… you say to them, you know, 'I've got this sort of, pain, I don't know how I'm going to move and that', it's like, 'well, lie on your side or lie on your back, for five/ten minutes' 443. [did a member of the group teach you about meditation?] They did, and… yeah, they did, and the pain	not… two or three 1039. [on needing support to make change] I know it's there, because there was a lady on the course, she only used to go as far as the front gate and back, really. Unless somebody was with her all the time, which was very rare. So, you know. 619. I said, 'it's different when you're all there and		through (pause) they don't really understand I don't think so. 484. although it's similar but still fibromyalgia and chronic pain is (pause) different (pause) cause everybody in that group (pause) they all- most of them are working 755. I think it's that emotional support I would say emotional yeah emotionally you know somebody's there 759. I think (unintelligible) that emotional

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		because you're not actually alone"…' 1331. 'like I said it is it was a lonely place, for two years because I didn't know anybody who'd got it' 1332. 'having to explain to [wife's name] my wife I can't- I, I haven't got the energy I can't do this and (pause) you know and for someone to actually understand, "well actually yeah you are really struggling with it" is, you know, it would have helped, it	to the pain management support group there was this woman and she goes " I do this fibromyalgia support group it's on Facebook" and then she gave it to me and then she told me what to do stuff and like she was helping like to go swimming and stuff, the GP will refer you if you ask…I haven't been to the GP in a while but I always follow her… and it just	where you learn how to manage things and I think that's important for people 708. So, I think that, that's important for people… and keeping contact with people who you know do at least understand that you've got pain. 832. occasionally it was in the group and then we'd probably all talk about (pause) different, you know, or chip in and hav- and we'd very much have a, sort of a, group discussion. 1142. whereas the pain management course that I attended this		management did as well. So, it was very helpful. 519. I think it's more a sense of relief, that you know they're going through similar things to you. And, you shouldn't be frightened of speaking out, because they're all in the same position as what you are 704. It's more of a relief. A	you've got group participation, and you've got… like you say, you see other people with it and you think – okay' 734. And, having somebody who, or people that knew what we were talking about. When we could say, 'oh you know, I really struggled to lift the duvet up this morning', you know, 'and people will go, 'I		support knowing somebody's there they understand what you're going through they know you're not making it up. 475. I can't say much about that because I originally thought I was gonna go to a fibromyalgia group but I ended up with, in a group (pause) chronic pain group so it's (pause) two different things. 480. because in that bit everybody with fibromyalgia so…we were all the same

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		really would have helped' 730. I found it useful because it was the first time I'd ever met someone who'd actually got the same condition…and we're all (pause) all different but we all had the same (pause) word that we had in common…so that was probably the only beneficial thing that I…that I took out of it that there are other people 762. 'But then when this came up it was just like "Wow! Okay, there	says "you're not the only person" and there's like loads of other people on there and you can just talk on there 809. Yeah (pause) because she created it herself when she was about- because she told me, she goes "when I was your age I felt the same as you" …and the pain like- I thought I was the only young one and like that but she goes there's many people out	time there was a lot more encouragement in terms of peer support and talking to one another and you know break for coffee and biscuits and everybody chatting. 1145. you'd have coffee and biscuits when you arrived so you…start to chat to people and then you know we were given exercises to work on with sort of um flipcharts and things, so you'd work in a small group and you get to know people…and start to talk to them more.		sense of relief, more than anything, if you've got somebody around you, to… and somebody that doesn't know your family, as well. That's outside of everything. 709. They're outside the box. You've got your family, they cope with the everyday, but then you've got somebody outside that's looking in, and they	know where you're coming from', do you know what I mean? But, other people just think, 'oh, you're just being a lazy so and so', you know. But, it is sometimes how it's perceived, because they don't understand that Fibro is painful, does make you more tired and more fatigued than you know, than normal.		(pause) whereas chronic pain is different people with different areas, with different pain 770. So in order to see somebody when you see somebody 24/7 (pause) physically when you see them you know what they're going through what (long pause) yeah you know what they're going through they're not making it up because if you don't see somebody you don't know. . How do you

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		are other people"' 765. 'it was, it was good, it's just, just what I needed' 854. 'listening to other people and having (pause) a greater sense of what it was and how to look after yourself better um which is what I put in place…um and I still, I still do that now'	there like you your age but people just don't come to this group the youngsters. Yeah and that- that's what she told me she goes "there's loads of people your age on this group" so I follow it and I see it every day.	1319. it was nice to have the contact and the peer support um (pause) nice to have the continuity I think so you didn't just get that cut off and be left dangling…that you could still go along to (pause) the once a month and talk to other people. 1324. you always pick things up from other people who've tried this or been there of whatever 774. I could understand when they said that their partners didn't understand…and they were expected to carry on as normal et		can tell you, 'this is the way I cope' 712. it's good that you've got somebody outside that box that can tell you a little bit more, and somebody else that you can speak to like that. 168. It's more, relief, than anything. Knowing that you're not on your own with it all. 200. since I started speaking to people like I	727. Yeah, I suppose it did before, really. But, knowing… having been on a general one, which was all I'd really got to compare it with, to me, doing the specific one was better than the general. Because of it being specific to, you know, to it as it was. 606. that's why I didn't want to do the original pain… because, they did that off the original pain		believe somebody who- when you just, you just hear them say "I don't feel very well. I've got a bad day or I'm in pain"

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				cetera I could understand where they were coming from (pause) because it, it is it's I suppose it's quite a hu- you feel hurt at the time 699. So, it is important for people and I recognise the importance of (pause) having contact…with other people (pause) and not just people- I mean it, it's, it's nice to be, I suppose, in contact with other people who y- you can go along and say "whew I just don't feel too good today but I've, I've made it I'm here" and it can		did, it gets you out of it 209. it just showed me that… just showed me that everybody can cope different and that, but if you let it get to you… why let anything get to you? You know, it's a… you've still got to live your life.	management. I said, 'well, I've done that before, and that's general, and I don't think I'd gain anything from it'. Whereas, doing the Fibro one, I felt I'd got a lot to gain because I didn't know so much about it anyway. 204. So, I said, 'well, it's not an age thing, but the best advice I'd give is to learn to pace', I says,		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				make you feel a bit better.			'because, it helps'. 862. We did have variance, 'well, why don't we try… we'll try so and so, or do so and so'. So, it was good because I remember we had quite a good group.		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
2.3 High functioning vs Doom & Gloom	2.3.1 Negativity			1085. I mean people turned up with- some people I think probably turned up with a		507. Other people, you know. People that you don't	868. And, medication was the other strong one [laughs], that was the	702. it was just asking us to put our feelings and our thoughts down on paper.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				different attitude, see I always go along with the attitude that I might learn something I might learn nothing but if I take just one thing away that's an improvement even if it's only one thing that helps then fine that's great um it's been worthwhile whereas I can remember sitting next to a guy and he said (pause) "are you- what are you here for?" and I said "oh fibromyalgia" and he said he had something wrong with his back I think it was and he said uh (pause) "I don't know why I'm here, do you?" and I said "well I		know, and I didn't know who they were, what they did, and how they were coping with this day and that day, you know – did I want to know what their life was like? When you're coping with your own, you don't want to know anybody else and what they're doing.	other big debate. And, 'oh no', you know. But I'm all – if it helps, it helps. Why struggle?	All the rest, I mean, they were loving it, but all the feelings and thoughts were negative. Not one of them came up with a positive side. And, every time I put my hand up or whatever, to say something positive, I'd kind of get… they'd all look at me as if to say, 'how dare you come in with that kind of mentality, don't you know how it feels?', or I don't know. It just… yeah, I was not comfortable at all. 756. I wouldn't want to be part of it now, actually, if I think about it. Because, I can't	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				just came along to see you know I might find something out" and he went "there's nothing they can tell me" he said "I might as well go home and weight train" I was like "what?" and you've got a back problem! And he'd gone by lunchtime 739. there was (pause) for some people an underlying and I suppose that's probably (pause) where I was once because there's that, certainly for me it was not getting a diagnosis people had been backwards and forwards to their GP not got any help and				cope with everybody else. Yeah, maybe that's my selfishness. I just can't cope with the way that other people handle it, when they're not handling it very well 889. my friend, she's always… bless her, you know, she's got a stick and a wheelchair, and all the rest of it, she's in a really difficult place, and I always try and offer my support to her and you know, say, 'take it easy', or, 'is there anything I can do to help?', or whatever it is, and that's fine. But,	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				eventually got to the pain clinic and a diagnosis I didn't know how everybody had got their diagnosis so there was certainly an underlying anger I think…and frustration (pause) and that becomes emotive				then I can't sit with her for more than two hours, because she just is on this trail of just, awful awfulness, and I don't know how to help it. 879. I mean, they're all very… they're very kind of, supportive of each other. I don't… you know, they'll say, 'oh, are you having a rough day? That's rubbish', to whoever has put whatever. You know, 'keep your chin up'. There is lots of camaraderie, but in a sort of, negative way if that makes sense. They'd be like, 'oh yeah, I feel like that too', or, 'I	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								have a week where I feel bleurgh, I know it's awful, chin up', whatever. So, it's… yeah, I just find it maybe… it's just… I can't manage it. It's not my way of thinking. 320. And, I'm part of these groups, you know, online. I don't like to look at them too much, because again, it is all a bit doom and gloom, and depressing. But erm, I feel there's a lot of people out there who are not managing it very well. Not by any fault of their own. 754. But, I think sitting in those sessions, it was just a little bit too	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								much, too soon. Maybe… it would be too much now. I wouldn't want to be part of it now, actually, if I think about it. Because, I can't cope with everybody else. Yeah, maybe that's my selfishness. I just can't cope with the way that other people handle it, when they're not handling it very well 783. Whereas they, you know… if you're in an environment where everybody is doom and gloom, and got something wrong with them or whatever else, then you're unable to… you	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								can't see the light at the end of the… you can't even see the tunnel [laughs]. You're just in the pits of doom, maybe. 415. But, she said it was a shame, because of course, if someone like me sat in the room and gave the flipside of how to manage it, it would help. But, I said, 'I can't take on 10 people, I'm not… I don't...', and you know, some people would say, I don't know, 'she's not got Fibro because she doesn't feel like we do', but I know that's not the case with such a wide range	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								of symptoms and it's all about, we can all have different thresholds can't we, and resolve of how to manage life? 592. There was one lady in there with Fibro, and again, she just… I don't think I even told her I had Fibro because she was just in the depths of hell [laughs], and I didn't want to be part of the conversation. Because, I don't want to be the person trying to tell somebody with Fibro, that it's not as crap as they think it is. 415. But, she said it was a shame, because of	

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								course, if someone like me sat in the room and gave the flipside of how to manage it, it would help. But, I said, ‘I can’t take on 10 people, I’m not… I don’t…’, and you know, some people would say, I don’t know, ‘she’s not got Fibro because she doesn’t feel like we do’, but I know that’s not the case with such a wide range of symptoms and it’s all about, we can all have different thresholds can’t we, and resolve of how to manage life? 702. it was just asking us to put our feelings and	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								our thoughts down on paper. All the rest, I mean, they were loving it, but all the feelings and thoughts were negative. Not one of them came up with a positive side. And, every time I put my hand up or whatever, to say something positive, I'd kind of get… they'd all look at me as if to say, 'how dare you come in with that kind of mentality, don't you know how it feels?', or I don't know. It just… yeah, I was not comfortable at all. 409. But, they were all just arguing with it	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								constantly, and I just said, 'look, it's no good for me sitting in there'. It was a bit like you know, I felt like, 'we should all just make a suicide pact' [laughs], 'just leave because we can't cope, because we've got Fibro', and I didn't want to be part of it 710. She even suggested that – they didn't in the end – if they needed somebody to do, you know, some sort of like, video or conference or whatever call, to give the other side of it so I didn't feel like I was in… you know, being fed to the lions, then	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								she would have been interested with me doing that because I could give the flipside, which is what they don't want to hear, but they need to hear.	
	2.3.2 I'm not like them		450. …and when I went it was alright but no one was my age which I didn't like they were a lot older than me and I was the youngest and I didn't go to a lot of them because I had college and it (pause) clashed 462. [why try the group?] It was because I think there's no harm in trying and I have to do it because when	615. and even sort of talking to them and trying to (pause) say to them that actually doing some exercise does help but just find what's right for you…you know (pause) um it was quite hard I found that people- some people were very reluctant to, to do that. 1097. I'd wondered whether there was a combination of	1031. So as well as I might be thinking something other people might be thinking things as well so you know you just keep going and give it a chance really		58. But, I'm not one of those that will let it beat me. 858. But, I think they… to me, they'd got it more. They'd got it far worse than I had. Rightly or wrongly, it was just my, you know, vision of it. 104. I'm not one to go, 'oh, it's this'. I'll just keep going, I just might be a bit quieter during	98. Why… erm, I think I believe in the power of positivity. And, I think Fibro can be very difficult to stay positive within, whereas that's my aim. I must stay positive and, just got to get on with it, regardless of having Fibro 101. You can let it affect your work life, you can let it affect your home life, you can let it affect your socialising,	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			I'm older and I'm working I'm going to have groups like that so like try and build up my confidence by just trying to go to it. So, I went to it and I felt fine but I just didn't like it because there was no one my age and no one really talk- spoke to me. 471. I: No one really spoke to you? P: Yeah, because they were all the same age apart from me I was... I: Right. P: ...I was 19 and they were about thirty, forty fifty. 718. They just asked "how does	people who really needed pain management (pause) people who were in pain and decided I'll go home anyway because I'm, I'm in too much pain and I've, I don't feel I've learned anything...and it ended up I think there were three or four of us at the end of the course that all that was left. 183. although at the time because I worked I couldn't fit in the things that you know people I was with didn't work I don't think anyone else on the course worked so they do a bit of hoovering and then lie on the sofa didn't really			the day, or… you know 176.… I said, 'I must admit, when I did the Fibro pain management course, compared to some of the candidates', I said, 'I actually felt, almost fraudulent'. Because, I wasn't walking with a stick or a frame, I wasn't spending days and… what I class as… well, would class as days and days in bed 184. But, I did feel very, you know, 'should I really be here?', when I was looking around the room.	whereas I think you just have to plough on and get on with it, basically. 595. I don't want to be the person trying to tell somebody with Fibro, that it's not as crap as they think it is. Because, it is rubbish. But, that's not how I tackle it. Yeah, so I don't know, it must be the perception that people have got of it, themselves when they have it. But, then that's… I'm not saying they shouldn't think like that, that's their prerogative, they can think how they want.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			fibromyalgia affect you?" and then people were talking about how it affects them and how like some of their partners don't understand and stuff like that. I: So, in a way (pause) it wasn't- wasn't things that you're usually (pause) dealing with? P: No cause I don't have a partner they just talked about how their partner and how they have kids…	(chuckles) fit with me at work. 627. I think some people needed to (pause) talk about how they felt about their fibromyalgia and to perhaps let go of some of that, which I'd probably had a little bit more time to do…because I'd had it for longer. 620. there is a benefit I've found… exercise but then again, I've come at it from a different route because I've always exercised so um it's a little bit different for me um (pause) I was surprised how emotive it was for some people. 1130. I did take things away so um			185. I thought, 'well yeah, because you've still got it', it's just I know the levels, and that varies. So… and your needs. It's like every, you know, like every other illness, some people have things quite au-fait and sail through, and others have to have anything and everything that's out there, so. 621. that was where looking, that was where I felt the fraudulent one, but then again, from the inside I'm thinking, 'hey, no' 623. I actually said it, I think it	But, that's not how I deal with it. Yeah. 921. [what would improve the PMP?] instead of having a room where you've got 10 people who are at the beginning of their journey, or… not the beginning in that they might have had Fibro for 10-15 years, the beginning of the journey of accepting that you've got to do something about it yourself, as much as the medication and all the rest of it, if they had something available for those of us where you have 10 of the positive-	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				you know I said there were things that didn't apply to me the hoover a quarter of the room and then lie on the sofa and have rest because I was working so those sort things didn't apply but I took things away and did things differently			was the last, or the last but one session, I said, 'do you know, I'm sat here and I almost feel a bit of a fool,	thinking scenarios, versus one that needs, you know, bringing up into a better mental state. That's all. 514. I'm on these sites, and I know there are lots of us that are positive, but we seem to be few and far between. So, I know… as I say, I don't want to take that path, I don't want to be on that road. 863. But, they're the… like I say, the elite… they're the high-functioning… so there seems to be a divide between us. There's the ones that are in the pits of gloom, and then there's the other ones	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								who are managing really well. 867. Maybe there is a… I think that's what they did on the psychologist one, she said there was about 95% of people with Fibro, who find it very difficult to tackle, and the bottom 5% are all suicidal. And then, at the top, you get 5% who are running marathons and enjoying their lives, and managing and all the rest of it. And, she said, 'you sit up there'. So, I think it's very difficult for all of us to interact and understand each other.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								227. Because, I think if you keep… if you stop moving, the Fibro takes hold. So, I think… they said to me on some of the pain management courses, that I'm what's classed as, 'high-functioning', because I can if I train for six months, run five K. Because, I can slowly… it's about the slow build-up. 241. I might then be in pain from that, and then I'll take some Morphine that night. But, then that's it. I'm not on any long-term continuous day in, day out, pill-popping [laughs]. Because, it just	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								does not appeal to me. I'd rather feel what I feel like, than adjust my life and masking it, and not knowing when I'm overdoing it or not 317. Maybe I am dealing with it the best way that you can, by doing the exercise and keeping the correct mental mind about it. But, I feel for other people who have got Fibro who, it's a huge struggle 517. that makes it sound like I'm saying that their lives are awful and it's terrible, but that's how I… I don't know, could I be so bold	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								to say, 'that's how they choose'? 762. What I need, maybe for my personality type, is somebody to go, 'that's crap [participant name], you should get on with it though, you'll feel better tomorrow'. 771. They weren't there. They were… I was here, and they were there. I was way ahead… so yeah, in that sense, I was way ahead. Like I said, I wasn't ready in one sense because it was too confronting, but in the other sense, I had already talked myself through the, 'how you	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								need to tackle this mentally', whereas they were all needing massive direction and help. 779. But, you've got to work your way up to that. And, these people were like… maybe they hadn't thought of it like that. 780. These people had not been given any tools, or maybe weren't raised already… I mean, maybe I already had the tools to overcome things that are incredibly difficult, through the power of thought. 863. But, they're the… like I say, the elite… they're the high-	

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								functioning… so there seems to be a divide between us. There's the ones that are in the pits of gloom, and then there's the other ones who are managing really well. 806. this could be to do with… it's my mother's religion, bless her, is exactly that. 'If you accept an idea, it becomes real'. So, if you don't, then it doesn't exist. Even though it does [laughs]. So yeah, I agree with you. 229. I'm what's classed as, 'high-functioning', because I can if I train for six months, run five	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								K. Because, I can slowly… it's about the slow build-up. I think normal, average people could probably get to that point in, I don't know, a month or two, whereas it might take me six to twelve months to get there, and I just have to incrementally raise the bar every time, very small amounts. And, that then doesn't counteract the pain, if that makes sense. 456. Because, the more you're negative about it, if I just whinge and whine and whatever else about it, or constantly draw	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								attention to it… so for instance, my son actually doesn't know that I have Fibromyalgia, because I don't wish him to feel like he's losing out or missing out on anything 465. Yeah, positivity… yeah, it's fragile for that sense, that's how I feel. 776. I'm not saying that Fibro… Fibro makes people feel horrendous and it is absolutely… it's awful. But, you've got to… you've got it, so you've just like I say, you've just got to get on with it	

Appendix 8c: Participant quotations to support theme 3

3. Making sense of & reactions to psychological approaches to fibromyalgia

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
3.1 Psychological approaches are a waste of time		795. ‘I think it what- a, a, it probably was spoken about, like I said I, I, my memory isn’t…isn’t, very good unfortunately’ 845. ‘I can’t remember…’ 854. ‘listening to other people and having (pause) a greater sense of what it was and how to look after yourself better um which is what I put in place…um and		556. The first general pain management course I did we had [name of psychologist] with us…and she did things like relaxation and things, so we had a tape to take home and do the relaxation but that’s about it really. 572. Yeah, the early one with [name of psychologist] (pause) I only remember the um doing	557. [what were the negatives of the PMP?] No um (pause) I (chuckles) yeah (laughs) I think we all felt the same way, I can’t really remember why we felt that way…but some of us started to feel like (pause) “what are we getting from this? Why are we here?” like “this is just empty” like we were not- this like empty information like “why, why are we here what	534. [on the peer support group] I did go, I think it was last year, for a couple of sessions. But, they were going over the same thing, and I didn’t feel like I needed to keep listening to the same thing over and over, if you know what I mean. 552. Obviously, you know, most of us	753. [PMP groups are designed to have CBT elements. Did that come across?] It did. Erm, but I think at the time, there were only a couple that felt they needed… this was kind of, where… I’m not going to say I switched off [laughs], but when I did my original pain management, general pain		314. Whatever they told me I already knew to be honest because from the internet…reading. 394. Cause whatever information the doctor and the other professionals were there, I already knew them by doing my own research. 421. It’s like you know whatever they’re saying we already know what you’re telling us we already know that, we’ve done our research. Tell

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		I still, I still do that now' 916. 'I can't really remember (pause) much about it really.'		the uh relaxation with her…and probably talking about sort of more cognitive techniques but then again, I don't know whether one of the physios talked about that I can't remember. 596. um (pause) gosh (long pause) there was quite a bit and I can't remember the rest (long pause) I can't remember the rest sorry. 1115.so there was that little sort of element of it	are we (pause) striving to come for?" 574.[on the negatives of the PMP] I dunno whether we felt "hang on a minute you're not teaching us anything here"… …like we're teaching you…like, "why, why are we here?" 631. [do you remember why you thought the information was empty?] No, what, what it was um I can't remember the questions that were asked but um (long pause) it was a case of we just felt that (long pause) there weren't	have the chronic side of it, where the chronic pain was ongoing and… they went through a bit, but most of it was like, you knew it anyway, sort of thing, in the back of your mind. 555. By that time, you'd already gone through it, so when they're speaking about it, it's like, 'well I do know really, what's going on'. So, it got to the point where, you know, there was no point	management course, that was covered a lot, as well as erm, medication and physio. 49. Because, I'd done a pain management course a long time ago, and didn't feel… before I had… was diagnosed it as Fibro, I did this, and it… I felt at the time like a box-ticking exercise, and I will admit it. 595. they had an early… the early one that they had would have been the normal pain management, which		us something that we don't know (pause) why is, why is there out there that will help us to be normal? 432. I know what they gonna- so whatever they're gonna to say is going to be useless if it's just medicine you go unless you're getting medication tried…maybe it will help.. 343. they went through what pain is, how to manage it (pause) medication (pause) and we had a few tai chi light exercise (pause) that's all I can remember. 350. [on thinking the PMP should have been more practical] Practical

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				as well (pause) um I can't remember much more from it to be quite honest. 1180. I'm trying to think what the other things were (long pause) I can't remember off the top of my head	teaching anything that we didn't already know. 637. So it was just a- the- when I say 'empty information' it j- I just meant by a- they didn't teach us anything we didn't know because what they were saying we, we were we've been through it, going through it or it was a bridge we'd crossed or…nearly crossing so yeah it was just like hmm, like this is a bit like, you know (pause) it doesn't help at all. 570. it was only til- we, we just um one of the	in me going again. 558. So, it got to the point where, you know, there was no point in me going again [laughs]. You know, there was nothing that… they weren't telling me how to cope with it, we were already doing. 700. You'll only grab a few little bits out of any of the programmes. It's not every single one, it just gets mundane and boring, to a	admittedly I hadn't done with this hospital, but I had done with another department, which is why I felt like I was a box ticking exercise. 825. So, I just found it very… I found it was a box ticking exercise, the first time around. I just thought, 'I'm here because you're going to tell me this, this, this and this. And, once you've done all that, that's it'. I was out on my own, and I didn't find that helpful at all.		in the sense of (pause) you, you know when we did tai chi rather than doing four half an hour something maybe they, they dedicated a whole session (pause) I mean with a break in between telling us, showing us how to do things (pause) maybe would have helped. It would have been good. 558. Umm (long pause) it doesn't help thought (long pause) "you have to stay active" how can I stay active if I can't even (pause) move from here to there?

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					ladies actually dropped out (coughs) and uh we just (pause) carried on going and then found the light (pause) to the tunnel…: …halfway through. 579. But it was only until somewhat through the course that we actually started to think "oh okay this is, this is alright". 583.But the first initial group the uh meeting uh I think you asked me earlier what a negative was to the first um (pause) it was um (pause) doing the exercises.	certain aspect of it.			

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					588. Yeah we were asked to do physical exercises but not warned about it. One thing they teach you with fibromyalgia is (pause) prepare yourself for what's to come and then it won't be a shock to you but that wasn't (pause) you know……known to us. So then it was like the first time I refused to do it because I wasn't prepared for it… 602. yeah because I just felt "when I go home" (pause) "I'm gonna be wiped out" I probably wouldn't even				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					be able to drive myself back so I refused to do it. 925. [Do you remember what was helpful in the PMP?](pause) No. 930.[on what was helpful in the PMP] Yeah, no I think it was just maybe because I had mentioned it maybe um (pause) the psychotherapist must hav- he probably mentioned something… 938. but it was positive although I can't remember! 988. [on peer support groups]…I've only been there				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					three times um (pause) sometimes the information you get is too much to grasp or… 1118. I thought "no disrespect but you've gone through how many years of university to sit there and listen to someone"…"I can talk to a friend or a family member"…that can sit there and listen" like you want a bit more interaction like you know 1150. so yeah that person uh just listened which you know (pause) some people may feel (pause)… …better speaking to a				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					stranger um (pause) and not getting anything back but I wanted just a bit of reassurance and a bit of you know (pause) interaction 1157. whereas you know (pause) you get nothing back yeah, mmm. [What would you have wanted them to do?] Just a bit of interaction. 1162. Yeah, a bit of interaction you know (pause) not just "how does that make you feel"…"or why do you feel that way?" you know. You know how you feel…because				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					that's why you there, do you know what I mean?				
3.2 Let down by professionals using psychological approaches		406. 'So I got re-referred to the pain management here… and what was really annoying was the fact that I had an appointment, they cancelled it because they didn't have any consultants they, they'd- they just, they were closing it because	1006. Yeah so- I have had it like I've had different psychologists but like they just didn't want me like I've had four different ones and after four weeks I've got discharged (pause) but they don't understand that I'm now going to trust in four weeks' time (pause) that's the impact I have. 1021. Mmm yes so then I phoned back [name of mental health	665. then you come in and you do your course and the first time it sort of ended and then off we went and there was never any follow up to that I never saw those people again that I'd been with… 871. we did have a psychologist come in *(pause)* now	1211. [did the MH professional have a plan?] No (pause) it was to just go there and talk about whatever was bothering you and that was that. 574. [on the negatives of the PMP] I dunno whether we felt "hang on a minute you're not teaching us anything here"… …like we're teaching you…like, "why, why are we here?" 1235. [on seeing a CBT therapist] It was, yeah it wasn't	453. [on being offered the PMP] Thoughts were, you know, 'I'm not going to somewhere like that, they're not going to know what… they're not going to know what's wrong, and this, that	929. Or, maybe there is not the funding and the rest of it, because of course the people that are most in need, are the ones who are taking medications, unable to work, etc. Is that it? 407. I always remember the pain management specialist, the first time		641. [was the CBT content noticeable in the PMP] Ummm no. I don't think so no. 96. it was the internet that gave me more knowledge more support than doctor themselves. 413. Cause to be honest you know all of us who are

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		there wasn't enough staff 413. 'then they gave me another appointment three or four weeks later ah, and they, they rang me to say that they'd double booked so missed that appointment'	team] and I go "I don't know where my counsellor has gone because he told me he'd- he'll message me" then I had another one because the referred me again the second one he discharged me after four weeks and then back to my GP I had a third one then he discharged me and I've never had support again. 1028. I had a mental health assessment and the woman literally just lied on the discharge paper cause I told her stuff, she didn't write on it (pause) she just	the one that worked here I think had was just leaving cause she left part way through the course I think *(pause)* I'm sure she left part way through the course…and she just had- we just had one session with her I think because obviously there was nobody else at the come to come and take- she'd either just left or was just leaving I can't	very helpful yeah. [can you remember any positives about it?] Not really, like I say you can you know you can (pause) go and meet up with friends and have a coffee… and have a chat, do you know what I mean and probably get more out of that you know cause you're getting a bit of advice or inspiration back but you know um or ring if it's fibromyalgia rate, late, related going into your group chat and speaking to one of the ladies in there. 1249. Cause sometimes when you have um (pause) people like that in uh (long	and the other. 455. They're not going to know what pain I'm in, and my every day bits and pieces I've got to do to try and get myself motivated every morning and every night, when I've got to go to bed and I'm, you know, having to go on a stairlift up to bed'.	I ever went, sitting with me and going, 'right, you've been referred to us, blah blah blah, and you now expect me to have all the answers, don't you?', and I remember looking at him going, 'yeah, but you haven't, have you?' [laughs]. He went, 'no'.		either suffering with fibromyalgia or any other chronic pain we know better than the doctors to be honest!

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			lied and then like she kept saying "you don't need it, you don't need it" then I said "I don't want it then" 1105. and then the third one seen me for one day and then discharged me. 1130. ...and then she left in December which had a huge impact on me as well because I told her everything about me and that had a huge impact because now I've got a new mentor but by the time I trust her I'll be leaving college, there's only little bit of things I'll tell her...	remember now. 1167. the um (pause) [peer support] group we- you know we were invited to the group that was being set up after the (pause) main pain management group the one that meets once a month so there was that continuity as well that wasn't available...	pause) in a, in a counselling session (pause) they're not equipped to answer questions because they're a psychologist they don't know anything about fibromyalgia...cause they haven't studied it so yeah, you're not even going to be inclined to get any (pause) uh support back from that either so yeah it doesn't really, it doesn't really help				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			1136. …and because of my first mentor I stopped having suicidal thoughts because she helped me so much but since she left they've come back again because I don't have her no more… 1156. and then when I had my second mentor I told her that it's affected me that she's gone and then like and then she goes "I know but professionals always leave" she goes "just write down the good things that she did and don't remember that she left"… and that she just left out of nowhere.						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			1166. and then like after- because I went on holiday I didn't see her the last week of Christmas and then so like then I got an email and she told me that she was leaving, so I couldn't even say goodbye because I was on holiday. 1387. There was one negative with the [name of a hospital for children] psychologist…she , she just used to ask too many questions about my religion and like…and like you can tell when someone's racist… she kept on saying "are you oppressed?",						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			“did someone force you to wear a scarf?”, “did someone do that?” …this was at the end she started asking me. 1398. [it wasn’t a good thing that you were asked about your religion] No, she wasn’t against me that’s what like but it was just like you’re a bit to intensive about my religion.						

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
3.3 Psychological treatment ingredients	3.3.1 Professionals trying to help	158. ‘I had um a little bit of counselling from work when I first got diagnosed’	558. Yeah, so we saw ourselves negatively sometimes, you can’t do stuff and	827. obviously what was said there um you could at any time go and speak to one	442. then the little handbook you can carry around with you that you know you need to reflect on	796. And, just asking you, and then speaking through how you can actually cope		200. They just… I think they just wanted to try all sorts of things to try and help me,	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		161. work put that in place for me to see someone um which was (pause) it was, it was beneficial' 830. 'but yeah no they were lovely…' 1187. 'obviously when we were at the group I was still in pain and they were trying to, you now, add this one, take that one do this, do that blah, blah 1385. 'it was just literally just uh somebody just sitting there and just listening…' '	then we learned about how to do it at your own pace because sometimes you just do it and you overdo it so they taught us how to pace it and not to overdo it because that makes it worse. So, like when you're really better, like, like even myself when really better I'll overdo things when I'm so better but we don't realise it has an effect on the next	of the nurses or [name of physiotherapist] or anybody if you wanted to. 1325. and to have people- so [name of psychologist] came in and did a session, [name of physiotherapist] does sessions, there were other invited guests about different things to help you um but you now it's, it's an ongoing and learning process.	something…you know, mmm so yeah it's very interesting. That was the initial first um twelve week course that I did. 523. it was a special group cause although you had your psychologist teaching you had nurses around you as well…and people from pain management there with you also…so different people and so (pause) physiotherapists, so you had different people around you, you know	with your every day bits and pieces. They were very good, very good to speak to and everything. 659. [on laughter yoga] It gives you a bit more… it brings you out of yourself a little bit, thinking, 'well, you can be bright and cheerful'. Even if you are in so much pain, you've got to bring it out a little bit. And, they did it like a sense of relief. I don't think I'd do it		which was nice. 390. But, I've never felt like that. I think everybody that I've seen has seen it at face value, and not… I don't think I've ever… no-one's ever said to me, 'oh, just…', I don't know, 'that's your Fibro', or whatever. They always seem to treat me as an individual, and look at the other alternatives 407. It almost sent you on the course because they're trying	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			day…yeah so, they said to pace it and take breaks and not to overdo it because it effects the next day. 372. …they've been helpful when I've (pause) been seen. 742. Yeah so it's been helpful…even though NHS takes too long but the NHS is quite helpful to me. 747. …even though NHS takes too long but the NHS is quite		who would step in and help and do certain things throughout uh the programme… 840. it will help you for what they teach us as well cause there's little diagrams in there where it shows like um (pause) let's just say like um I don't know it's like a, a dinosaur let's say and this dinosaur is the thing that is (pause) instructing your pain. Your balance, your, your fatigue and it's like you're on another side	again, but you know, for that one time, it did help a little bit. It's not something that I'd do on a regular basis, sitting there and looking at people, and just laughing. 680. [were there any changes to your fibromyalgia or MH after the group?] I think it's more, your thought process. It gives you a little bit more of a wide scope on, you know, what people deal		to steer your thought process towards positive and you know, exercising and all the rest of it. 643. I don't know if that was actual CBT, or they're advising us to look into CBT. I think I was… maybe that's what the second one was, the actual Fibro group. Maybe that was CBT sessions with the Psychologist. 702. it was just asking us to put our feelings and	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			helpful to me. 1163. [What were the good things your mentor did? Like cared for me did stuff for me, thingy like if I asked her to stuff- do something for me she would do it straight away (pause) and then like we used to talk every single Monday. 1251. [of CAMHS psychologist] And then like we used to talk through like writing and cards		you'll have something really nice but this dinosaur's saying "no that's really horrible so go and direct" and so it sends an army to attack this thing that's good er, which causes the pain…causes the imbalance, which causes the you know so (pause) that helps to uh (pause) help you with you, your cognitive uh therapy. 850. that helps to uh (pause) help you with you, your cognitive uh therapy um even saying like (pause) instead	with, and how certain… what the strategies are of doing everything. And, I think before, you know, your head's not all with it, sort of thing, when you go into these groups. You don't expect to get anything out of it when you first go in, but I did. 865. [on how the group changed your views of your fibromyalgia] It gives you a different mindset altogether, doesn't it, really? You		our thoughts down on paper. All the rest, I mean, they were loving it, but all the feelings and thoughts were negative. 838. I said what I found great about it and the people that were involved. I think it wasn't just erm, the Physiotherapists, I think we did have people come in, maybe for like, the sleep bit, you'd have somebody from the sleep department come in to talk	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			and stuff because like I never used to speak…and then because I don't want to speak because I was scared because I've always had a trust issue I don't know why… but that was a big thing for me. And my confidence was always quite low so like she used to play games with me and cards just to show that she's not something to be afraid of.		of trying to walk to the shop try and walk a few paces down the road you know try walk to three houses…turn back and go home you know it might seem a bit sinister but it actually helps to train your brain into you know "actually this is okay we didn't do that much 862. and then you get a folder which helps if you're going through any certain things it you know um (pause) has a back-up plan to help you get up again	know that if you're… you know that you're going to be in a certain amount of pain, so you… it's trying to get into that mindset, 'I'm not going to let it get to me, I'm going to go and I'm going to do what I need to do, every day' 798. [on physiotherapists supporting MH] They were very good, very good to speak to and everything. And, you knew you'd		to you. So, it was good. We just had different views, everyone discussing. 709. But, I did raise that with the Psychologist, and she was very understanding and said, 'this is not for you'.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					eventually yeah. 869. Yeah I do use it um (pause) but if somethings out of sight it's out of mind so if something's in front of you your more inclined to pick it up and look at it really but yeah mmm, it's useful, very useful, it's very good. 1193. Well the first appointment she said um "oh it's just, you can speak about whatever it is you want" 1257. [what's different about private therapy?]Um you we- you get	only got like, half an hour, unless you did…			

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					the interaction back (pause)…as well as you speaking you get the interaction back…and the inspiration the uplifting, that spring in your step when you leave do you know what I mean, you feel, you know, it's been worthwhile…you know so that's the difference yeah. 1384. in that book as well that they give you I forgot to mention there's a relaxation CD, in the back…that helps you as				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					well so that's quite good…and it helps you to completely relax your whole body so yeah and breathing techniques…which are very, you know deep and invasive on the body…which is also very good so my meditation stemmed from that. 1271. but again it's just giving that positive feedback back you know and helping you to feel uplifted, suggestions you know things like that yeah..				

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
	3.3.2 CBT 'rammed down your throat'			1110. there was an element of sort of like cognitive stuff so sort of being in the supermarket and you've got I can remember them saying you've got pain and trying to think of something different and…(inaudible) duh, duh, duh, duh			760. But, I think it's because – and I can only talk from a personal experience here – I decided I didn't like the way it was being put across, and that erm, I almost felt like I was being told it was all in my head. Which, I know it wasn't 767. I have my moments, and I'm not disputing, but I almost felt like I was being told at the time that	634. So, I think CBT was part of it, Cognitive Behavioural Therapy. Erm, in your… which is… I am very interesting in the training, that thought can create further problems, or make it better depending on how you tackle it. 696. I just remember, it was definitely a lot about your thought process, erm, talking about your feelings. So, like I said at the beginning, 'I don't want to be talking	549. Because I know it's not only me with things, it's not in the head. That, that's another thing when doctors say it's in the head it really does (pause) bring you down cause we know it's not in the head.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							it was all in my head. And, I'm thinking, 'it's not all in my head, because I do put a positive front', and I know I have done since. And, I mean, if I wasn't positive, I wouldn't have got halfway up Snowden, and certainly to the top 796. But, I think that's where I was kind of, put off. And, it kind of, didn't… at the time, it really didn't sit well with me.	about it in depth', because I just find it really awkward, and it was all of that. 699. So, maybe it was me confronting stuff way too soon after the scenario. Whereas, now I think because I've gone through it, I'm a lot more… I can manage it. 704. Not one of them came up with a positive side. And, every time I put my hand up or whatever, to say something positive, I'd	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							817. But, that's what did me for that first course. But, it wasn't… it was very different when we did it with the Fibro. [what was different?] I don't know. Perhaps I took it… it wasn't so much… I don't want to say, 'rammed down your throat', because that's the wrong… but do you know what I mean? It wasn't pushed at you so much.	kind of get… they'd all look at me as if to say, 'how dare you come in with that kind of mentality, don't you know how it feels?', or I don't know. It just… yeah, I was not comfortable at all 743. [what was it like thinking about your thoughts and feelings?] I didn't like it, particularly. Because, I'd rather just get on with it. So, it was like, presenting me with the problems and then asking me to put	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							And, I think more because it was perhaps, a group, than when I did it before, it was individual. 844. Perhaps it was just because it was different people, and I kind of, just felt that on this particular one-to-one, I was kind of being bump, bump, bump, bump, bumped with it all, and… I can't put it any other way, to be honest.	down how I tackle it, whereas I'd rather just do that. Because, if it's in front of you… I try to ignore the problem bit, and just look at the solution. Like I said, putting everything in the drawers and shutting them. I know they're there, but I don't want it to… I don't want it to be right in my face.	
	3.3.3 Opening	1423. 'it's actually been (pause)	552. we did a bit of physio and people	627. I think some people needed to	942. so I think uh feelings were discussed	712. it's good that you've got	863. So, it was good because I		390. Meeting other

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
	up & offloading	beneficial (pause) to actually come here and just to chat about it because I don't have (pause) I don't talk about it…very much' 1477. 'but just sitting here and just talking about it has actually "wow!" so it's probably been the first time in about two years or so that I've actually really (pause) opened up about it which is probably a good thing' 164. 'there was a lot of, a lot of anger that it, it, it brought up a	just used to mainly talk about their feelings and how it affected their daily life…and what's the positives and negative of fibromyalgia. 1307. I was just able to speak about my feelings and just speak about school because I had no one to speak to in school. Yeah. 552. we did a bit of physio and people just used to mainly talk about their feelings and	(pause) talk about how they felt about their fibromyalgia and to perhaps let go of some of that, which I'd probably had a little bit more time to do…because I'd had it for longer. 1204. we discussed other issues as well sort of but (pause) I suppose though over the years I have, I have become more assertive in knowing what I want and saying no to people	and you know how we view things and how we perceive things, how we deal with things uh emotionally and physically and how it can have an impact on you so that really, really helped yeah. 902. So being at the course whilst that happened helped me a lot yeah um to, to, to even be able to cope with that so that helped my emotions. 1116. coming over when I did that I was actually able to speak to somebody but it didn't really	somebody outside that box that can tell you a little bit more, and somebody else that you can speak to like that. 703. But, to talk to other people when you're in there, is one of the best things you can do. 401. Family, friends, anybody that's on the Internet. You know, if you've got that coping strategy to speak to somebody… it's like anything, you've got to	remember we had quite a good group. I mean, we used to have quite good group discussions about whatever it was we did, but I remember it was… I do remember it was quite erm… I can see faces, more than remembering names, and we did get into quite a bit of a, yeah, a discussion on that one, so.		people going through the similar things, sharing your feelings and thoughts with them and staying within the room (long pause) I'd only say them, nothing else. 180. So that does help, I think that group is helping me you know when I'm having one of those days and I

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		lot of emotions of how I was in the past’ 175. ‘- basically talk about how- how I felt about, the condition um, um and all of that around it really and the impact it was having on my relationship and, and me as a person’ 753. ‘the person that I was speaking to at work was just someone who was just sitting listening really…for me just to (pause) you know spout off about how much I hate fibromyalgia and all those	how it affected their daily life. 434. [of mentor at college] They’re involved in the college so people who have mental health or health conditions or autism etc they help those people… and you can just go to them and just talk and say whatever you want, however you’re feeling. 1124. [What’s	about various things 1204. we discussed other issues as well sort of but (pause) I suppose though over the years I have, I have become more assertive in knowing what I want and saying no to people about various things 1216. so we discussed some of those sort of issues um (pause) I don’t really have- I suppose I’ve (pause) worked	help cause it was just me talking like she said that she was there to listen and I thought “no disrespect but you’ve gone through how many years of university to sit there and listen to someone”… 1170. So you know just probably a bit of initiative to be- just to throw in a little incentive or you know a little bit of inspiration or something you know…just to feel good when you walk away not to expect to be lighter because you’ve	let it out, if you don’t let it out….			go “I can’t share it with the kids I don’t to, let me share it with the group and get it out of my system” once you type it you do feel (chuckles) you do feel better. 365. so you know swear as much as you want, say what you want they understand they won’t give you the eye “oh she’s in

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		kind of things really' 1348. 'it was just a- wasn't a proper counsellor it was just somebody that you could just go and offload.' 1353. 'it's your place to go and (pause) offload about whatever is it you want to offload about um and for me to sit there and say "right I've, I've got this and blah, blah" it was just a case of me just literally just talking…wasn't really (pause) like any in depth questions	been the impact of talking to your mentor on your fibromyalgia ?] That was helpful because I've just been able to tell someone something and then she told me she goes "if you ever have thoughts you can take it out on me over email if you want to, if that helps you" and she allowed me and then she helped me so much… 1150. Like I was able to speak to her	through lots of different things as life goes on you tend to work through any different issues and things yourself so we touched on one or two things 1158. we did sort of some cognitive techniques and talked through those sort of things again with the psychologist	offloaded something				that mood"…they know because you're in that mood you're getting it out of your system (pause) it was good… 372.: …for example at, at home if you feel one of those days and you feel like getting out of your system the only way is swearing or screaming 575. Have I found myself

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		coming back because the person didn't really know (pause)…anything about it'1368. 'it was a good thing that I had something because I didn't have anything else so I had something um (pause) and for me to be very open and honest with them (pause) um has you know, has maintained me to still, to still be working there' 1440. '- I think I've surprised myself with some of the things that I've	about her- anything then I used to tell her you can't tell certain stuff to teachers and then she used listen to me and teachers never used to know and just talk about my feelings and like every time I had thoughts like she just used to make me like "you are thoughtful, you are clever enough" and that "I'm proud of you" and stuff like- stuff like that						changed um (long pause) to be honest no (pause) apart from in the back of my head if I need to let it out I let it out in the group (pause) other than that.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		said as well and it's nice just to…open it up.'	helped me because she believed in me						
	3.3.4 Learning about fibromyalgia & management techniques	1250. 'I guess it, like I said, it just gave me more of an insight about how I need to (long pause)) how I- how I need to live…and to take onboard, you know, (pause) listening to other people about their (pause) you know, their, their stories and their kind of how they've managed it then (pause) it's helped me because I've taken some of	500. [what do you remember about the PMP?] Yeah so after every session at the end we used to do tai chi. [And what was that like?] Um that was alright some people did it standing up and some people did it sitting down. I did it sitting down…because I can't stand up for too long. Yeah and we all enjoyed	584. Um we discussed what fibromyalgia meant for us the consultant came in and talked about (pause) fibromyalgia and what they think causes fibromyalgia and about the nervous system et cetera 611. going down into the gym uh that was fine I mean I exercise anyway um so (pause) it	509. [of the PMP] teach(es) you not to push yourself too much……take little steps and not big steps you know, so yeah that was, that was very positive. 674. Like I said um (pause) helping you understand what's happening to your body, helping you um (pause) not overexert yourself, teaching you that when you do x, y and z this could happen, you know so	786. 'how are you actually coping? We'll sit in, we'll do exercises but you can sit and do them, sitting down. You haven't got to get up. We'll do these breathing exercises, but you know, as you're doing some of these exercises, we'll talk to you and see how you're feeling and that', and that really did help. 649. You know, they	707. So, it was really good. And, it's that little bit that, if you're not somebody I suppose, who is motivated or can be, it's something that you can do, even if you only do two or three of them a day. You're still doing that bit of exercise, if you like. That bit of movement, so. 351. I learnt a lot off that,	545. And, we had a session each week, one would be on sleep, one would be on exercise, one would be on medication. 608. I think they did… they talked about the cycle of pain. So, the generic one was all about pain, and how it connects from being in pain, not sleeping, mental capacity, you know, being not in a great place, that	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		them onboard…' 714. 'They obviously a- you know, advised me possibly to take up, you know, maybe yoga, tai chi…all those kind of things, which is what I tried but for whatever reason my body just didn't accept it um and that actually while I was doing the tai chi (pause) um the pain was just…intense and I thought I can't, I can't go through it cos I need to enjoy it'	that because it's not like it's not a very hard exercise it's not that intensive so that's why I liked it. 514. [of the PMP psychologist] Yeah, so like he pretended the lizard- pretend the lizard has the pain and just giving it all to the lizard so your pain goes away…so it's a metaphor… Yeah and some, some people found that helpful.	was just a little bit extra than I would normally do so I didn't mind doing it 613. I could see the value for people who didn't do any exercise because I think there were quite a lot who didn't do exercise because they have pain. 647. but um that's- that's quite useful as well because it- it's ongoing and there's an encouragement to do exercise so somebody comes in at	it's, it's um important information and like I said it didn't come (chuckles) to later on in the course… 713. and reflexology my brain tends to be a bit overactive and think you know um "this is awful" you know and then it brings more pain on me…and then more fatigue and headaches and things like that instead of "oh this is uplifting" you know (pause) "this is fine let's relax. 857. I tried it in the group I	did used to bring people in to have a talk. I think… so the last person that came in, she did something for… just sitting there and doing a laughter yoga. And, it's so weird. You don't expect to sit there, and just sit there laughing at each other, but when somebody starts and you listen to them laugh, then you start, you think, 'how stupid are people?'. But,	and how to sort of, utilise the information I'd got. And, in some ways, how to just totally ignore the information I had. 554. But, it's that not knowing, and then it's that knowing, but okay you know what it is, but then you've got to learn what it is and how it can affect, and what you can do and sort of, not do to help. So, it's that complete learning curve.	then leads to no sleep, that leads to pain. And, it just goes round and round and round in circles. And, they were constantly teaching us how to break between each part of the cycle. 620. There's lots of little things, and if you adjust your environment, you're then complimenting what it is that you're actually trying to do. And, if you can break the cycle, you can't get rid of the pain but	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		909. 'but you know them saying about different foods and stuff, trying to maintain (pause) um which is (pause) I have good days and bad days (pause) um part of me still thinks I have some form of an eating disorder but it's certainly not what it was…thirty odd years ago um (pause) but I have a better relationship with food now than I did so that's, that's the main thing really'	1322. [of the CAMHS psychologist] Yeah and she did pain management with me as well…because she was both of them (pause) I've still got that at home. 1326. [of the CAMHS psychologist] That was good because she told me like how to like when I'm stressed how to breathe how to like, like when I'm having a panic attack just to blow into a bag um like	the end and does tai chi and things like that and that's a follow on and it was nice to have that follow on so you weren- you're not just left hanging… don't just do the course and go away 1199. I found them really useful um I was introduced to mindfulness … I found very useful (pause) uh because I wanted to get off the sleeping tablets so I was referred	walked to the shop which was about in total probably a thousand yards in total and I came and I was just down and out like I just couldn't do it. I: Mmm. P: Uh and I never done it since, I was gonna to try it again the other day last week and I just didn't 1010. It can be um (long pause) I think the last one was medication I think you ju- and you can speak about um (pause) cognitive therapy 1016. the last session was	it does help, actually. 439. it's like going to do meditation with it, you've got to do breathing exercises and take yourself off somewhere else in your own mind for a bit, and just have the peace and quiet. And, it seems to work. 784. I mean, they didn't just do the physical side, they did help with the mental side of it as well. 386. It was just to explain how to… they	566. Once I'd got that, 'this is what we're saying it is, this is what it's all about, this is what you know, may or may not help, this is where we roll with it', if you like. Once I'd got that, I was a lot better at accepting it, and learning, well, what to do with it and how to cope with it. 650. There was a whole section on diet and you know, different medications and things like that, and	you can help yourself in other areas. 661. What I've learnt from going to university, is there are certain places that give you better, sounder knowledge and information, than say, Wikipedia or wherever it is. So, I loved that going in, I was hearing from professionals, where they've studied a certain scenario or they've talked about going to hydrotherapy, or they've	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			that…and I've still got that from years ago. 1334. Yeah and I still have it, sometimes I'll go back to it. [So, you still use it] Yeah because it's a booklet and I used to- I used to take it to her every four weeks.	to [name of psychologist] specifically for sleep issues. 1225. she introduced me very gradually to sort of breathing techniques first of all and gave me a particular website that I've downloaded things from and, and used (pause) um but it was almost sort of slowing your breath down…so we did those types of things and different	about the (pause) medication and how, how you keep out of pain and things like that 436. and it's, it's, it's kind of widespread because you get a folder and you get a booklet…so you've it's you've got like a (pause) handbook for life really with every situation starting from A to Z like whatever may occur or "this is what you should do" or "try this" and so yeah that helps yeah. 694. [what differences has	would explain how to deal with the pain, and what chronic pain was and how to cope with it, and just your strategies, you know. 546. … I think it was mainly saying, you know, what is… it's a coping strategy, you've got to, you know… how to go through the different levels of pain that you're in, and then what is chronic and what, you know – what's	that I found really useful, because a lot of us had tried different medication that had helped some, helped others. Me, I wouldn't touch some of them again with a bargepole, because I just didn't like how they made me feel. 669. It's like… but the course itself… I mean, because you had a different input	talked about acupuncture and its benefits to you. That was really important to me 824. I think the first one, as I say, was definitely beneficial to have. People who are, you know… it's their remit, it's their area of expertise, giving me advice or discussing situations, that was very useful, and I did change things based on that. 659. I think it… there's only so much	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				breathing patterns 199. so I suppose for me because it had been a very long time that I'd had fibromyalgia um I've picked up things along the way for me but you still learn and pick up things and it was good to do the course 1119. Oh, they did sort of they did a session at the end that was um (pause) about sex and being in pain for people who wanted that um so	the PMP made] I'm not in so much pain as I was, other things happen but I'm not in so much pain. I learn now how to ah (pause) use my body itself…to ease certain pain um and even with an ordinary person I'm like- they'll say "oh this hurts" I'm like "oh well do this" and they're like "oh yeah that helps!" I'm like "yeah!" (laughs) so yeah and just learning things… 798. Well I do a different type of meditation to what they	chronic Fibromyalgia, and what's the other form of it that, you know, it's not as chronic? 589. But, going to physiotherapy and them just saying, 'we're not going to do an exercise, we're actually just going to get you to breathe'… they said, 'because, the amount of pain you get in, you get flustered and you breathe from your chest, you don't breathe from your	anyway, and they spoke to us about sleep and the different sleep patterns. 693. But, that was a topic they covered as well as erm, one of the Doctors came in and covered that. We have medication covered, we had diet, we had pacing. We had some physio. Little bits of physio sessions as well. Because, that was good.	research you can do yourself, you can read stuff and like we know, on the Internet, a lot of stuff is a load of rubbish. What I've learnt from going to university, is there are certain places that give you better, sounder knowledge and information, than say, Wikipedia or wherever it is	

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				yeah, but it was a, a much broader…thing. 1140. So I took things away that you know I, I could adapt and use for me at work and things. 1153. the consultant came in and talked to (pause) um us and family members about you know what fibromyalgia is um (pause) um and parts- so partners were included and partners went off and chatted with other	did, they did a visualisation meditation where I do a deeper meditation. Um (pause) which is hard at first like I say with the mind you know and you've got a thousand things going on, you're trying to relax it takes time to settle even now I'm still trying to (pause) not think about other things where you have to bring your mind back to your meditation and carry on you know… um yeah so yeah meditation it	stomach where you're supposed to breathe through, from your stomach and through your chest'. And, with getting me to just lie down, whichever way… wherever you're comfortable, on your side, back or anything, just get comfortable, lie down, and practically, have a sleep. It's going into that mindset – breathe through your nose and out through your mouth, and	722. So, to me it was a positive, because I didn't know that much about it. So, if they were able to teach me, or you know, teach me about it, teach me how to deal with it or you know, things that I could do to help, then because of the type of person I am, then yeah, I was definitely up for that 730. So, I found it really good that one, it could be offered, it		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				partners and discussed things and came back and fed back sort of what had come back and things like that so that was um quite different to the first one. 1230. so we did those types of things and different breathing patterns um I was introduced to and the one thing that I (pause) I took away from there the one big things for me was if I couldn't follow a	helps, helps a lot. 810. [How does meditation help?] It, it uplifts my mind, clears my mind, even though when I'm doing it I might think that you know I'm swaying to things like "oh gosh I need to go and do the washing up" or "what am I going to make for dinner or whatever" um it actually uplifts me for the day and um helps me to relax to keep somewhat relaxed probably keep a routine, you know that I'm	take it really long and slow. And, it's taking you off into a different world. It's really good 601. It's the only thing that does… it relaxes absolutely every part of your body. Which, you know, it does help for a bit. Sometimes, the amount of pain you're in, you've got to do something to alleviate it. And, pills and medication only work so far. 469. the pain management	was there, and two, that I actually got to do it. Because, I did find it really helpful and very informative. 57. So, I learnt a lot on there about erm, pacing, and sort of, not putting yourself through it 638. We had… we had sessions on learning to pace. Pace yourself with what you did, and how you go about doing things. [0:59:55] So you know, if it's the		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				relaxation or breathing pattern and I found my mind wandered off it didn't matter I could just bring it back 1244. then the one big thing that [name of psychologist] did was say "it doesn't matter" she said "it really doesn't matter. If you're mind wanders just acknowledged that when you come back to and it and just say 'okay' and just carry on (pause) with	trying to incorporate whether it's bake a cake at two o' clock you know or have a ten minute nap or you know at half past two read a few scriptures of a book that I should have read the day before or something so yeah um it, it does help manage especially when the house is empty you have that time for the for yourself. 1036. [what are the good things about the PMP?] Getting the information. Learning	team's been fantastic in... and the physio. I mean, the physiotherapy, to get you to... to make you learn to relax 474. I think I take to her a lot more with getting moving and getting motivated and everything else, and she got me in the right mindset to say, 'look, if you just lie here and do your breathing exercises, instead of breathing from your	simple thing that... as it was put, if I remember along the lines – you go around the house on a morning with the duster, it might have took you, you know, half an hour to do the whole house a while back, but you know, one room can be... or a couple of rooms, is enough. If you're starting to feel you're flagging a bit, then stop, have a break, or change		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				wherever the tape is just carry on" and that was a big thing for me because I found it quite difficult to sort of do that beforehand so it was I almost just went "oh okay thank God for that. If my mind wanders it doesn't matter I can just bring it back to the tape and that's it" and that really helped just that one thing really helped and I found the mindfulness	different techniques of relaxation 1044. So I think it's just looking forward to you enjoy, looking forward to the information…that you might receive, asking questions that you know your GP probably can't answer and things like that so yeah.	chest, breathe throughout and take yourself off into a different world, put a bit of music on if need be. Just say – I'm relaxing now, see you later'.	the job or the role that you're doing. 647. So, you sort of, you know, you don't limit what you do, but you listen to what your body's telling you you're going to do or you're not going to do. 911. I certainly, certainly took the pacing on board, a lot. Unless there were things I really, really, really wanted to do, and then it kind of, used to go out of the		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				very useful (pause) so I still do that… 1329. that's quite useful cause then you keep up to date with what might help fibromyalgia and I think that's important for people, otherwise you're still left- if you don't have that continuity and people informing you about things that have come out…you get left with whatever you've got at that			window just a tad 1020. I said that. I said, 'if she gets to do a pain management course…', they just don't have anything like that. And, I'm sure she said she was, Stoke. It might have been sort of, that way. And, I says, 'because I've got to be honest', I said, 'it's been one of the best things that I've certainly done with it'. I said, 'because, it's taught me		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
				particular moment or that particular time.			about it, and it’s taught me, you know, ways to manage and deal with it. 475. and being able to do the course and gaining the information from the course as well, and from… I say, ‘some’, not, ‘all’, because erm, when you Google, ‘Fibromyalgia’… and I mean, you come up with weird and… if you Google any topic, you can come up with weird		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							and wonderfuls for whatever. 474. So, I must admit, it's pain management that have been my God-send with my Fibro, because they've… and being able to do the course and gaining the information from the course as well,		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
3.4 Outcomes	3.4.1 'A positive mindset'	292. 'but I guess out of- out of all of it, it would be	494. And since because of that group I've been	182. …I think um that was- that was	691. [has the PMP course made any difference to your fibromyalgia?]	629. So, doing them breathing exercises,	629. I'd say anyone who's got Fibro, can	444. Absolutely. Yeah, absolutely. It	810. But um family been saying you

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		something that would be beneficial for people in the future, from my own experience’ 1368. ‘it was a good thing that I had something because I didn’t have anything else so I had something um (pause) and for me to be very open and honest with them (pause) um has you know, has maintained me to still, to still be working there’ 918. ‘It was a very good experience and that and you	going to other groups because I have a bit more confidence. 1267. [Did the CAMHS psychologist affect your mental health at all?] Yeah it supported me a lot because I was mainly having problems at school	more general and I did take away some things were useful	Yes I’m not in so much pain as I was, other things happen but I’m not in so much pain. I learn now how to ah (pause) use my body itself……to ease certain pain um and even with an ordinary person I’m like- they’ll say “oh this hurts” I’m like “oh well do this” and they’re like “oh yeah that helps!” I’m like “yeah!” (laughs) so yeah and just learning things… 1397. [do you think the course supported your mental health?] Massively yeah. Massively, especially having nothing it’s something…so yeah, it, it, it does yeah. Yeah it keeps you calm and relaxed	showed that everything can relax and you feel everything going… it’s just brilliant for anybody that’s got any sort of pain or anything else, it takes you away from it all. It’s like doing a form of meditation, but not sitting around everywhere. You can do it anywhere, lying down, sitting up, wherever you are. It does help. 468. and you know, like I	get on the Fibro pain management course, then they should. Because, it was just so informative if it’s something you don’t know about, and you can take so much away with you, to either store until you need to use it, or to use it. 1014. The pain management programme, I wish it was something that everybody	can. So, it’s like training your brain, that’s how I feel. I’ve trained my brain to be positive about it. 737. So, it’s not like it all hit me at once. I can have a day when something… I don’t know, my hand starts hurting and, ‘why is it doing that?’, and a lot of the time I’d say, ‘oh, it’s just the Fibro’ 577. I didn’t know that there was a difference between it being Fibro-	know “you find it hard sit down and do it” cause you can sit down and do it I go “no I ain’t going to do it- sit down no”…”I’m going to still try, I’m not going to give up” 546. I: do you think that helped your mentality? P: It has helped.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		know I can't speak highly of it I just wish it had come twelve months, eighteen months earlier…' 929. 'Yeah but it would have been (pause) yeah it would have been very, very useful, pretty much straight away or certainly within six months (pause) and I think that would have helped because it helped when I was there. 943. 'It would have been exactly what that group was (pause) the,			and collected, you know so yeah. 894. again when things happen (pause) um even just to manage (long pause) uh just k- just keeping calm, keeping your composure being humble 1024. just leaving that door open to meet people a bit more yeah 296. probably positives like that, helping (pause) helping me to understand (pause) more about it and how to help my family understand. 1287.I remember it and then the second lot was um (pause) free but it wasn't run by the NHS it was run a different company that was provided free…yeah	said, I would go back to speaking to people and that, the pain management team's been fantastic. 862. Can you think of any other ways that going through the treatments, [has the pmp changed your views on yourself or Fibromyalgia?] It gives you a different mindset altogether, doesn't it, really? You know that if you're… you know that	does, and everybody can have access to. Because, I know not everybody does a specific… and because I just know, you know, from different things that have been said from you know, different trusts, different areas… because, the Nurse who was talking to me about her [unclear 1:34:29], they don't have that sort of thing.	specific or generic, it just happened that the generic one came up first. Erm, but they covered all the areas that I needed help on how to deal with.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
		the group I can't, like I said I can't speak highly of it and it was exactly what I needed' 964. 'I think it was (pause) um, no it was it was a very, very good experience…a good experience' 978. 'so um but no it was uh it was just a very, very good experience.' 1131. 'it just exactly everything that I needed…so (pause) so yeah I can't speak highly of it (pause) it was a very good, very good thing to have'			it was called the "Record Again" it was positive (chuckles) so I remember it! And they were called "Believe to achieve". So that was very, very good also and that helped me tremendously yeah. 1296. [What was helpful about it?] Ah just (pause) it was helping you to become a better person, like if you know you can't do something but you're such a kind person you always say "yes" you don't learn to say "no" so they teach you, you know "if you can't do x, y, z don't push yourself because you're just going to put pressure on yourself knowing	you're going to be in a certain amount of pain, so you… it's trying to get into that mindset, 'I'm not going to let it get to me, I'm going to go and I'm going to do what I need to do, every day' 881. Which, you know, sounds stupid in a way, but in another way, it's helping me with just staying out… you know, locking myself away from	1026. It's… and I know the NHS and everybody's different, but I just think it's something that should be, quite simply, across board access. Because, it's just something that can be just, so… it's only so many weeks, but that short clump of time has got to have more of an ongoing ripple effect, surely, than not having it, and having people		

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		1258. 'so (long pause)) yeah so it, so it helped…um definitely the emotional side'			that you can't do it having to cancel or say "actually no I can't actually do this"" you know… yeah it was positive in those aspects, so yeah again things like that you remember.	everybody else for a little while, just to get into that mindset, and get out of that. You've got to get out of the box, with it. 869. It does get harder every day that you do it, but if you don't stay in the positive mindset with it all… you've got to stay positive with everything. [and, is that quite a lot of pressure, to try and stay positive all the time?] It can be, it can be.	coming in and out with… because, you kind of, know then that, 'I don't need to see the Doctor or anything today, because I know I'm just having a bad day' 899. Whereas, being on the pain management Fibromyalgia course, gave me those erm, if you like, the directions to go and things that I could do.		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							1048. Mental health has been, against my Fibro, has been a lot better. I admit that. Whereas my Fibro is concerned, it's… because, I try to be positive, and because I know the answers – she says – and I know how to deal with them better, then I've found that has been a lot easier. 1077. So, but I try to keep that		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							positivity that, you know, 'I can do this, I will do this' 798. But, I always would have considered myself as quite a positive person anyway, and I quite often told, you know… 'do you ever think…', I said, 'well yeah, I mean, we could always sit on the edge of the bed in a morning and go – right, oh this could happen, and this could		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							happen, you know. Everything else'. But, I says, 'you've just got to go out there and go, 'right, I'm going to do this. I can do this', otherwise you wouldn't. 1077. So, but I try to keep that positivity that, you know, 'I can do this, I will do this' 1042. if it was out there and accessible to all, it would, it would have that affect		

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							elsewhere. And, resources, some resources would be a little bit lighter. I’m not, you know, miracle-working but you know what I mean, where I’m coming from?		
	3.4.2 ‘I just take it at my own pace’		571. I liked that bit because like (pause) I used to do everything for everyone so now like I pace it at my own pace and I go “if I can’t do it I’m not going to do it	536. [of the pain clinic psychologist] Oh, um I got referred to her for sleep um and I worked with her and I no longer take the tablets.	876. [have you noticed any changes in the way you view yourself or fibromyalgia?] P: Yeah mmm hmm. Um (exhales) not beating myself up so much. Stop and give myself time, don’t beat myself up uh stop trying to push through things uh trying to get things	865. [on how the group changed your views of your fibromyalgia] It gives you a different mindset altogether, doesn’t it, really? You know that if you’re… you	792. But, I quite often hit points and I’m there thinking, ‘oh, I don’t want to do this, I’ve had enough now’. But then, the positive side of me will	580. the Physiotherapist sits there, it’s their arena, talking with you about how… we did like, exercises each week and we planned what exercises we needed to do,	605. It’s like when I feel the uh the pain is really too much (pause) I tell myself “I remember being in the group when he says body

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			and I'll do it when I can". 737. But me doing stuff at pace it helps my pain…and I'm quite independent, like I can travel… Yeah so, it's been helpful… 933….so that's that so, like I can pace myself now 947. I just take it at my own pace like (pause) before I wasn't able to walk that much I can walk compared to before. 1497. Like with fibromyalgia	636. [of the pain clinic psychologist] in fact some of the work I did with [name of psychologist] I found very helpful around that and relaxation I found very helpful the work I did with [name of psychologist] 1287. So that was, that was much better (pause) so yeah so, I found mindfulnes	done…you know. It's okay to leave something half-finished and come back to it um (pause) yeah just things like that really. 747. [on what supports her fibromyalgia] yeah um (long pause) and relaxation…meditation big, big one meditation yeah…amazing, it really, really helps. 906. It helped me suppress (pause) my emotions in order to (pause) uh (pause) not overexert my body… horrible as it might, might sound like um (pause) it, it well it's not horrible but it, it just helped me to (pause) uh cope uh deal with things…	know that you're going to be in a certain amount of pain, so you… it's trying to get into that mindset, 'I'm not going to let it get to me, I'm going to go and I'm going to do what I need to do, every day' 876. [how do you manage the pressure of having to stay positive?] Sometimes, I don't know. It can be very hard. Just take yourself off into your	turn around and go, 'yeah, really [name of participant]? Come on, you know you can, you know you can do it', you know. 1048. Mental health has been, against my Fibro, has been a lot better. I admit that. Whereas my Fibro is concerned, it's… because, I try to be positive, and because I know the answers – she says –	and that's where I realised I had to do things in a much slower pace, because my… prior to Fibro, I was incredibly athletic. So, it was difficult for me to take something on, on a much slower pace. But, I knew that I had the muscle memory or whatever it was, to be incredibly athletic, I just needed to take a very slow approach about it. 620. There's lots of little	tells you to rest you rest" I do no matter I'll just give up and I'll go, go to my bed and I'll rest. Cause the old me is "something needs to be done it needs to be done" 620. [on learning to do less housework] But now they stack it up, I don't mind that, I don't even say anything. I just ignore it, I've

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			like you can't do everything in one go, you have to take breaks and sometimes you have to say no even if someone's giving you too much jobs to do in one go…that's what I learnt… because I used to do everything in one go and now I don't… 579. Before I used to tidy my room up in one go and then my back would hurt and now I do it half and half so it doesn't affect me.	s really helpful. 192. so I got used to managing things and try to take things away that I could adapt and make work for me I've also done the fibromyalgia course as well, which again was useful… 1265. I still sometimes have nights where I'm tossing and turning but then I have nights where I do sleep better so I'm quite		own little world for a bit . Now, I can go off for a little drive somewhere and just sit there, and have that bit of time to myself just to unwind and get away from everybody. 885. I think that's what it is, you're stuck in a box and you've got to try and get outside that box, to free yourself a little bit. 480. It's been brilliant to just go off and have that five	and I know how to deal with them better, then I've found that has been a lot easier. 892. I did, because I learnt more about managing it on the course, than I had about… or, knowing what I was doing before it. Which, as I said, it was really informative for me. 954. [have there been any changes in how you view yourself or Fibromyalgia	things, and if you adjust your environment, you're then complimenting what it is that you're actually trying to do. And, if you can break the cycle, you can't get rid of the pain but you can help yourself in other areas 637. Or, things like, I don't know, instead of pushing yourself to buy – this is just a silly one – to buy a carton of milk, you could have it delivered, you could	learnt to ignore it I just get out of the kitchen and go to my room (pause) if they do it they do it, if they don't when I have the energy I will do it 180. So that does help, I think that group is helping me you know when I'm having one of those days and I go "I can't share it with the kids I don't

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			975. Uh, it's- it was about mainly getting my impendence back because I'm young and I see other people do stuff so I just wanted to get back to that pace. So, because of pain management programme and the support I had before that I started slowly getting back to it…it wasn't a rush it's just slowly and slowly. Sometimes I'd have my bad days when I have to taxi but it's	happy that I've come off the sleeping tablets and I'm quite grateful for working with [name of psychologist] on that and that's something doctor [name of doctor] did along with sending me to the fibromyalgia said "I'll also refer you to address sleep issues" so I'm very happy 1297. the biggest one		minutes to yourself. 786. [how are you actually coping?] We'll sit in, we'll do exercises but you can sit and do them, sitting down. You haven't got to get up. We'll do these breathing exercises, but you know, as you're doing some of these exercises, we'll talk to you and see how you're feeling and that', and that really did help.	] Yes. I certainly view Fibromyalgia very different, because I have a better understanding of it. What it is, and sort of, what it does. I know with… I listen to myself more. I listen to what my body says, 'look, you've done this for a bit now. Enough, have a rest', or… do you know what I mean? 204. So, I said, 'well, it's not an age thing,	have the milk and deliver it to your house. So, it's like cutting out little things that are exacerbating your condition, in order to feel a bit better. 679. Yeah, I think stuff like, I probably changed my sleep environment, like I say, I started wearing ear plugs, I made sure that my… I think I doubled up my curtains to make it more blacked out in my	to, let me share it with the group and get it out of my system" once you type it you do feel (chuckles) you do feel better. 596. I- the only thing I'd say (pause) since the group when I have those days where I feel like crying and screaming and yelling (long pause) I'd say I tell myself "I'm

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			better than before. 528. [on the techniques from the PMP psychologist] Yeah so that was one example and some people tried a different way so when I'm in pain I try to distract myself and not think about it. When I'll- I'll go into a bath if I'm in pain…or I'll just watch something to feel better about the pain and pret- pretend the pain's not there…	for me I would say would be the mindfulness with [name of psychologist] and that was a huge thing for me being able to come off the sleeping tables and at least get some quality sleep			but the best advice I'd give is to learn to pace', I says, 'because, it helps'. Which is why I'd always got so many things half done around the house, that it just looked like I couldn't be bothered [laughs] 494. we sat and we went through my little book of little tricks [laughs]. Even little erm, like, cartoon things that made you smile, or you know. And, I	bedroom. Erm, definitely took heed of the whole, 'not having caffeine'. I think I gave up drinking Coca Cola, it's just… little changes like that helped. 685. I think food has a lot to do with it, so making sure that you're not eating lots of processed rubbish or whatever, because that can then make… exacerbate the whole Fibro thing. Again, because Fibro	not useless, I can get through this (599. if my body tells me to rest I must rest, forget the housework, forget the shopping, forget everything" (long pause) I think that's it.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							thought, when you're having like, a flare-up and you're on a bad day, it's nice to have something to make you smile 501. They just laugh at me, but it's just one of my little coping mechanisms, it's something that makes, you know, you smile on a dull day, 689. And, I curl up with a book. Because, that is my form of relaxation, other than	is so new, we're not actually sure what is and what isn't affecting it. 452. I try and shut those drawers, and then open the positivity drawers [laughs], and go, 'I can do this'. And then, run around with you know, my son and family, and join in with all the things that they do, with a positive mindset 901. Like I said about going… doing something instead of just	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							crafting. And, I'm sort of, curled up with a book, and it just feels nice 901. So that's, I suppose, really when I started managing it properly, and not just hit and miss, you know, 'I'm tired today, I'll liven up tomorrow', kind of thing. Because, I knew what it was more about, then 958. Yes. I certainly view Fibromyalgia very different,	sitting at home thinking, 'oh, that hurts really badly'. If you're out doing something, it doesn't hurt so bad. It's still there. 334. I suppose it gives you like, a euphoric sense, that when you have a week where you feel relatively normal and you think, 'oh, this is great, may it continue?' [laughs]. Then, when I go back into the depths of gloom, I just remember	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							because I have a better understanding of it. What it is, and sort of, what it does. I know with… I listen to myself more. I listen to what my body says, 'look, you've done this for a bit now. Enough, have a rest', or… do you know what I mean? 1052. I know that a bad day is a bad day, and it's not… sometimes it isn't because I've pushed myself, it just is how it is. I	that I can have these glimpses which is nice, and just aim for those again. 448. you could look at it that your brain is, I don't know, it's like the archives of a giant library or something. And, I have all my little drawers where there is all the stuff about Fibro, I know that they exist and I know it's rubbish, and I know it makes me feel like crap. But, what I do is, I try and	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
							know that I'm, you know – okay, if it's a bad day, rather than stay under the duvet and not face anything 480. But, I did look a lot, through, and found I'm… I kind of, took chunks that I felt were relevant to me and that might help. You know, I'd think, 'oh, you kind of do things like that'. Or, maybe if you… so I've made, you know… like, I've got a	shut those drawers, and then open the positivity drawers [laughs], and go, 'I can do this' 35. I wake up in the morning and I have a certain amount of energy that can vary on different days, and I have to be careful with what I'm assigning that energy to. And, if I go above that, then I can end up with less energy the next day. So, it's all… I think it's massively about	

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							book, a little notebook and I call it my 'wellbeing book'. And, little things like, if I've either seen it and I've written it down, or if it's been in a magazine, something I, you know, things I like, just to do with health in general, but specifically I started doing it for my Fibro, and I used to stick them in the book or write… and so I've got it to go back	management, managing yourself. 55. So, it's all about me managing what I can manage, if that makes sense. And, if I'm not coping, I have to go away, think about it, and adjust whatever it is that's not working for me [laughs]. 222. Other people can do as much as they can, and give you medication and send you on these courses, but the main person who	

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							through and think, 'oh, what was it if such and such?', you know, and I've flicked through it and thought, 'ah yes, I remember now' 386. So, I know I'm sensible in some ways, and acknowledge it, but then I can… the way my body tells me, I'm thinking, 'that's not a right feeling to have', so. But, yeah. We get there [laughs].	can help you, is yourself. 283. Lots of people do have it, and it's a choice how you manage it. I believe it's a choice of how you manage it. I don't know if other people with Fibro would see that, but that's how I see it. 344. And again, it's all about management. So, if you manage yourself properly, you're more likely to have that scenario occur where you're not in	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								pain for a week 434. I might think, 'really what I want to do, is just lie in bed, but actually what will be better for me is to power through the pain, go to the event and sit through it, and maybe get more out of that' 437. You've got to weigh… it's all about weighing it up, I think, of how you're going to feel and what you're willing to get on with.	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
	3.4.3 'I didn't really get much from it'	757. [of work counsellor] 'They didn't really have any benefits really um I think was probably [place of work] just wanting to look as if they're supporting…their colleague really,' 1389. 'I: it sounds like offloading wasn't enough at that point… P: Not, not really because I didn't really know what I was saying and I didn't really know what I wanted back…'	983. [did the programme impact your mental health?] Not my mental health. I never used to speak about anything. 1542 [Did it change the way you view yourself?] That- no because I still don't have the confidence or belief in myself…it's taking time because I haven't had that mental health support yet. 1093. So, for with my first counsellor we		1170. [on attending psychology] So you know just probably a bit of initiative to be- just to throw in a little incentive or you know a little bit of inspiration or something you know……just to feel good when you walk away not to expect to be lighter because you've offloaded something but… 733. so with [pain management facilitator's] class um in pain management when he mentioned tai chi (laughs) I'd be out the door! (laughs). Right that's the end of the session for me I'm going because that causes me to plummet.I love doing it…but the effects	539. [on the peer support group] And, it's like, you don't want to be reminded of everything all the time.. 889. [on trying to maintain a positive mindset post-PMP] You just feel like you're locked all the time. You're locked away. You've got chains on that, you know, won't release, sort of thing, if you know what I mean. So, it can be very hard that way.		555. if there was a room of 10 people with the same mindset as me, I probably would have been okay, because we'd have shared all that sort of stuff. But, they all just… as I say, I just felt like we were just… it was all over for all of us, 'why are we even here?' [laughs]. I couldn't cope. 759. Even though I have times where I don't handle it… I don't want to be going into a	575. Have I found myself changed um (long pause) to be honest no (pause) apart from in the back of my head if I need to let it out I let it out in the group (pause) other than that. 221. I: Has there been anything particularly good or useful that you've been offered or… P: Um (long pause)

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
			were just talking about college life and everything and just that- and then like I had him for about two or three weeks and then, and then he went, we were just talking about family life and "how was school" because I didn't tell them deep stuff because I don't trust easily…because my trust has been broken in the past.		afterwards no. My body doesn't like yeah. 1116. coming over when I did that I was actually able to speak to somebody but it didn't really help cause it was just me talking like she said that she was there to listen and I thought "no disrespect but you've gone through how many years of university to sit there and listen to someone"… 1178. [did you feel better after speaking to the CBT therapist?] No. It's a waste of time. Yeah, just like it was a waste of time. 1223. Yeah (pause) I didn't really get much form it so there was nothing to miss…it's not like I			scenario and saying, 'I can't handle this', and them all going, 'oh no, I feel exactly the same', that wouldn't help me. 402. But, they allowed me to bow out. I met the Psychologist that was running it and just said to her, 'look, my mental state is so positive, but that doesn't mean it's not fragile, so if I sit in a room with 10 people who are literally just moaning and whinging and don't	apart from the infusion I'd say nothing else is good (pause) pain killers they just help you to function a bit. I: Hmm (long pause) nothing else about the treatment is a… P: No… I: …positive? P: …nothing else positive. 479. So had I been into a

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					thought "oh this is really great I can't believe I'm not going to have it anymore"… 1235. [on seeing a CBT therapist] It was, yeah it wasn't very helpful yeah. [can you remember any positives about it?] Not really, like I say you can you know you can (pause) go and meet up with friends and have a coffee… and have a chat, do you know what I mean and probably get more out of that you know cause you're getting a bit of advice or inspiration back but you know um or ring if it's fibromyalgia rate, late, related going into your group chat and speaking to one			want to look for a solution…', which is what I felt, which is why they were on the course. 409. But, they were all just arguing with it constantly, and I just said, 'look, it's no good for me sitting in there'. It was a bit like you know, I felt like, 'we should all just make a suicide pact' [laughs], 'just leave because we can't cope, because we've got Fibro', and I	fibromyalgia group itself maybe I would have (pause) come out with different thought 580. I: Okay (pause) has it affected your fibromyalgia or how you manage the symptoms at all? Silence 2 sec P: The group? I: Mmm. Silence 4 secs

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
					of the ladies in there.			didn't want to be part of it 716. if you continue to be in a spiral of feeling rubbish, and it's doom and gloom, it might sound controversial, but then that feeds into the... you can't get back to work, you have to remain on the benefits, because if you solve it you come out of that, and you can then go back into the, you know, society, and thrive and I don't know, better	P: Mmm. Silence 3 secs. P: No (long pause) it hasn't.

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								yourself. But, if you're feeling… once you're in the benefit system, you kind of, have to continue to be in that mindset to stay within the system, if that makes sense. 797. It's almost as if – and this might sound weird – if I talk about it, it happens. So, if I'm talking about Fibro and I'm saying, 'oh you know, it makes my arms feel like lead, blah blah blah', then I might	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								find in the next two or three days, my arms feel like lead. So, it's as if because I've said it, it will then occur. Whereas, if I can completely switch it off and put it all away… so as I say, this could just be the way that I view it might be absolute rubbish, my arms may have felt like lead three days later whether I'd said that I feel like lead, or not. But, the way I feel it happens, is	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								that it occurs because I think it. 400. I think… there was two I was sent on, one of them I really enjoyed, that was here, and then the second one, I can't remember what it was called, but I really didn't like it 407. It almost sent you on the course because they're trying to steer your thought process towards positive and you know, exercising and all the	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								rest of it. But, they were all just arguing with it constantly, and I just said, 'look, it's no good for me sitting in there 413. I didn't want to be part of it. And, she let me bow out after the second session, which was what was good for me 754. But, I think sitting in those sessions, it was just a little bit too much, too soon. Maybe… it would be too	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								much now. I wouldn't want to be part of it now, actually, if I think about it. Because, I can't cope with everybody else. Yeah, maybe that's my selfishness. I just can't cope with the way that other people handle it, when they're not handling it very well 895. And, I don't want to be… and like I say, when I talk about it, I sometimes feel it brings on the symptoms	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								that I don't want to feel [laughs], that maybe again, I mask myself, mentally. Maybe, you can control how bad something feels by you know, distraction techniques. 792. [on the other participants being 'doom and gloom'] Yes. It does make… it did make it worse. And, it does. Even when I speak to people that I know now, who've got it, they keep telling	

Ordinate themes	Subordinate themes	Quotes P1	Quotes P2	Quotes P3	Quotes P4	Quotes P5	Quotes P6	Quotes P7	Quotes P8
								me how awful they feel 827. But, the second one just taught me that I need to just carry on with my positive ways, and get on with it.	

Appendix 9: Health Research Authority (HRA) Ethics Approval Letter

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr Alexander J Smith
Trainee Clinical Psychologist

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

02 October 2019

Dear Mr Smith

HRA and Health and Care Research Wales (HCRW) Approval Letter

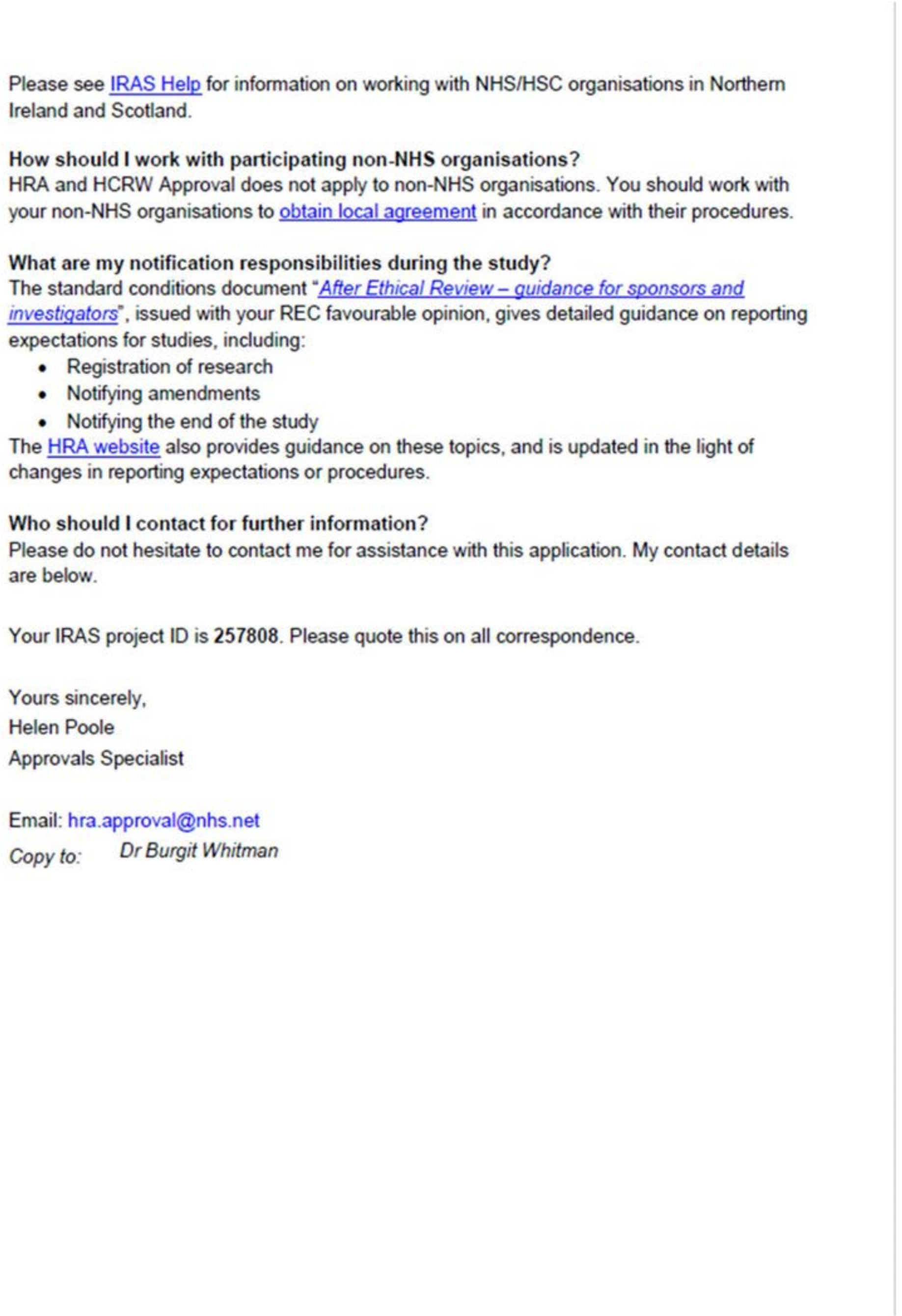
Study title:	**What are people with fibromyalgia's experiences of psychological treatments for their condition?**
IRAS project ID:	**257808**
REC reference:	**19/EM/0254**
Sponsor	**University of Birmingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

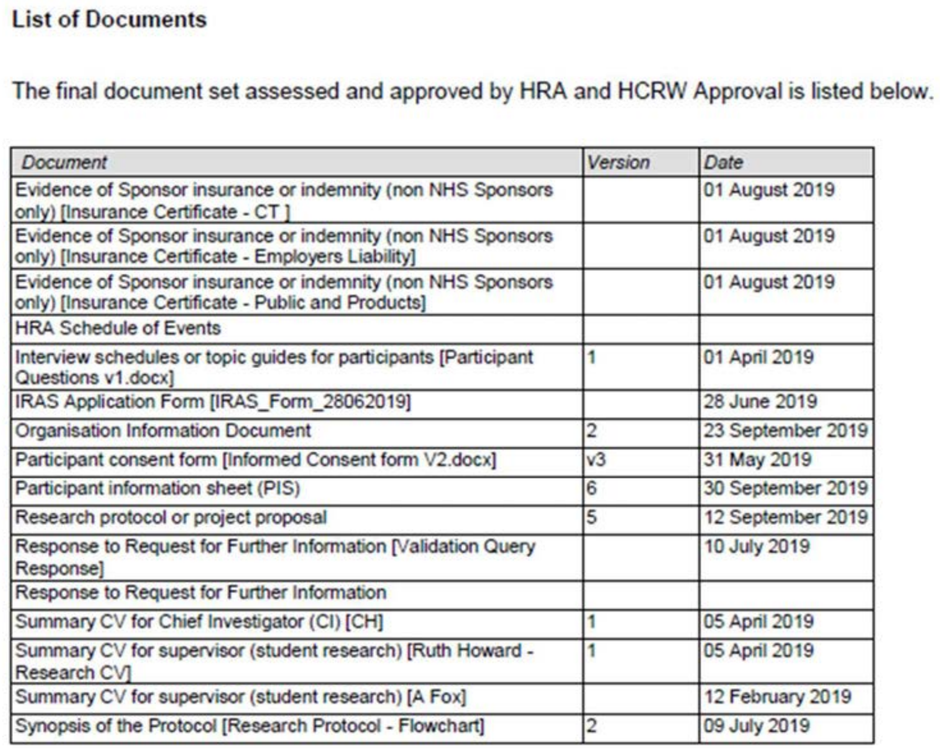
The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **257808**. Please quote this on all correspondence.

Yours sincerely,
Helen Poole
Approvals Specialist

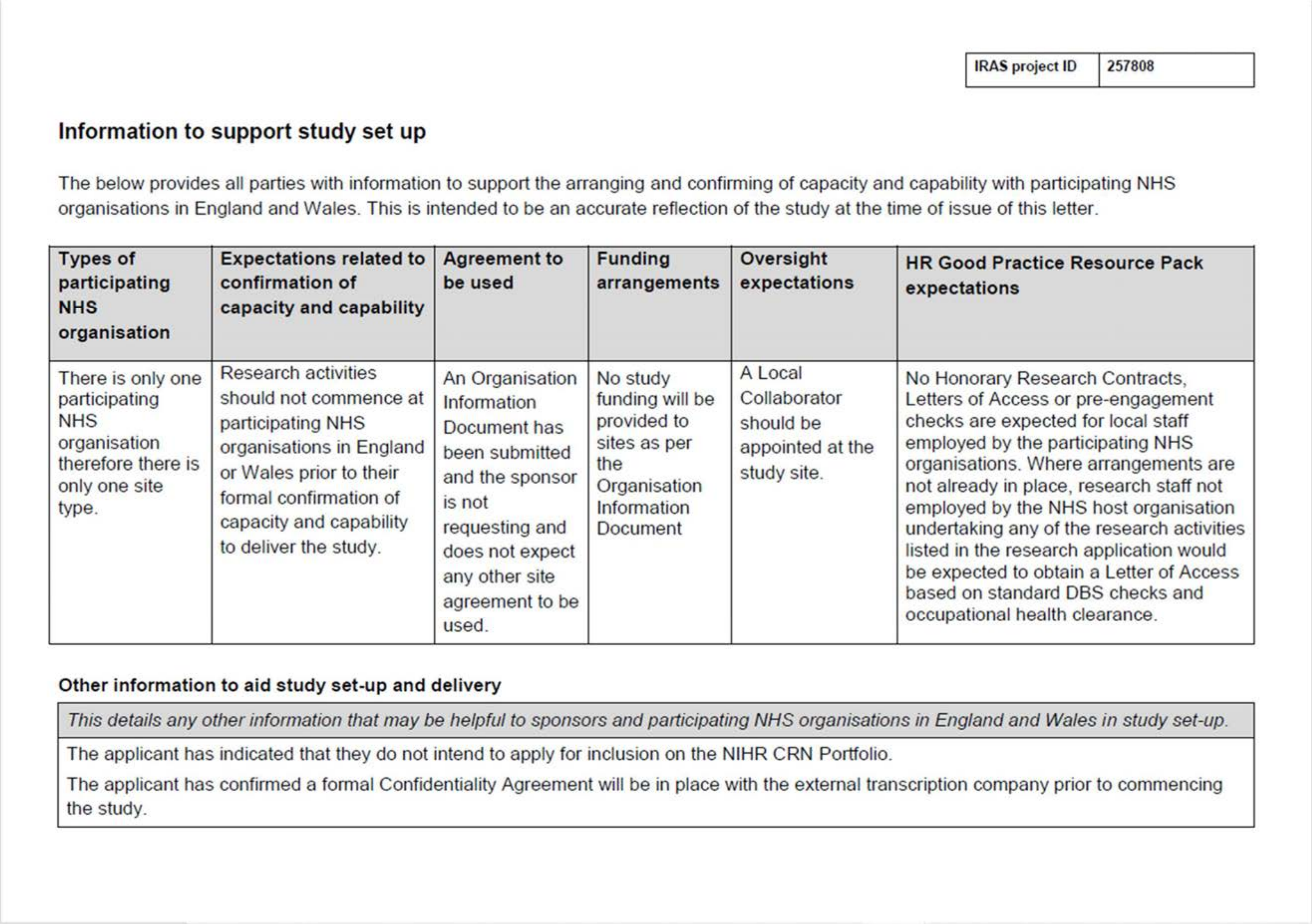
Email: hra.approval@nhs.net
Copy to: *Dr Burgit Whitman*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate - CT]		01 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate - Employers Liability]		01 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate - Public and Products]		01 August 2019
HRA Schedule of Events		
Interview schedules or topic guides for participants [Participant Questions v1.docx]	1	01 April 2019
IRAS Application Form [IRAS_Form_28062019]		28 June 2019
Organisation Information Document	2	23 September 2019
Participant consent form [Informed Consent form V2.docx]	v3	31 May 2019
Participant information sheet (PIS)	6	30 September 2019
Research protocol or project proposal	5	12 September 2019
Response to Request for Further Information [Validation Query Response]		10 July 2019
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [CH]	1	05 April 2019
Summary CV for supervisor (student research) [Ruth Howard - Research CV]	1	05 April 2019
Summary CV for supervisor (student research) [A Fox]		12 February 2019
Synopsis of the Protocol [Research Protocol - Flowchart]	2	09 July 2019



IRAS project ID	257808

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites as per the Organisation Information Document	A Local Collaborator should be appointed at the study site.	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio. The applicant has confirmed a formal Confidentiality Agreement will be in place with the external transcription company prior to commencing the study.