A Qualitative Exploration of the Family Relationships of Individuals with Fibromyalgia

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology (ClinPsyD) in the Faculty of Biology, Medicine and Health

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Thesis Abstract

'A Qualitative Exploration of the Family Relationships of Individuals with Fibromyalgia'

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University of Manchester, Doctor of Clinical Psychology, April 2020.

This thesis presents an in-depth qualitative exploration of the family relationships of individuals with fibromyalgia and consists of three separate papers.

Paper one presents a qualitative systematic review and thematic synthesis that sought to understand how women with fibromyalgia experience and understand family relationships. Data from 27 studies were thematically synthesised and five analytical themes were identified: 1) The impact of fibromyalgia on women and family life: *"there was nothing left of me, just pain, what if I can't take care of my children"*, 2) A changing view of the present and future self: *"How can you love me now, if I'm not the person I was"*, 3) Searching for understanding and support in the midst of an invisible contested illness: *"I'm having a bad day and you need to understand what that means"*, 4) Hidden pain and feelings: *"I don't want to give up ... I don't want to show people that I am in pain"*, and 5) Accepting and moving towards the future-self: *"he decided that he is going to be there forever, no matter what"*. A changing view of the self, relational difficulties, and communication barriers may have implications for well-being and family adjustment. In light of these findings it appears that treatment approaches with an increased focus on interpersonal difficulties and communication skills could be beneficial.

Paper two presents an empirical study that explored the romantic relationships of individuals with fibromyalgia who remained distressed or disabled by their pain despite receiving tertiary-level treatment in a multidisciplinary pain management programme. Seventeen semi-structured interviews were conducted and analysed using inductive thematic analysis. Three core themes were identified: *the relational impact of fibromyalgia*, *factors contributing to relational distress,* and *moving towards the future*. Results demonstrated that fibromyalgia can lead to changed relationships, interpersonal difficulties, and relational tension. However, participants generally struggled to adapt to and accept these changed circumstances. A range of potential contributing factors were identified including a perceived lack of communication, understanding, and support. It therefore appears that treatments with a specific focus on relational difficulties, partner support, and communication skills may enhance therapeutic outcomes for some.

Paper three presents a critical appraisal of the work conducted within this thesis and the researcher's personal reflections on the research process. The critical consideration of the work encompasses the planning, methodology, and implementation of the systematic review and empirical study. The implications of the work and dissemination plans are also discussed.

Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Lastly, I would like to thank my amazing friends and family for their endless support. Fin, thank you for always loving, encouraging, supporting (and tolerating) me! Finally, to my mum and dad, thank you for your unconditional love, support, and pride. You have always believed in me and I couldn’t have done this without you.

Paper 1: Systematic Review

How do women with fibromyalgia experience and understand family relationships? A qualitative systematic review and thematic synthesis.

This paper has been prepared in accordance with the publication guidelines of Social Science & Medicine (Appendix 1). This journal allows up to 15,000 words for systematic reviews including references.

Word Count

Complete text *(including references)*: 13,587

Main text *(excluding references but including tables, figures, and footnotes)*: 11,127

Abstract

Background: Numerous qualitative studies have commented on the implications of fibromyalgia for family life and relationships. This is the first review to systematically identify, appraise, and synthesise these findings to consider how women with fibromyalgia experience and understand family relationships.

Methods: Five electronic databases were systematically searched (CINAHL, Embase, MEDLINE, PsycINFO, and Web of Science) to identify peer-reviewed research studies containing qualitative data on the family relationships of women with fibromyalgia. Twenty-seven papers met the inclusion criteria and were appraised for methodological quality; data from the studies were thematically synthesised.

Results: Five analytical themes were identified: 1) The impact of fibromyalgia on women and family life: *"there was nothing left of me, just pain, what if I can't take care of my children"*, 2) A changing view of the present and future self: *"how can you love me now, if I'm not the person I was"*, 3) Searching for understanding and support in the midst of an invisible contested illness: *"I'm having a bad day and you need to understand what that means"*, 4) Hidden pain and feelings: *"I don't want to give up ... I don't want to show people that I am in pain"*, 5) Accepting and moving towards the future-self: *"he decided that he is going to be there forever, no matter what"*.

Discussion: Women with fibromyalgia can become distressed if they are unable to fulfil the gendered expectations associated with their family role. Relational difficulties may give rise to communication barriers which can have implications for family adjustment. It is possible that this population, and their family members, may derive benefit from treatment approaches with an increased focus on interpersonal difficulties and communication skills.

Keywords: fibromyalgia, women, family, relationships, qualitative, thematic synthesis

Introduction

Fibromyalgia is a chronic pain condition characterised by generalised persistent pain and heightened pain sensitivity (Wolfe et al., 2016). Individuals with fibromyalgia can also experience a range of concurrent symptoms such as sleep disturbances, fatigue, cognitive impairments, and psychological difficulties (Atzeni et al., 2011; Wolfe et al., 2010). Fibromyalgia has an estimated prevalence rate of 5.4% among the UK population (Fayaz et al., 2016) and predominantly affects women (Wolfe et al., 2018).

Fibromyalgia can be a very disabling condition and is said to impact every aspect of an individual's life (Wuytack & Miller, 2011). Occupational and social functioning are often impaired (Bolwijn et al., 1994; Palstam & Mannerkorpi, 2017; Söderberg & Lundman, 2001), which can lead to consequences such as financial uncertainty (Arnold et al., 2008) and feelings of isolation and grief (Kelley & Clifford, 1997; Raymond & Brown, 2000). These changes can have a profound impact on the identity of individuals with fibromyalgia (Arnold et al., 2008; Ashe et al., 2017), often leading to thoughts of a changed, and potentially unwanted, future (Hellström et al., 1999; Söderberg & Lundman, 2001). Crucially, the impact of fibromyalgia is not only felt by the affected individual but also by their family members (Evans & de Souza, 2008). Experiencing chronic pain conditions, such as fibromyalgia, in a family context can exaggerate the complexities of family life and highlight the restrictions imposed by the condition (Richardson et al., 2007).

Although there is a paucity of literature specifically examining the impact of fibromyalgia on family relationships, the implications of fibromyalgia for family life and relationships repeatedly appears as a theme within existing qualitative studies. For instance, it is noted that romantic relationships can change or become damaged (Collado et al., 2014; Marcus et al., 2013) and sexual functioning may be impaired (Bazzichi et al., 2012; Kalichman, 2009). Relationships with children may also become strained (Marcus et al., 2013), perhaps due to difficulties coping with the physicality of parenting and concerns around being unable to provide the necessary level of care (Ashe et al., 2017). Household responsibilities are often redistributed among family members (Hallberg & Carlsson, 1998; Söderberg et al., 2003) and social lives may suffer (Asbring, 2001; Söderberg & Lundman, 2001). Some individuals with fibromyalgia also feel misunderstood by their family members and appropriate support may not be offered as a result (Arnold et al., 2008; Juuso et al., 2014). The impact of fibromyalgia on the family can give rise to negative self-perceptions such as burdensomeness (Ashe et al., 2017; Kelley & Clifford, 1997), guilt (Ashe et al., 2017; Sallinen et al., 2012), and feelings of frustration (McMahon et al., 2012; Rodham et al., 2010).

It is clear that fibromyalgia can have a significant impact at an individual, familial, and relational level. Yet research has also demonstrated that family relationships appear to influence the experience of fibromyalgia itself. For example, perceived levels of stress and family relationship functioning have been found to predict future symptom intensity in individuals with fibromyalgia (Murray et al., 2006), while negative interpersonal events have been found to predict higher levels of fatigue (Parrish et al., 2008).

Despite these research findings, no systematic review has been published to date with a specific focus on the impact of fibromyalgia on family relationships. Previous meta-syntheses have sought to understand the overall subjective impact of fibromyalgia (Sim & Madden, 2008), and how individuals experience the process and consequences of receiving the diagnosis (Mengshoel et al., 2018). However, these meta-syntheses do not offer a detailed insight into how family relationships are experienced and understood by individuals with fibromyalgia. Consequently, little is known about how to effectively support affected individuals and their significant others to manage the difficulties associated with experiencing fibromyalgia in a family context.

In this paper we present a meta-synthesis of qualitative research on the family relationships of individuals with fibromyalgia. Qualitative methods have largely been utilised to explore this topic and, in comparison to quantitative approaches, these methods have the potential to provide richer data regarding family dynamics and relational processes (Ganong & Coleman, 2014) and an individual's experience of these. The decision to focus specifically on the experiences of women with fibromyalgia reflects a similar stance in the qualitative literature, likely due to the increased prevalence of fibromyalgia in this group (Wolfe et al., 2018). Social constructions of femininity and masculinity also influence how individuals view themselves, their behaviour and, importantly, their relationships with others (Fillingim, 2000; Saltonstall, 1993). It was therefore felt that it could be reductive to synthesise the relational experiences of men and women without commenting on the potential gender differences that might exist. However, this is impossible given the current paucity of qualitative research on men's experiences.

This review aimed to address an identified gap within the current literature by systematically identifying, appraising, and synthesising qualitative literature in order to explore how women with fibromyalgia experience and understand family relationships. We also aimed to consider the implication of these findings for future research and clinical practice (Sandelowski et al.,1997).

Methods

This systematic review was registered on PROSPERO (CRD42020169754) and is presented in accordance with PRISMA Guidelines (Moher et al. 2015) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Checklist (Tong et al., 2012).

Search Strategy

A preliminary literature search was conducted to develop the research question and to identify a comprehensive range of relevant search terms. A systematic search strategy (Table 1) was then developed using the Context, How, Issue, Population Tool (CHIP; Shaw, 2010). To ensure a comprehensive search of all relevant literature was conducted five electronic databases were searched: CINAHL, Embase, MEDLINE, PsycINFO, and Web of Science (Core Collection). The search, including all years to ensure maximum retrieval, was conducted in July 2019 and repeated in April 2020. Forward and backward citation searches were conducted for all included papers and reference lists were hand searched. Google Scholar was also used to search for any additional articles. EndNote (X9) was used to manage all identified articles.

Table 1: Systematic search strategy.

	Domain	Search Terms
C	Context	relationship* OR interpersonal OR spouse* OR wife OR husband OR partner* OR peer* OR friend* OR others OR family OR familial OR relate OR social* OR roman* OR sexual* OR interact* OR communicat* OR psychosocial
H	How	interview* OR thematic* OR observ* OR "focus group" OR phenomenol* OR "grounded theory" OR "discourse analysis" OR idiograph* OR narrative* OR "content analysis" OR qualitative OR "mixed method*" OR "conversation analysis" OR finding*
I	Issues	view* OR experience* OR opinion* OR attitude* OR perc* OR belie*
P	Population	fibromyalgia OR "fibromyalgia syndrome" OR "chronic widespread pain"

Inclusion Criteria

Peer-reviewed English language studies presenting qualitative data, obtained through the use of recognised qualitative data collection and analysis methods, on the family relationships of women with fibromyalgia were considered relevant for inclusion in this review. The following definition of 'family relationships' guided decisions regarding inclusion: *"behavioural, psychological, and social relations among various members of the nuclear family and the extended family"* (Cochrane Library, n.d.).

Exclusion Criteria

Studies presenting multiple perspectives and/or which were conducted with mixed samples (e.g., those including males with fibromyalgia, family members, or women with other health conditions) were only included if subjective data specifically relating to the experiences of women with fibromyalgia could be extracted (e.g., if findings were reported separately or could be separated). Similarly, studies applying mixed method approaches were accepted for inclusion if qualitative data were reported independently from quantitative data. Studies which had not been through a peer review process and grey literature (e.g., reviews, commentaries, letters, case studies) were excluded.

Study Identification

The results of the search strategy are presented in a PRISMA diagram (Figure 1, p. 17). Initially, the searched returned 3,333 articles. Following duplicate removal (n = 1,263), the first author screened all remaining titles and/or abstracts (n = 2,070) to determine eligibility for inclusion within the review. A second reviewer, external to the research team, also screened 27.2% (n = 563) of the identified articles (99.3% agreement). Following discussion, agreement between the two reviewers was reached. If eligibility could not be established from the title or abstract, the full-text article was acquired. The first author read the full texts of all potentially eligible articles (n = 73) and assessed these against the inclusion criteria. A second reviewer, external to the research team, also completed this process for 50% of the potentially eligible articles (n = 36) and, following discussion, agreement between the two reviewers was reached. Any uncertainties regarding eligibility were discussed with the research team and resolved before progressing to the next stage of data collection.

Quality Appraisal

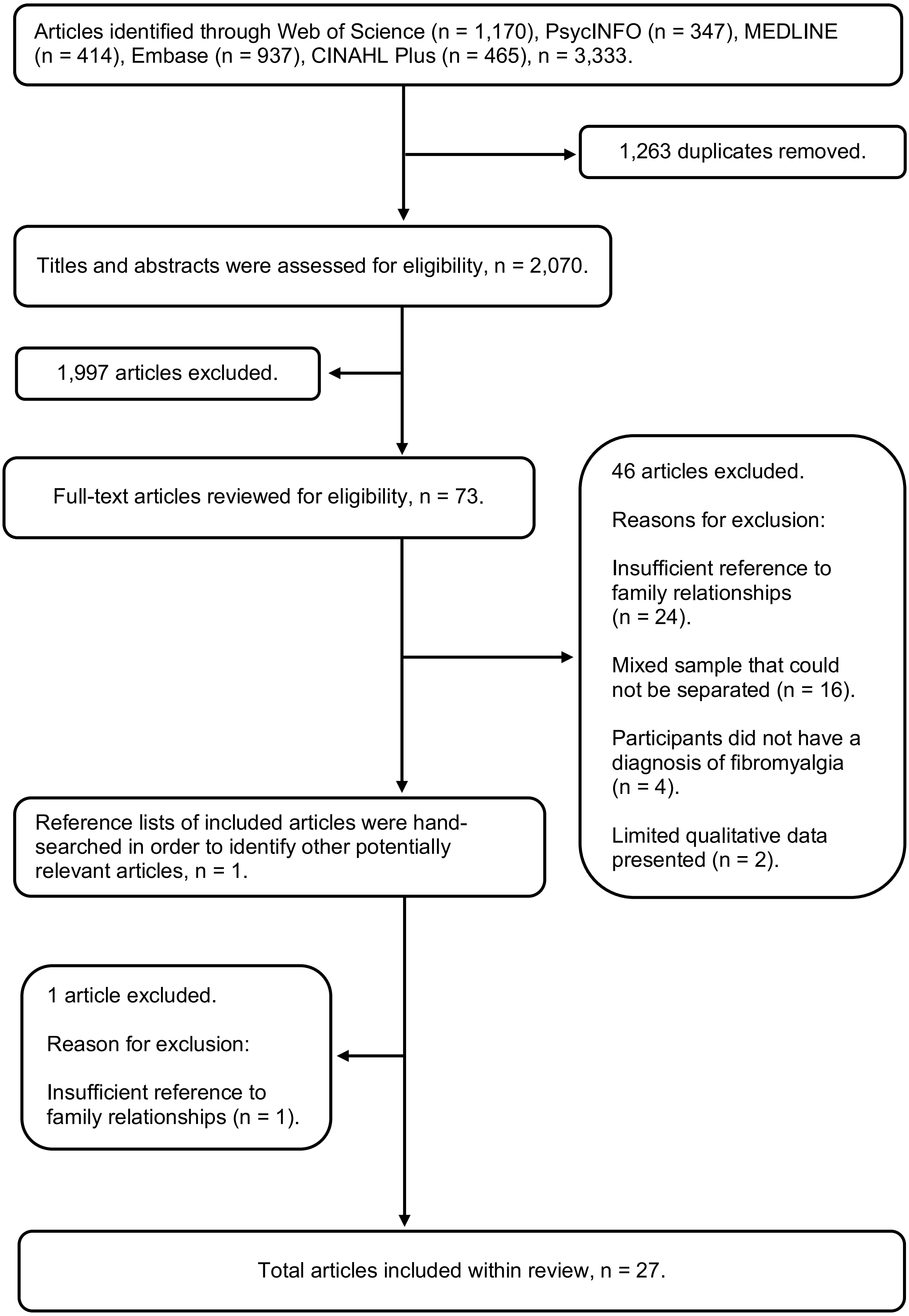
In order to assess methodological and interpretive rigour, the studies within the review were evaluated using a modified version of the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018; Appendix 2). The CASP consists of 10 questions that are designed to facilitate appraisals of credibility, rigour, and relevance within qualitative research. The checklist prompts readers to consider:

If there was a clear statement of aims; the appropriateness of qualitative methods, the research design and the recruitment strategy; if data were *collected in a way that addressed the research issue; if there was an adequate consideration of the relationship between researchers and participants; if ethical issues were taken into account; if the data analysis was sufficiently rigorous; if there was a clear statement of findings and if the research was of value.*

The modified version of the CASP used within this review included a ‘somewhat’ response option for all questions answered ‘yes’, ‘no’, or ‘can’t tell’. This response option was used to indicate when a criterion had been addressed to an extent but lacked some key elements (Long et al., 2019). The CASP was chosen as it has been widely used in a number of qualitative systematic reviews (Davenport et al., 2019; Ruffell et al., 2019). The first author independently appraised the quality of all studies (n = 27). Four articles reported two studies but these were appraised separately as they answered different research questions. A second reviewer, external to the research team, also appraised a third of the studies (n = 9) which were chosen at random. The results of the appraisal were discussed and any areas of uncertainty or discrepancy were resolved through discussion with the research team.

There were some concerns regarding the methodology of five studies (i.e., Arnold et al., 2008; Cooper & Gilbert, 2017; Dennis et al., 2013; Henriksson, 1995; Löfgren et al., 2006). However, it was agreed that these methodological concerns were not significant enough to warrant exclusion, as excluding articles from meta-syntheses for reasons of quality is generally discouraged (Sandelowski et al., 1997). Nevertheless, there were concerns about the trustworthiness of these findings and therefore no new codes were developed using the data extracted from these studies. Instead the data were used to support the codes generated by analysing the findings of the other studies included within the review (Thomas & Harden, 2008).

Figure 1: PRISMA flow diagram illustrating results of search strategy and identification of studies included in review.



Data Analysis

A thematic synthesis based on the method described by Thomas and Harden (2008) was conducted. This is an inductive approach which involved the systematic coding of data and allowed for the development of descriptive and analytical themes via a three-stage process:

Stage One: The first author repeatedly read the included studies to fully immerse themselves in the data. Inductive line-by-line coding was then undertaken, using QSR International's *NVivo* (Version 12), to generate descriptive codes. Verbatim participant quotations were coded initially, followed by all other forms of extracted data (i.e., the original author’s interpretation of the data). Each line of data had at least one code applied, although several codes were applied to most lines of data in order to fully capture its meaning and context. Newly created codes were added to a coding bank which was used when analysing the findings of subsequent studies. This coding bank was applied to the findings of the five studies with methodological concerns but no new codes were created using these findings.

Stage Two: Descriptive themes were developed and labelled by comparing and grouping codes based on their conceptual similarities and differences, allowing for the translation of concepts across studies.

Stage Three: Analytical themes were generated by identifying conceptual links across descriptive themes and by considering the descriptive themes in relation to the review aims. This critical stage allowed the review to ‘go beyond’ the findings of the primary research studies (Thomas & Harden, 2008). Analytical themes and the resultant thematic structure were formulated, refined, and agreed through regular discussions with the wider research team.

Results

Study Characteristics

The characteristics of the included studies are summarised in Table 2. The studies were from nine countries: Sweden (n = 10), the USA (n = 5), Spain (n = 4), Belgium (n = 2), Canada (n = 2), Norway (n = 1), Finland (n = 1), South

Africa (n = 1) and the UK (n = 1). The aims of the studies varied, but they generally sought to describe the subjective experiences of individuals living with fibromyalgia. One study specifically examined the experiences of African American women living in the USA (Schaefer, 2005). The 27 studies reported on 24 samples, representing the views of 436 women with fibromyalgia. The average sample size was 19 participants per study. The age and socioeconomic status of participants varied both between and within studies. Most studies used purposive sampling, with participants largely being recruited from healthcare settings and/or patient associations and support groups. Three studies used community advertising to recruit participants.

Two of the studies from Spain (Granero-Molina et al., 2018; Jiménez et al., 2017) and Sweden (Hallberg & Carlsson, 1998; Hallberg & Carlsson, 2000) used the same sample to answer different research questions. Another study (Juuso et al., 2013) recruited a subgroup of the sample that had participated in an earlier study (Juuso et al., 2011). Although the majority of the studies specifically recruited women with fibromyalgia, two studies included a sample of women with other health conditions (Cuesta et al., 2019; LaChapelle et al., 2008) and one study included males with fibromyalgia (Dennis et al., 2013). Only data specifically relating to the experiences of women with fibromyalgia was extracted from these studies.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Armentor	2017	USA	To explore the various approaches used by individuals with fibromyalgia to manage their social roles and negotiate their relationships with others including family members, friends, co-workers, and medical professionals.	Semi-structured interviews.	Grounded theory.	20 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 32-80 years (*M* = 49 years). Participant reported ethnicity (*n*): White (16), Hispanic (3), African American (1), Asian Indian (1).	Convenience sampling using flyers posted in rheumatologists' offices, a counselling centre and coffee shops. Also used snowball sampling techniques to recruit new participants via existing interviewees. Average interview length: 58 minutes. Interview setting: Locations chosen by participants (e.g., researcher's office, a coffee shop, or participants' homes).

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Arnold et al.	2008	USA	To elicit and assess important symptom domains and the subjective impact of fibromyalgia on patients' quality of life and functioning.	Focus groups.	Grounded theory.	48 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Age range: 31-72 years (*M* = 51 years). Participant reported ethnicity (*n*): White (45), African American (1), Asian (1), Other (1).	Purposive sampling from outpatient rheumatology clinics. Average focus group length: 150 minutes. Focus group setting: University medical centres and a rheumatology private practice.
Briones-Vozmediano et al.	2016	Spain	To explore how gender shapes women's experiences of living with fibromyalgia and how it affects their private lives.	Semi-structured interviews.	Thematic analysis.	13 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 24-61 years (*M* = 45 years). Participant reported ethnicity (*n*): Spanish Caucasian (13).	Convenience sampling from patient associations. Interview length: 60-90 minutes. Interview setting: Participants' homes.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Calsius et al.	2015	Belgium	To describe how fibromyalgia patients experience their body.	Focus groups with a semi-structured interview format.	Interpretative phenomenological analysis.	15 women with fibromyalgia (9 in an alexithymic group and 6 in a nonalexithymic group). Diagnostic criteria: All participants fulfilled the American College of Rheumatology Criteria (N.B., the year of the criteria is not reported). Mean age of 43 years in the nonalexithymic group and 46 years in the alexithymic group. Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from hospital and physical therapist practices. Average focus group length: 60 minutes. Focus group setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Cooper & Gilbert	2017	South Africa	To explore the role of social support in addressing the various challenges presented by the complexity of fibromyalgia, through a discussion of the narratives of people living with fibromyalgia.	Semi-structured interviews.	Thematic analysis.	15 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 23-59 years (*M* = 38 years). Participant reported ethnicity (*n*): White (13), Black (2). 14 women were South African, 1 was British.	Purposive sampling through informal peer networks and using snowball techniques. Interview length: 60-180 minutes. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Cuesta et al.	2019	Spain	To analyse subjectivity construction processes in people with fibromyalgia, chronic fatigue syndrome/myalgic encephalomyelitis, and multiple chemical sensitivity.	Interviews to obtain life stories.	Integrative approach proposed by Conde (2009).	5 women with fibromyalgia, 2 women and 1 man with chronic fatigue syndrome, and 1 woman with multiple chemical sensitivity. Diagnostic criteria: Not reported. Age range of women with fibromyalgia: 39-67 years (*M* = 52 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from patient support groups. Interview length: 50-150 minutes. Interview setting: Locations chosen by participants (e.g., participants' homes, patient support groups, or cafeterias).

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Dennis et al.	2013	UK	To investigate how people with fibromyalgia understand and experience all of their difficulties and to include issues associated with home, work, diagnosis, and clinical symptoms.	Email interviews.	Interpretative phenomenological analysis followed by a template analysis.	19 women and 1 man with fibromyalgia. Diagnostic criteria: Not reported. Age range of women with fibromyalgia: 18-64 years. Participant reported ethnicity (*n*): Data not presented.	Convenience sampling from a patient support group and an online support group. Interview length: On average, the exchange was between two and four follow-up emails. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Granero-Molina et al. [2]	2018	Spain	To explore and understand the experiences and expectations of women with fibromyalgia regarding social support systems for female sexual dysfunction.	Focus group and semi-structured interviews.	Hermeneutic phenomenology; modified form of the method developed by Fleming et al. (2003).	13 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 22-56 years (*M* = 44.8 years). Participant reported ethnicity (*n*): Data not presented.	Convenience sampling from a fibromyalgia patient association. 5 women took part in a focus group and 8 participated in interviews. Focus group length: Data not presented. Focus group setting: Local Fibromyalgia Association. Average interview length: 35 minutes. Interview setting: Local Fibromyalgia Association.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Hallberg & Bergman	2011	Sweden	To generate a substantive theory, based on interviews with women with fibromyalgia, explaining how they manage their main concerns in daily life.	Interviews.	Grounded theory.	23 women with fibromyalgia. Diagnostic criteria: 11 women fulfilled the American College of Rheumatology Criteria (N.B., the year of the criteria is not reported). The medical records of the remaining women were not available to the researchers. Mean age: 53.9 years. Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a rheumatology hospital, general practitioners and a patient support group. Interview length: 60-120 minutes. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Hallberg & Carlsson [a]	1998	Sweden	To describe, from the perspective of women with fibromyalgia, their own experiences of pain and its origin, and how family and social life is affected by this chronic pain condition.	Open-ended interviews.	Grounded theory.	22 women with fibromyalgia. Diagnostic criteria: 14 women fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). 8 women fulfilled the criteria outlined by Yunus et al. (1981). Age range: 22-60 years (*M* = 43 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a Swedish National Insurance Hospital. Interview length: 60-90 minutes. Interview setting: Swedish National Insurance Hospital.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Hallberg & Carlsson [b]	2000	Sweden	To describe, from the perspective of patients with fibromyalgia themselves, their experiences of having to live with chronic pain and how they manage their situation.	Open-ended interviews.	Grounded theory.	22 women with fibromyalgia. Diagnostic criteria: 14 women fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). 8 women fulfilled the criteria outlined by Yunus et al. (1981). Age range: 22-60 years (*M* = 43 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a Swedish National Insurance Hospital. Interview length: 60-90 minutes. Interview setting: Swedish National Insurance Hospital.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Henriksson	1995	Sweden	To explore how women with fibromyalgia, living in two different countries, perceive and describe their situation. The focus was on the women's encounter with the social environment and the consequences of fibromyalgia for their life situation.	Semi-structured interviews.	Qualitative content analysis.	40 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Mean age: 42 years. Participant reported ethnicity (*n*): Caucasian (40). 20 women were living in the USA and 20 were living in Sweden.	Convenience sampling with a group of women who were concurrently studied using a quantitative approach (Henriksson & Burckhardt, Unpublished). Interview length: 35-50 minutes. Interview setting: Outpatient clinic.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Jiménez et al. [1]	2017	Spain	To explore and understand the perceptions and experiences of women with fibromyalgia regarding their sexuality.	Focus group and semi-structured interviews.	Hermeneutic phenomenology; modified form of the method developed by Fleming et al. (2003).	13 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 22-56 years (*M* = 44.8 years). Participant reported ethnicity (*n*): Data not presented.	Convenience sampling from a fibromyalgia patient association. 5 women took part in a focus group and 8 participated in interviews. Focus group length: 40 minutes. Focus group setting: Fibromyalgia Patient Association. Average interview length: 35 minutes. Interview setting: Fibromyalgia Patient Association.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Juuso et al.	2011	Sweden	To elucidate meanings of pain for women with fibromyalgia.	Narrative interview method.	Hermeneutic phenomenology.	15 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Age range: 38-64 years (*M* = 54 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a rehabilitation centre and a patient association. Interview length: 45-115 minutes (*M* = 76 minutes). Interview setting: Participants' homes (n = 13), Fibromyalgia Patient Association (n = 2).

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Juuso et al.	2013	Sweden	To elucidate meanings of feeling well for women with fibromyalgia.	Telephone interviews using a narrative interview method.	Hermeneutic phenomenology.	13 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 38-64 years (*M* = 55 years). Participant reported ethnicity (*n*): Data not presented.	Convenience sampling: subgroup from another qualitative study included within this review (Juuso et al., 2011). Interview length: 20-61 minutes (*M* = 44 minutes). Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Juuso et al.	2014	Sweden	To elucidate meanings of being received and met by others as experienced by women with fibromyalgia.	Narrative interview method.	Hermeneutic phenomenology.	9 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 40-65 years (*M* = 59 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from patient associations. Interview length: 51-147 minutes (*M* = 82 minutes). Interview setting: Participants' homes (n = 6), participants' workplace (n = 1), Fibromyalgia Association (n = 1), or at a university (n = 1).

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
LaChapelle et al.	2008	Canada	To explore personal definitions of acceptance and the factors that facilitate or hinder acceptance.	Focus groups with a semi-structured interview format.	Thematic analysis.	45 women with fibromyalgia or arthritis (20 women with fibromyalgia, 15 women with both fibromyalgia and co-morbid arthritis, 13 women with arthritis). Diagnostic criteria: Not reported. Age range: 23-75 years (*M* = 51.4 years). (N.B., Specific age range of women with fibromyalgia is not presented). Participant reported ethnicity (*n*): Data not presented.	Convenience sampling using community advertising. Focus group length: 90-120 minutes. Focus group setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Löfgren et al.	2006	Sweden	To understand more about how women with fibromyalgia, who manage to keep on working, are coping with their symptoms.	Diaries, focus group discussions, and thematised individual interviews.	Content analysis and grounded theory.	12 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 30-63 years (*M* = 49.8 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a multi-professional rehabilitation programme. Diary length: Participants were asked to complete a diary for 2 weeks, 5 days or more each week. Focus group and interview length: Data not presented. Focus group and interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Råheim & Håland	2006	Norway	To gather rich descriptions of women's lived experience of chronic pain and fibromyalgia.	Life-form interviews.	Modified descriptive phenomenological methods (Giorgi, 1985).	12 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 34-51 years (*M* = 43.3 years). Participant reported ethnicity (*n*): White Norwegian (12).	Purposive sampling from general practitioners (n = 1), private physiotherapy clinics (n = 1), and a fibromyalgia patient organization (n = 10). Interview length: 90-120 minutes. Interview setting: Locations chosen by participants (e.g., participants' homes, participants' workplace, or interviewers' workplace).

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Reibel & Pearson	2017	USA	To gain an understanding of the lived experiences of women with fibromyalgia.	Phenomenological interviews.	Thematic analysis, van Manen's (1990) methodology.	3 women with fibromyalgia. Diagnostic criteria: Not reported. Aged 18+ Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a fibromyalgia support group. Interview length: Data not presented. Interview setting: Data not presented.
Sallinen et al.	2011	Finland	To explore how fatigue was experienced and explained in life stories of women with a long history of fibromyalgia to gain a deeper understanding of fatigue as a phenomenon.	Narrative interview method.	Narrative analysis (Polkinghorne, 1993; Riessman, 2001).	20 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 34-65 years (*M* = 54 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a fibromyalgia rehabilitation course. Interview length: 120-240 minutes. Interview setting: Locations chosen by participants, largely participants' homes.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Schaefer	1995	USA	To describe the experiences of women living with fibromyalgia.	Interviews.	Grounded theory.	36 women with fibromyalgia. Diagnostic criteria: Not reported. Age range not stated. Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from community programmes and using snowball techniques. Interview length: 60-150 minutes. Interview setting: Locations chosen by participants. No further information is presented.
Schaefer	2005	USA	To enter the lifeworld of African American women with fibromyalgia to understand the meaning of their lived experience of fibromyalgia.	Interviews.	Thematic analysis, van Manen's (1990) methodology.	10 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 37-59 years (*M* = 46.5 years). Participant reported ethnicity (*n*): African American (10).	Convenience sampling using an advertisement in a community newspaper. Interview length: 30-60 minutes. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Söderberg et al.	1999	Sweden	To elucidate the meaning of women's experiences of living with fibromyalgia.	Narrative interview method.	Hermeneutic phenomenology.	14 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Age range: 35-50 years (M = 43.3 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a hospital rheumatological clinic. Interview length: 15-60 minutes. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Söderberg & Lundman	2001	Sweden	To illuminate the transitions experienced by women with fibromyalgia.	Narrative interview method.	Thematic content analysis.	25 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Age range: 35-60 years (*M* = 46.8 years). Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from a rehabilitation centre and a rheumatological clinic. Interview length: 35-110 minutes. Interview setting: Researchers office or in participants' homes.
Sturge-Jacobs	2002	Canada	To describe and enhance the understanding of the experience of living with fibromyalgia.	Unstructured interviews. Followed by 2 subsequent telephone interviews to clarify material and obtain further information.	Thematic analysis, van Manen's (1990) methodology.	9 women with fibromyalgia. Diagnostic criteria: Not reported. Age range: 30-56 years. Participant reported ethnicity (*n*): Data not presented.	Purposive sampling from an education program at a tertiary care facility. Interview length: 60-90 minutes. Interview setting: Data not presented.

Table 2: Main characteristics of included studies.

Author(s)	Year	Country	Research Aims	Data Collection	Method of Analysis	Participant Characteristics	Sampling & Data Collection Methods
Wuytack & Miller	2011	Belgium	To gain a better understanding of the subjective experience of fibromyalgia, focusing on the personal, occupational, and social impact of the condition on patients' lives. This included exploring views about the future.	Semi-structured interviews.	Thematic analysis, using a thematic framework.	6 women with fibromyalgia. Diagnostic criteria: All participants fulfilled the American College of Rheumatology 1990 Criteria (Wolfe et al., 1990). Age range: 36-66 years (*M* = 51 years). Participant reported ethnicity (*n*): Data not presented.	Convenience sampling from a self-help group. Interview length: 15-45 minutes. Interview setting: Participants' homes (n = 4), hospital (n = 2).

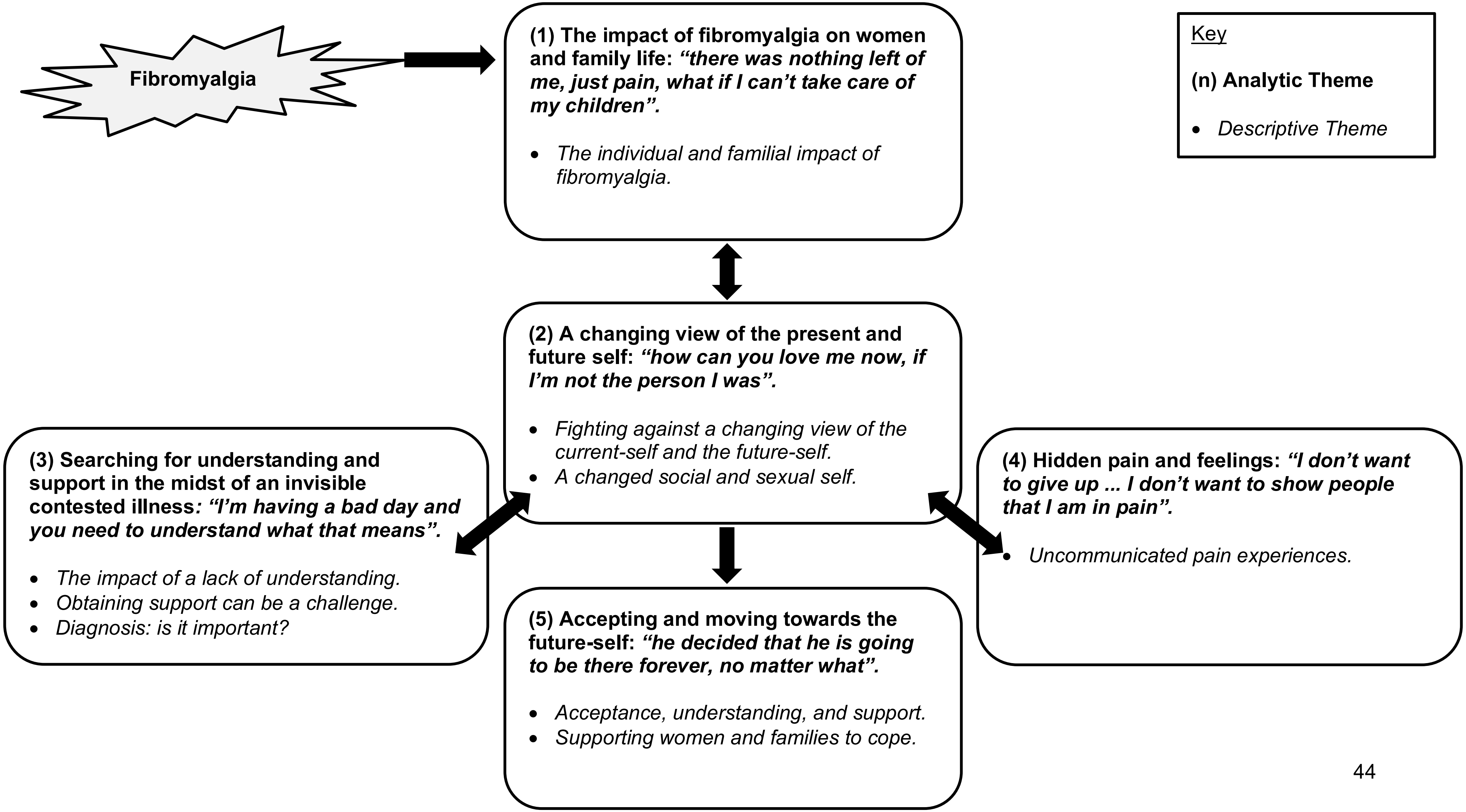
Quality Appraisal Results

There has been significant debate and a subsequent lack of clarity on how to determine the ‘quality’ of qualitative studies (Carroll & Booth, 2014; Garside, 2014). Although it was apparent that the studies included within the review were of mixed quality (Appendix 3), traditional classifications (e.g., ‘good’ and ‘moderate’) were not assigned given the potentially arbitrary divide between classifications. In the majority of studies there was little or no evidence that the authors critically examined their own role, potential bias, or influence on the study design, data collection, or data analysis process. Despite the sensitive nature of the studies included within the review, most studies did not describe how participant distress was managed nor did they refer to a debrief process. Appraisals of study methodology and data analysis processes were limited by the lack of detail provided by the majority of authors.

Thematic Synthesis Findings

The findings from the 27 primary studies were synthesized into nine descriptive themes which are detailed in Figure 2. From these descriptive themes, five analytical themes were produced: 1) The impact of fibromyalgia on women and family life: *“there was nothing left of me, just pain, what if I can’t take care of my children”*, 2) A changing view of the present and future self: *“how can you love me now, if I’m not the person I was”*, 3) Searching for understanding and support in the midst of an invisible contested illness: *“I’m having a bad day and you need to understand what that means”*, 4) Hidden pain and feelings: *“I don’t want to give up ... I don’t want to show people that I am in pain”,* and 5) Accepting and moving towards the future-self: *“he decided that he is going to be there forever, no matter what”.* These themes are described in more detail below, accompanied by relevant extracts from primary studies.

Figure 2: Thematic map presenting the proposed thematic structure.



(1) The impact of fibromyalgia on women and family life: *"there was nothing left of me, just pain, what if I can't take care of my children".*

- *The individual and familial impact of fibromyalgia.*

(2) A changing view of the present and future self: *"how can you love me now, if I'm not the person I was".*

- *Fighting against a changing view of the current-self and the future-self.*
- *A changed social and sexual self.*

(3) Searching for understanding and support in the midst of an invisible contested illness*: "I'm having a bad day and you need to understand what that means".*

- *The impact of a lack of understanding.*
- *Obtaining support can be a challenge.*
- *Diagnosis: is it important?*

(4) Hidden pain and feelings: *"I don't want to give up ... I don't want to show people that I am in pain".*

- *Uncommunicated pain experiences.*

(5) Accepting and moving towards the future-self: *"he decided that he is going to be there forever, no matter what".*

- *Acceptance, understanding, and support.*
- *Supporting women and families to cope.*

The impact of fibromyalgia on women and family life: *"there was nothing left of me, just pain, what if I can't take care of my children"*.

The impact of fibromyalgia on women was often profound and disabling. The traditional family roles occupied by women as a partner, mother, and grandmother were disrupted by symptoms such as chronic pain and fatigue (Hallberg & Carlsson, 1998). Major lifestyle changes were often required, which had a significant impact on quality of life at an individual and familial level.

The physical demands of routine childcare suddenly became overwhelming for many women. Tasks which had previously been completed with ease such as dressing children (Söderberg et al., 1999), attending to personal care (Briones-Vozmediano et al., 2016), and lifting infants (Råheim & Håland, 2006) were now viewed as challenges. One woman noted that, on a bad day, she could only do the most important things for her children's survival:

> *"I don't end up playing a lot with the children, they play by themselves. I make sure that they get to and from school, are fed and get dressed"* (Hallberg & Bergman, 2011, p.6).

Many women felt that their ability to play with their children had diminished and that other forms of recreational activity had become inaccessible. For some women, precious energy had to be channelled into work rather than the non-essential aspects of family life and children received less attention at home as a result (Hallberg & Carlsson, 1998; Wuytack & Miller, 2011).

Women commonly described experiencing difficulties completing household tasks including shopping, cleaning, and cooking (Briones-Vozmediano et al., 2016; Henriksson, 1995; Söderberg & Lundman, 2001). Changes in working life were also salient, with some women reporting a reduced working schedule and others leaving work entirely (Dennis et al., 2013; Löfgren et al., 2006). This had economic implications for the family and for some partners who had to work more to supplement the family income (Briones-Vozmediano et al., 2016; Råheim & Håland, 2006).

It is clear that fibromyalgia can significantly disrupt family life and the roles occupied by individual family members often have to be renegotiated as a result. This adaptation process often takes place in an atmosphere of uncertainty (Wuytack & Miller, 2011) and can prove to be more difficult for some families than for others (Sturge-Jacobs, 2002).

The child's role within the family may evolve, with children becoming more responsible for their own needs, their mother's needs, and the wider needs of the family unit. For instance, children may have to prepare their own food (Armentor, 2017; Briones-Vozmediano et al., 2016; Reibel & Pearson, 2017), assist with their mother's personal care (Briones-Vozmediano et al., 2016), and become more involved with housework (Söderberg et al., 1999; Söderberg & Lundman, 2001). However, some children are reported to be unwilling to help around the home and will only do so *"when they can see that it's absolutely necessary"* (Briones-Vozmediano et al., 2016, p. 843). The evolving role of the child can be a source of tension within women's romantic relationships:

> *"My youngest had to start making her own peanut butter and jelly sandwiches. It caused a problem between her father and me. He didn't feel like I was being a responsible parent at the time"* (Reibel & Pearson, 2017, p. 72).

Partners constitute *"one of the basic support pillars for women"* (Jiménez et al., 2017, p. 1652) with fibromyalgia and they are said to have the greatest assisting role (Wuytack & Miller, 2011). Partners are required to offer more emotional and practical support after the onset of fibromyalgia (Cooper & Gilbert, 2017; LaChapelle et al., 2008), often taking responsibility for tasks which may have traditionally been performed by women such as housecleaning, shopping, and cooking (Hallberg & Carlsson, 1998). They may also have to step in and provide care for close relatives including ageing parents (Briones-Vozmediano et al., 2016). Although some partners are noted to have *"jumped in full force"* (Reibel & Pearson, 2017, p. 73) into this new role, others struggled to fulfil and adapt to the additional demands placed on them. Women may feel frustrated when household tasks are not completed to their standards (Hallberg & Carlsson, 1998) and some feel that their partners continue to *“just help with the basics”* (Briones-Vozmediano et al., 2016, p. 843) despite their significant difficulties and relationships may become strained as a result (Henriksson, 1995; Sturge-Jacobs, 2002).

A changing view of the present and future self: “*How can you love me now, if I’m not the person I was”.*

Women struggled against a changing view of themselves as a partner, mother, and grandmother (Sturge-Jacobs, 2002) and reported a want for the life that they lived prior to fibromyalgia (Söderberg et al., 1999). A desire to maintain and present the former healthy-self was commonly expressed in order to uphold a sense of normality for the benefit of themselves and their family members:

> *“I have two small children, and I don’t want them to say when they’re older, we couldn’t do this or that because my mom was sick. They’re entitled to better than that. As far as I can possibly do it, we live a normal life and do normal family things”* (Sturge-Jacobs, 2002, p. 27).

Women described an exhausting ongoing struggle in which attempts were made to engage in the normal activities of family life (LaChapelle et al., 2008) whilst continuing to interact with their family members in a manner that maintained their ascribed role (Schaefer, 2005). The gendered expectation of caring for others and the home appeared to be a particularly important component of the women’s self-concept in a family context (Briones-Vozmediano et al., 2016). The ability to fulfil this ‘traditionally feminine’ role was associated with maintained self-esteem and wellness by some (Wuytack & Miller, 2011), whilst an inability to fulfil this previously occupied role was linked with profound feelings of burdensomeness, uselessness, guilt, and resentment (Briones-Vozmediano et al., 2016; Henriksson, 1995; Wuytack & Miller, 2011). Obtaining support from family members challenged the healthy self and gave rise to uncomfortable feelings of dependency and disability (Armentor, 2017; Briones-Vozmediano et al., 2016). Some women therefore did not ask for help, which was a source of frustration for family members:

> *"How can I [the husband] know when you need help, if you don't say anything"* (Söderberg & Lundman, 2001, p. 623).

The envisaged future-self had also been disrupted by fibromyalgia and had become uncertain and feared. In particular, women were concerned that their future-self may be unable to provide the appropriate level of care for their children, grandchildren, or elderly parents (Råheim & Håland, 2006; Söderberg & Lundman, 2001).

This changing view of the self was also influenced by an increasing sense of social isolation. Women reported that, due to chronic pain and fatigue, previously enjoyed leisure activities and hobbies had become inaccessible, resulting in a changed shared social life (Hallberg & Carlsson, 1998; Henriksson, 1995). Family members can struggle to accept the woman's changed social-self and may resent the consequential impacts that it has on their own social life (LaChapelle et al., 2008):

> *"Obviously sometimes they [the children] feel that I am boring. They would like us to have guests and do more of that kind of thing, and I don't have the strength"* (Söderberg et al., 1999, p. 580).

As a result, some women felt pressured by their significant others, who may not understand the restrictions imposed on them, to push through the pain and retain their previous level of social functioning:

> *"I acknowledge you're not feeling well. Wouldn't you be better off if you just pushed through it"* (Armentor, 2017, p. 468).

When they failed to do so, women felt that their family members viewed them as boring (Söderberg et al., 1999), lazy, and selfish (Cuesta et al., 2019). These perceived negative appraisals were a source of relational conflict for some (Henriksson, 1995; Reibel & Pearson, 2017). Some women felt guilty for imposing a changed social life on their family and to compensate they appeared to accept the loss of the former social-self and encouraged their family to socialise without them (Briones-Vozmediano et al., 2016).

Within and between studies, there was variation in women's attitudes towards sexuality. Women largely recognised sexuality as an integral component of their identity and quality of life. However, others felt that their sexuality had diminished to the point of becoming irrelevant (Jiménez et al., 2017) and this led some women to feel as if they had become a *"different wife"* (Briones-Vozmediano et al., 2016, p. 849).

Fibromyalgia interfered with women's ability to engage in intimate and sexual relations with their significant others. Desire and libido were commonly decreased, resulting in a decline in the frequency and quality of sexual and intimate activity. Women identified pain (Arnold et al., 2008; Henriksson, 1995), fatigue (Sallinen et al., 2011), limited movement (Briones-Vozmediano et al., 2016), medication side effects (Schaefer, 2005), and low mood (Jiménez et al., 2017) as some of the main obstacles that either impeded sexual relations or made them less enjoyable.

Women also experienced bodily changes associated with fibromyalgia, such as weight gain and generalised inflammation, and could self-impose a negative body image as a result (Granero-Molina et al., 2018; Jiménez et al., 2017). Although partners generally provided reassurance in response to concerns regarding a changing body image, this was described as difficult to accept (Granero-Molina et al., 2018) and women continued to fear that they were *"not meeting expectations"* (Jiménez et al., 2017, p. 1653). Although some women felt that sexuality was no longer a part of their identity, others were determined to maintain their sex life for the sake of their relationship (Jiménez et al., 2017). Some women felt that their sexuality had transformed to focus almost exclusively on fulfilling their partner's needs:

> *"I do it for my husband. Yes, it's for him because I don't feel like having sex at all"* (Jiménez et al., 2017, p. 1652).

A decrease in the frequency of sexual activity (Briones-Vozmediano et al., 2016) was, in some instances, met with a lack of understanding which led to relational conflict (Granero-Molina et al., 2018). Women felt responsible for putting their marital life at risk and *"lived in constant fear that their partner,* *faced with an unfulfilling sexual life, will tire of the situation and leave them"* (Granero-Molina et al., 2018, p. 304).

With time, it was possible to adapt to the changed sex life that fibromyalgia can bring. It is noted that partners can play a crucial role in supporting women to understand both the sexual problems associated with fibromyalgia and the potential solutions (Granero-Molina et al., 2018). Communication appeared to be particularly important and helped to achieve a shared understanding:

> *"We have solved it by talking about it. That is easier for me, so he just had to listen. Long nights talking, because it was important that he should understand my situation, that he should know I loved him just as much, and that it was the pain"* (Råheim & Håland, 2006, p. 752).

However, this was difficult for some, perhaps due to concerns around the credibility of their sexual experiences (Jiménez et al., 2017).

Searching for understanding and support in the midst of an invisible contested illness: "*I'm having a bad day and you need to understand what that means".*

The invisibility of fibromyalgia led some family members to misunderstand and question the credibility of women's experiences (Henriksson, 1995). Women repeatedly stated that the contradiction between their outwardly healthy appearance and the extent of their difficulties seemed paradoxical to their significant others and also themselves:

> *"I looked so good, yet I felt so rotten. This makes me feel like a fraud"* (Sturge-Jacobs, 2002, p. 24).

This appeared to be particularly true in the early stages of the condition. In some cases, the numerous negative medical investigations that preceded a diagnosis of fibromyalgia undermined women's credibility. This led some family members to assign labels such as crazy, lazy, and hypochondriac to women with fibromyalgia:

> *"Everything kept coming back normal. Nothing was showing up in any of the tests, and it had gotten to where ... my family thought I was crazy, uh, that I was a hypochondriac, and there was nothing wrong with me and it was all in my head"* (Reibel & Pearson, 2017, p. 72).

Experiences of being repeatedly doubted led some women to question their own sanity and identity (Reibel & Pearson, 2017; Schaefer, 1995). In response, some described attempts to convince their family members that their illness experiences had "medical recognition" (Cooper & Gilbert, 2017, p. 1025). Women generally felt that their family members did not understand their illness experience, even post-diagnosis (Armentor, 2017), and this gave rise to feelings of sadness, anger, and frustration (Juuso et al., 2011; Juuso et al., 2014). This perceived lack of understanding created a growing sense of distance between women and their significant others (Råheim & Håland, 2006). Ultimately, this could lead to relationship tension, particularly with partners, and relationship breakdown (Briones-Vozmediano et al., 2016; Granero-Molina et al., 2018; Wuytack & Miller, 2011). Women felt that their family members were not provided with sufficient information and hypothesised that this may have hindered their understanding of the condition (Briones-Vozmediano et al., 2016; Henriksson, 1995; Söderberg et al., 1999). However, there was a general recognition that family members cannot possibly understand the extent of the experience of living with fibromyalgia if they themselves do not have the condition:

> *"If he's not in your shoes, he can't possibly know what you're going through"* (Briones-Vozmediano et al., 2016, p. 844).

In some cases, this lack of understanding was associated with a reportedly inadequate level of physical and emotional support from family members (Cooper & Gilbert, 2017; Råheim & Håland, 2006; Reibel & Pearson, 2017). Women noted that the invisible nature of their difficulties made it easy for their family members to forget about their difficulties and thus not provide support:

> *"If you have a broken leg, and it's in a cast, then your family doesn't expect you to get up, and clean house, and do dishes, and run five miles"* (Armentor, 2017, p. 469).

Women described feeling deeply misunderstood in response to their families' unwavering expectations (Briones-Vozmediano et al., 2016). Given that support was not offered, some women described attempts to maintain their previous role despite their pain (Cooper & Gilbert, 2017). However, in such instance's women felt that their credibility was still questioned by their family members:

> *"You aren't believed, so you feel all the time that you have to explain. Explain what you have done and what you are suffering from and you have to say; now I've been in bed for 3 days because I've done that and that. Maybe you have seen me changing curtains or something"* (Juuso et al., 2011, p. 3).

Although some women were frustrated and disappointed with the support that they received from their family members (Söderberg & Lundman, 2001), they were reluctant to ask for additional support. Women frequently expressed concerns that they were a burden to their support systems (Hallberg & Carlsson, 2000; Sallinen et al., 2011; Schaefer, 2005) and a desire for additional support was often dispelled by a fear of abandonment (Sturge-Jacobs, 2002). Others explained that they did not ask for help due to other people's judgemental attitudes (Juuso et al., 2011), whilst some women simply felt that they could get tasks done quicker themselves (Briones-Vozmediano et al., 2016).

In some cases, diagnosis appeared to play a particularly important role in facilitating family understanding and support. Prior to receiving a diagnosis, women struggled to provide their family with a concrete explanation of their difficulties and they felt doubted and misunderstood as a result (LaChapelle et al., 2008; Schaefer, 1995). These feelings were perpetuated by diagnostic delays and consequentially family relationships were damaged for some (LaChapelle et al., 2008). However, as Armentor (2017) explained, for some women receiving a *"diagnosis of a medically defined condition, although controversial and misunderstood, changed the meaning of their behaviour and lifted the associated stigma"* (p. 468). Through receiving a diagnosis, difficulties were legitimized and some women reported that this led their family members to provide additional support (Armentor, 2017; Granero-Molina et al., 2018). Others noted that receiving a diagnosis allowed them to educate themselves and their family members about the condition:

> *"It was also good to be able to explain to friends and family what was wrong and that it was not all in my head"* (Dennis et al., 2013, p. 772).

An expanding knowledge of fibromyalgia and its potential impacts empowered some women to be clearer with their family about their needs. However, for other women, receiving a diagnosis only led to further stigmatization (Armentor, 2017).

Hidden pain and feelings: "*I don't want to give up ... I don't want to show people that I am in pain".*

Some women appeared to internalise their experiences and endeavoured to hide pain and its emotional consequences from their family members:

> *"I clench my teeth when in pain ... I will not show them [family] that I am in pain"* (Hallberg & Carlsson, 2000, p. 34).

> *"If I'm not feeling good or I'm really down and uncomfortable. I don't reach out to anybody; I just kinda suck it up and deal with it on my own"* (Armentor, 2017, p. 469).

Despite attempts to conceal the illness experience many women reported that, with time, the hidden signals of pain seemed to be received by their family members (Hallberg & Carlsson, 2000). Women explained that their family members were able to detect when they were not feeling well on the basis of their appearance (Armentor, 2017), tone of voice (Hallberg & Carlsson, 2000; Juuso et al., 2014), and behaviour (Schaefer, 2005). Some women viewed verbal communication as unnecessary, given that family members were thought to have some awareness of their internal experience:

> *"She knows me well enough that she sees—so I don't really have to explain a lot to them"* (Armentor, 2017, p. 466).

However, it is possible that the resultant communication deficit may have actually contributed to the lack of understanding reported by many. Women also described a number of other barriers that prevented them from communicating with their family members. Some struggled to find the words to explicitly describe their experiences and needs, which they viewed as implausible:

> *"How can you always explain that? It's like ... it's a bit ridiculous"* (Jiménez et al., 2017, p. 1651).

Other women actively avoided communication because they were disinterested in repeatedly explaining their illness to their significant others (Juuso et al., 2014) or because previous attempts had been met with disbelief and misunderstanding (Armentor, 2017; Dennis et al., 2013). Some of those who did endeavour to communicate with their family members reported feelings of disappointment when their attempts were simply not received or taken seriously (Juuso et al., 2011; Juuso et al., 2014; Råheim & Håland, 2006).

Accepting and moving towards the future-self: "*He decided that he is going to be there forever, no matter what".*

Ultimately, women were required to grieve for the loss of their former-self and relinquish the struggle against the ill-self in order to accept and move towards the future-self. This acceptance was said to come with time and only after the losses brought by fibromyalgia had been mourned (Sturge-Jacobs, 2002).

Whilst the negative impacts of fibromyalgia on family relationships are noted to hinder this acceptance process; feeling understood, supported, and needed by family members appeared to be faciliatory (Juuso et al., 2014; LaChapelle et al., 2008; Wuytack & Miller, 2011). Supportive family environments are noted to contribute to the capacity of women with fibromyalgia to make sense of their experiences (Cooper & Gilbert, 2017) and can *"decrease their state of uncertainty, bring hope and ultimately empower ... women in such a way that they are able to face the reality of living with a relentless, invisible, and* *incurable illness*" (Reibel & Pearson, 2017, p. 73). Some women felt incredibly grateful to have supportive family members:

> *"The support of my husband is worth gold!"* (Wuytack & Miller, 2011, p. 5).

In some instances, women described that fibromyalgia had not created a sense of distance in their relationship with their partner but had actually brought them closer together (Råheim & Håland, 2006; Reibel & Pearson, 2017).

Women recognised that reciprocal communication played an important role in the shared adjustment process. Although this was difficult for some, communicating effectively with family members allowed for the development of shared understanding (Briones-Vozmediano et al., 2016; Råheim & Håland, 2006), the de-escalation of relational tensions (Råheim & Håland, 2006), and the provision of appropriate valued support (Granero-Molina et al., 2018; Schaefer, 1995). Women found that communication strategies, such as comparing fibromyalgia to well-known illnesses and remaining clear and specific, were helpful when supporting others develop an understanding of the experience and consequences of living with fibromyalgia (Armentor, 2017). Being acknowledged as they were and listened to by family members was described as strengthening (Juuso et al., 2014; Råheim & Håland, 2006) and allowed women to feel well (Juuso et al., 2013).

Interestingly, some women stated that they themselves felt well when their family was functioning well (Juuso et al., 2013). This suggests that support provisions which aim to improve family functioning and relationships, may lead to enhanced outcomes for some women with fibromyalgia. Women point to the dissemination of knowledge regarding the consequences and effects of fibromyalgia (Henriksson, 1995; Jiménez et al., 2017; Söderberg et al., 1999), patient support groups (LaChapelle et al., 2008), and relationship counselling (Briones-Vozmediano et al., 2016) as potentially helpful therapeutic interventions.

Discussion

Overview of Findings

Five analytic themes were developed to describe how women with fibromyalgia experience and understand family relationships.

It is apparent that fibromyalgia can have a profound impact on family life, the roles and responsibilities of individual family members, and family relationships. Women struggled against a changing view of themselves as a partner, mother, and grandmother and attempts were made to continue to fulfil the expectations associated with these roles. However, an inability to do so was associated with feelings of burdensomeness and frustration. The envisaged future-self had also become uncertain, as women were fearful that they may be unable to care for their family members. This changing view of the self was also influenced by an increasing sense of social isolation. Women felt misunderstood when their family members expected them to maintain their previous level of social functioning and thus encouraged their family to socialise without them. It was also difficult for some women to engage in intimate and sexual relations which led them to fear that they had put their marital life at risk.

Family members misunderstood and questioned the credibility of invisible pain experiences. This created a growing sense of relational distance and led some women to question their own sanity and identity. In some instances, this lack of understanding was also accompanied by a perceived lack of physical and emotional support. Women found it difficult to ask for additional support for a number of reasons such as other people’s judgemental attitudes. However, attempts to function without support were noted to perpetuate doubts regarding credibility. Receiving a diagnosis provided some women with a sense of legitimacy that empowered them to be clearer with their family about their needs. However, for others receiving a diagnosis only led to further stigmatization.

Despite attempts to conceal pain and its emotional consequences, seemingly hidden signals of pain appeared to be received by family members. Some women therefore questioned the necessity of verbal communication, given that their family members seemed to have an awareness of their internal experience. Other communication barriers included a perceived inability to explicitly describe experiences and a disinterest in repeatedly explaining the condition.

It was necessary for some women to grieve for the loss of the former-self in order to accept and move towards the future-self, however this was noted to take time. Communicating effectively with family members and feeling understood, supported, and needed appeared to facilitate this process. It is important to note that a diverse range of experiences were described and although fibromyalgia had a negative impact on some family relationships, other women associated fibromyalgia with relationship growth and an increased sense of closeness.

Relevance to Existing Literature

Existing qualitative literature has demonstrated the significant impact that chronic pain conditions can have on family roles. For instance, women with chronic muscular pain also described a changed physicality that interfered with their ability to engage with household tasks and childcare commitments (Werner et al., 2004). It is also documented that family and social roles have to be restructured as a consequence of chronic back pain (Strunin & Boden, 2004). The findings of this meta-synthesis suggest that women may experience distress when they are unable to fulfil the gendered expectations associated with the 'traditional feminine' role. This is consistent with existing neuropathic pain literature which argued that the loss of perceived femininity contributed to difficulties associated with reformed family roles (Closs et al., 2009).

Themes relating to an altered relationship with the self are consistent with previous research findings. Snelgrove and Liossi (2013) identified a changed sense of self as a key theme within their meta-synthesis of patients' experiences of chronic low back pain. A similar conceptual process was described which involved mourning the loss of a previous valued life whilst living with a 'fearful self'. They also noted that the inability to fulfil previously occupied family roles had psychological consequences. Smith and Osborne's (2007) conceptualisation of *"pain as an assault on the self"* (p. 517) captured the profound impact of chronic low back pain on relationships with the self. They argued that individuals reject the self with pain as this often undermined their valued self, the women in this review described a similar struggle to dispel the ill-self and maintain their former healthy-self.

In line with the findings of this meta-synthesis, individuals with other contested illnesses also describe a search for understanding, legitimacy, and support. For instance, individuals with chronic fatigue syndrome found that the credibility of their experiences was repeatedly doubted due to their seemingly healthy appearance (Ware, 1992). Themes relating to hidden pain experiences and the importance of communication also resonate with literature which suggests that communication difficulties in chronic pain can have important implications for family adjustment (Porter et al., 2008).

The themes developed within this meta-synthesis corroborate and supplement findings from previous reviews that have considered the experiences of individuals living with fibromyalgia. For instance, the role of diagnosis in social legitimacy is discussed in a recent meta-ethnography (Mengshoel et al., 2018), whilst the association between fibromyalgia and female sexual dysfunction is highlighted in a previous narrative review (Kalichman, 2009). The impact of fibromyalgia on an individual's social life and social relationships has also been considered within an existing meta-synthesis (Sim & Madden, 2008). The current meta-synthesis expands upon the findings of these existing reviews by specifically considering the experiences of women with fibromyalgia in a family context, with a particular focus on potential relational and psychological implications.

Strengths & Limitations

This thematic synthesis is the first systematic review that has specifically considered how women with fibromyalgia experience and understand family relationships. This review makes an important contribution to existing knowledge given that research has demonstrated an association between fibromyalgia, relational difficulties (Collado et al., 2014; Marcus et al., 2013), and pain variables such as symptom intensity and fatigue (Murray et al., 2006; Parrish et al., 2008). An explicit and systematic methodology was used in an attempt to identify all potentially relevant primary studies and a thorough assessment of methodological and interpretive rigour was completed. The thematic synthesis followed clear and existing methodological guidelines to allow for future replication (Thomas & Harden, 2008). The findings are also presented in accordance with the ENTREQ Checklist (Tong et al., 2012) and PRISMA Guidelines (Moher et al., 2015).

The results of this thematic synthesis should be considered with reference to the general limitations of qualitative systematic reviews. For instance, the quality of the completed analysis and the robustness of the findings partly depend on the quality of the included primary studies. Additionally, a thorough search for grey literature was not conducted and studies which were not published in peer-reviewed journals were excluded. This decision was made to ensure that a systematic and transparent search was completed which allowed for future replication and ensured that included studies were of, at least, publishable quality. However, it is possible that this may have led to the exclusion of other forms of potentially pertinent qualitative data that may have influenced the findings presented above.

It is also important to acknowledge that the thematic synthesis depended upon the reliability of the original author's interpretation of the data and the representation of the verbatim participant quotes chosen for publication. Several studies are represented to a greater extent within the findings presented above (e.g., Armentor, 2017). However, this is generally reflective of the extent to which studies specifically focused on the family relationships of women with fibromyalgia.

Research & Clinical Implications

The results of this review highlight the transformative impact that fibromyalgia can have on women's sense of self. It appears that the conflict between women's previous healthy-self, ill-self, and feared future-self can have significant psychological and relational implications. Women may benefit from being supported to redefine and form a more positive view of their current and future-self following the onset of fibromyalgia. Research could consider if some individuals, such as those with a pre-existing fragile sense of self, would be more likely to benefit from such interventions.

The women within this review repeatedly noted the importance of time and pointed out that relationships with the self and family members often evolve. However, to date no longitudinal research has been published that focuses on the relational experiences of women with fibromyalgia. Future research could consider how relational issues, such as a perceived lack of understanding and stigmatisation, may change over time from symptom onset, through to diagnosis, and in the years that follow.

In terms of clinical interventions, it has been argued that women with fibromyalgia are likely to derive the most benefit from attending a comprehensive pain management programme (Reilly, 1999). However, these programmes are often grounded in cognitive-behavioural principles (Wilson, 2017) and typically may not target the intrapersonal and interpersonal difficulties described within this thematic synthesis. On the basis of the findings of this review, it appears that some women with fibromyalgia may derive benefit from treatment approaches with an increased focus on relational difficulties such as Psychodynamic Interpersonal Therapy (Hobson, 1985). However, further research is necessary to consider the applicability and efficacy of this approach within chronic pain populations.

The findings of this review also suggest that some women endeavour to hide the experience of pain from their family members. However, in line with previous findings (Newton-John & Williams, 2006; Schlesinger, 1996), it is argued that effective reciprocal communication plays an important role in the shared pain-related adjustment process. Thus, it appears that clinical interventions that aim to improve communication skills and seek to empower women to educate others about their condition and support needs may be beneficial (Monsivais, 2013). Women, and their family members, may also benefit from receiving explicit information regarding the consequences and effects of fibromyalgia to facilitate understanding. Arguably, such interventions could be delivered by involving family members within existing pain management programmes (Newton-John & Williams, 2006).

Conclusion

Fibromyalgia is a chronic pain condition that can have a profound impact on family life and relationships. Disabling symptoms can disrupt the family roles occupied by women with fibromyalgia and a role renegotiation process is often required to redistribute their previous responsibilities. Women may struggle against a changing sense of self which is influenced by evolving family, social, and sexual relationships. They can feel misunderstood, doubted, and unsupported by their family members who may struggle to understand their invisible difficulties. For some, receiving a diagnosis can facilitate family understanding and support whereas for others this may only lead to further stigmatization. A number of communication barriers interfere with women's ability and desire to communicate their pain related experiences to their family members. Time is required to allow women to mourn the loss of their former-self, accept their changed family life, and move towards their future-self. Several recommendations have been made, in both a clinical and research context, which may help to improve care for women with fibromyalgia.

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Paper 2: Empirical Study

Understanding the romantic relationships of people with fibromyalgia who remain distressed or disabled by their pain following treatment.

This paper has been prepared in accordance with the publication guidelines of Qualitative Health Research (Appendix 4). This journal has no word count or page count limit and specifically states that longer manuscripts will be considered.

Word Count

Complete text *(including references)*: 11,245

Main text *(excluding references but including tables, figures, and footnotes)*: 8,559

Abstract

The interpersonal functioning of individuals with fibromyalgia appears to have complex, and relatively unexplored, implications for treatment outcomes. This study investigated the romantic relationships of individuals with fibromyalgia who remained distressed or disabled by their pain despite receiving tertiary level multidisciplinary treatment. Seventeen semi-structured interviews were conducted and analysed using inductive thematic analysis. Three core themes were identified: *the relational impact of fibromyalgia*, *factors contributing to relational distress,* and *moving towards the future*. Results demonstrated that fibromyalgia often leads to changed relationships, interpersonal difficulties, and relational tension. However, participants generally struggled to adapt to and accept these changed circumstances. A range of potential contributing factors were identified including a lack of communication, understanding, and support. These interpersonal difficulties may contribute to the ongoing distress and disability experienced by participants. It appears that an increased focus on relational difficulties, partner support, and communication skills may enhance therapeutic outcomes for some patients.

Keywords: fibromyalgia, romantic relationships, treatment outcomes, pain management programme, qualitative, thematic analysis

Introduction

Fibromyalgia is a common chronic pain condition characterised by persistent generalised pain and an array of additional symptoms such as fatigue, depression, sleep disturbances, and memory or concentration problems (Clauw, 2014; Wolfe et al., 2016). The population prevalence rate within the UK is estimated to be 5.4% (Fayaz et al., 2016) and is typically lower in men than women (Wolfe et al., 2018). Fibromyalgia is a contested illness (Häuser, 2015) that typically arises in the absence of any known physical abnormality (Conrad & Barker, 2010).

Fibromyalgia can be a very disabling and disruptive condition (Pagano et al., 2004) with complex occupational, social, and relational implications (Wuytack & Miller, 2011). The complexity of the condition presents a major therapeutic challenge (Kwiatkowska & Amital, 2018), necessitating a biopsychosocial approach that recognises chronic pain as a subjective *"multifaceted experience emerging from the dynamic interplay of a patient's physiological state, thoughts, emotions, behaviours, and sociocultural influences"* (Roditi & Robinson, 2011, p. 41).

Pain management programmes (PMPs) are the current treatment of choice for individuals experiencing persistent pain that has a significant impact on physical and psychological functioning (Wilkinson & Whiteman, 2017). Psychological interventions, typically based on cognitive-behavioural principles (Dysvik et al., 2004), are woven throughout these programmes and aim to improve coping skills and maximise health-related quality of life (Turk & Adams, 2016). Although PMPs and cognitive behavioural therapy (CBT) are generally regarded as efficacious (Hoffman et al., 2007), these approaches do not appear to lead to clinically significant gains for a considerable number of patients (Morley et al., 2008) and effects are often not maintained consistently over time (Sturgeon, 2014; Williams et al., 2012).

Within the broader chronic pain literature, there have been calls for researchers to move towards an interpersonal model of pain (Romeo et al., 2017). These calls have been prompted by research which has demonstrated the significant relational impact of chronic pain and how interpersonal factors can contribute to health-related processes and outcomes. For example, a significant proportion of individuals with fibromyalgia report difficulties in their relationships with their partner (Collado et al., 2014; Marcus et al., 2013). These difficulties appear to be related to a variety of factors including impaired sexual relationships (Bazzichi et al., 2012; Kalichman, 2009), changed household responsibilities (Hallberg & Carlsson, 1998; Söderberg et al., 2003), and perceptions of burdensomeness (Ashe et al., 2017; Kelley & Clifford, 1997).

Evidence suggests that interpersonal difficulties of this sort are associated with, and potentially contribute to, negative pain outcomes for some individuals. For instance, Murray et al. (2006) found that perceived stress levels and family relationship functioning predicted future symptom intensity in individuals with fibromyalgia, whereas Parrish et al. (2008) found that negative interpersonal events predicted increased fatigue. Within the broader chronic pain literature, various relational factors, such as spousal criticism and hostility, have been associated with pain variables including pain intensity and pain behaviours (Burns et al., 2018). Research has also found that interpersonally distressed individuals with chronic pain appear to derive less benefit from traditional cognitive-behavioural based PMPs (Verra et al., 2011). This sub-group, identified using the Multidimensional Pain Inventory (MPI: Kerns et al., 1985), report lower levels of marital satisfaction and a greater number of hostile pain responses from their partners in comparison to other patients with chronic pain (Broderick et al., 2016).

Given these findings, it is possible that some patients benefit less from current treatment options due to an insufficient focus on interpersonal difficulties. To date, however, no research has been conducted which has explored the romantic relationships and interpersonal functioning of these individuals in depth. This is problematic as the prognosis for individuals living with fibromyalgia is often poor (Sumpton & Moulin, 2008) and an increased focus on relational difficulties, interpersonal problem-solving, and communication skills may enhance therapeutic outcomes for some (Thieme et al., 2004).

In this paper we present a qualitative research investigation which sought to fill this gap in the literature and enhance our understanding of the romantic relationships of people with fibromyalgia who remain distressed or disabled by pain after receiving tertiary level treatment in a multidisciplinary PMP.

Methods

This study was approved by the North West Liverpool East Research Ethics Committee (19/NW/0172, Appendix 5) and the National Health Service (NHS) Health Research Authority (Appendix 6).

Design

Qualitative methods are excellent for investigating interpersonal relationships and dynamics (Ganong & Coleman, 2014) and were therefore utilised here. Data were collected through semi-structured interviews and analysed using thematic analysis (Braun & Clarke, 2013).

Recruitment & Sampling Procedure

Purposive sampling was used to recruit a group of individuals with fibromyalgia who identified as being within a romantic relationship and who remained distressed or disabled by their pain despite receiving multidisciplinary tertiary level treatment.

The majority of participants (n = 10) were recruited from a registry of patients who had previously completed an NHS multidisciplinary PMP in the North West of England. The patients on this registry had consented to be contacted about future research opportunities. A clinical psychologist in the research team, with legitimate access to the registry, used the study inclusion criteria (Table 3) to identify a sample of potentially eligible participants (n = 207). These individuals were sent study documentation including an invitation letter (Appendix 7), advertisement (Appendix 8), and participant information sheet (Appendix 9). These documents directed those who were interested (n = 23) to a website where they could complete an online eligibility screen (Appendix 10). Those eligible to participate were directed to an appointment booking page where they could select a date and time for the interview to take place.

Participants were also recruited through online support groups who agreed to share study documentation on their social media platforms. Interested participants (n = 34) were directed to the website where they could complete the online eligibility screen. Seven additional participants were recruited using this approach. Recruitment continued until theoretical saturation was reached, i.e., when enough data had been generated to fully develop recurrent patterns and themes from the data (Ando et al., 2014).

Table 3: Inclusion and exclusion criteria.

Inclusion Criteria

Aged 18+ years.

Primary diagnosis of fibromyalgia.

Previously attended an NHS multidisciplinary PMP.

Identify as being in a ‘committed’ and ‘long-term’ romantic relationship.

Score ≥ 5 on an 11 point pain distress numerical rating scale or score ≥ 4.3 (the mean normative score) on the Pain Interference Scale of the Multi-Dimensional Pain Inventory (Kerns et al., 1985).

Exclusion Criteria

Unable to provide informed consent independently.

Unable to participate in a verbal discussion in English.

Data Collection

Interviews were conducted face-to-face or over the telephone depending on participant preference. All interviews were conducted by the first author and recorded using an encrypted audio recorder. Prior to each interview, participants were invited to review the participant information sheet before completing a consent form (Appendix 11). Participants interviewed over the telephone were read consent points verbatim and their responses were recorded separately from the subsequent interview. Participants then completed several descriptive measures to capture the physical and psychological characteristics of the sample. Eight interviews were carried out over the telephone, six took place in participants’ own homes, and three were conducted in an NHS clinic room. All interviews were conducted individually to provide participants with a confidential space to share their experiences openly. Interviews followed a semi-structured format and a bespoke topic guide (Appendix 12), containing exploratory open-ended questions, was used throughout. Follow-up questions were also used to generate rich and detailed accounts (Charmaz, 2006). The topic guide was adapted during data collection to explore emerging concepts in more depth. The average interview duration was 65 minutes (range = 43-96 minutes).

Descriptive Measures

Demographic Questionnaire (Appendix 13) capturing age, gender, condition duration, work/educational status, relationship status, and length.

Numerical Rating Scales (Appendix 14) capturing pain intensity (rated from 0 - no pain, to 10 - the most intense pain imaginable) and pain distress (rated from 0 - no distress, to 10 - extremely distressed). These scales are recommended for use in chronic pain clinical trials and have established psychometric properties (Dworkin et al., 2005).

The Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001; Appendix 15) assessed the severity of depressive symptoms over the previous two weeks. Higher scores on the PHQ-9 represent more severe depressive symptoms. The scale is a valid and reliable measure of depressive symptoms in patients with medical conditions including chronic pain (Bair et al., 2008; Dobscha et al., 2009). Psychometric studies indicate that the internal consistency of the scale is adequate (α = 0.74-0.89; Titov et al., 2011).

The Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006; Appendix 16) was used to measure anxiety severity. Higher scores on the GAD-7 represent more severe anxiety symptoms. The measure has been validated for use in chronic pain populations (Dear et al., 2013), and the internal consistency (α = 0.79-0.91), convergent validity, and divergent validity of the measure are good (Dear et al., 2011).

The Multidimensional Pain Inventory (MPI; Kerns et al., 1985; Appendix 17) is a 52-item self-report measure based on the cognitive-behavioural conceptualisation of pain. The MPI consists of multiple empirically derived subscales: pain severity, pain-related interference, affective distress, perceived life control, perceived social support, perceptions of the behaviour of significant others, and performance of common activities. Responses are averaged to obtain subscale scores. The measure has adequate to excellent internal consistency ($\alpha = 0.7$-0.9) and test-retest reliability ($r = 0.62$-0.91) (Kerns et al., 1985).

The Pain Self Efficacy Questionnaire (PSEQ; Nicholas, 1989; Appendix 18) is a 10-item questionnaire assessing confidence performing activities whilst in pain. The PSEQ covers various functions including household chores, socialising, and coping with pain without medication. The PSEQ has a high degree of internal consistency ($\alpha = 0.92$) and test-retest reliability ($r = 0.73$, $p < 0.001$) (Asghari & Nicholas, 2001).

The Pain Catastrophizing Scale (PCS; Sullivan et al., 1995; Appendix 19) is a 13-item measure designed to assess catastrophic thoughts and feelings that often accompany and affect the pain experience. The PCS is reliable, both internally ($\alpha = 0.95$; Osman et al., 2000) and across periods ranging from 8-12 weeks ($r = 0.70$, $p < 0.001$; Sullivan et al., 1995).

Participants

Seventeen participants diagnosed with fibromyalgia agreed to participate, 16 women and one man (*M* age = 45 years, *SD* = 13.09, range = 20-61 years). The average time elapsed since diagnosis was 6 years 9 months (range = 8 months-20 years). Ten participants were unemployed, 4 were working full-time, 1 was working part-time, 1 was retired, and 1 was a student. All participants identified as being within ‘committed’ and ‘long-term’ heterosexual relationships, the average relationship length was 13 years 9 months (range = 1.5-37 years) and eleven of the participants had children. Nine participants were married, 4 were partnered, 2 were engaged and 2 were co-habiting.

All participants resided in the United Kingdom and interviews were conducted between July and September 2019. The demographic details of individual participants have been withheld to protect participant anonymity.

Data Analysis

Thematic analysis, a flexible method for identifying, analysing, and describing patterns or themes across a data-set (Braun & Clark, 2006), was conducted. An inductive approach was employed to analyse data at the semantic and latent level in order to capture and interpret hidden, yet potentially imperative, thematic concepts (Braun & Clarke, 2013). To facilitate procedural replicability, the analysis followed the staged approach outlined by Braun and Clark (2006).

The first author sought to immerse themselves in the data throughout the collection and analysis process; they therefore conducted and transcribed all interviews. Transcripts (Appendix 20) were pseudonymised to protect participant anonymity and were read on multiple occasions to increase data familiarity. Emerging ideas and hypotheses were noted down to facilitate the subsequent analysis.

A systematic line-by-line coding process (Appendix 21), which sought to capture the context and meaning of data, was undertaken using QSR International's *NVivo* (Version 12). Generated codes were added to a coding bank that was applied to data from the remaining manuscripts. Codes were reviewed and collated into potential themes based on their conceptual similarities and differences. Thematic maps were used to identify and evaluate the potential relationships between themes and the different levels of themes (Appendix 22). Sub-themes were collapsed into a number of overarching themes based around a central organising concept; these were reviewed, refined, and re-categorised on several occasions to ensure that they were reflective of the overall data set. In the final stage of the analysis, themes were named and defined to provide a coherent story of the data contained within them and individual illustrative data extracts were selected.

Reflexivity

A number of steps were taken to ensure that transparency and reflexivity were maintained throughout the research process. The use of a reflective diary allowed the first author to record reflections on their role within the data collection and analysis process, in order to identify and maintain an awareness of potential assumptions. Where appropriate, these reflections were shared and discussed within research supervision.

The researcher is a trainee clinical psychologist with experience of providing psychological support to individuals experiencing physical health conditions. The study was largely supervised by two clinical psychologists with a particular interest in relational and psychodynamic approaches. It is acknowledged that the shared knowledge and professional experience of the research team may have had an impact on the interpretations drawn from the data.

It is argued that gender relations and dynamics shape the interview process and influence the type of data obtained (Herod, 1993; Huddy et al., 1997). Thus, it is important to acknowledge that all interviews were conducted by a male researcher and the majority of interviewees identified as female. It is possible that the researchers gender and age may have influenced the topics that participants were willing to discuss within interviews. For instance, female participants may have found it difficult or uncomfortable to have in-depth intimate discussions with a younger male researcher.

The ontological and epistemological position underpinning the study is critical realism. The first author believes that participants are able to perceive a real social world and that their *"experiences and explanations of a phenomenon may in fact prove most accurate in explaining [their] reality"* (Fletcher, 2017, p.188).

Validity Checking

The preliminary coding framework and subsequent themes were formulated, refined, and agreed through regular discussions with the research team. This investigator-triangulation process discouraged bias and ensured that findings were grounded within data (Krefting, 1991; Mohammed et al., 2016).

Results

Sample Characteristics

Table 4: Mean scores on descriptive measures. Comparative mean scores within chronic pain populations are also presented to facilitate interpretation.

Domain (Measure)	Mean (*SD*)	Range	Comparative Mean Score (*SD*)
Pain Experience			
Pain Intensity (NRS)	7.53 (0.78)	6 - 9	7.21 (1.71) [a]
Pain Distress (NRS)	6.76 (1.99)	3 - 10	6.77 (2.21) [a]
Pain Interference (MPI)	4.96 (0.75)	3.33 - 5.89	4.3 (1.2) [b]
Psychological Functioning			
Depression (PHQ-9)	15.12 (3.88)	8 - 21	9.1 (6.3) [c]
Anxiety (GAD-7)	13.18 (4.23)	5 - 20	5.9 (5.6) [c]
Pain Self Efficacy (PSEQ)	20.06 (10.22)	3 - 44	22.63 (12.03) [a]
Pain Catastrophising (PCS)	30.06 (11.77)	8 - 51	27.65 (12.3) [a]
Perceived Partner Responses			
Support (MPI)	4.82 (0.74)	3 - 6	4.28 (1.82) [b]
Negative Responses (MPI)	1.66 (1.28)	0 - 3.25	1.71 (1.59) [b]
Solicitous Responses (MPI)	4.33 (1.43)	0.83 - 6	3.27 (1.57) [b]
Distracting Responses (MPI)	2.93 (1.43)	0 - 5.25	2.51 (1.54) [b]

Notes:

NRS = Numerical Rating Scale, MPI = Multidimensional Pain Inventory, PHQ-9 = Patient Health Questionnaire-9, GAD-7 = Generalised Anxiety Disorder-7, PSEQ = Pain Self Efficacy Questionnaire, PCS = Pain Catastrophizing Scale.

[a] Retrieved from Smith et al. (2016). Pre-treatment data from 760 chronic pain patients attending a UK multidisciplinary PMP.

[b] Retrieved from Kerns et al. (1985). Data derived from a population of chronic pain patients (n = 170-190) admitted to a US pain management centre.

[c] Retrieved from Kroenke et al. (2016). Baseline data from 250 patients enrolled in a US primary-care based trial of chronic pain.

The overall physical and psychological characteristics of the sample were largely comparable to existing samples of individuals with chronic pain. However, in comparison to the normative data presented by Kerns et al. (1985), the sample reported higher levels of perceived support and solicitous partner pain responses (characterised by demonstrations of sympathy and attention). Participants also reported ‘moderately severe’ levels of depression (Kroenke et al., 2001) and ‘moderate’ levels of anxiety (Spitzer et al., 2006).

Thematic Analysis

Three core themes were derived from the data: 1) *the relational impact of fibromyalgia*; 2) *factors contributing to relational distress*; and 3) *moving towards the future*. These themes are broken down into further sub-themes below and the proposed thematic structure is presented in Figure 3 (p. 97).

Theme 1: The relational impact of fibromyalgia.

1.1 Transformed sexual and intimate relationships: ***“it’s just not on my radar”.***

Participants reported that fibromyalgia had a profound impact on sexual and intimate relationships. A loss of libido was frequently reported, influenced by factors such as pain during sex, a changed body image, and low mood. This changed libido was associated with a decline in the frequency and quality of sexual activity, which left some participants with a pervading sense of selfishness and guilt:

> *“I am always knocking him back because of my pain ... I just feel like I am being really selfish.”* (Participant 11)

As a result, some felt obliged to maintain a sexual relationship with their partner irrespective of the associated discomfort:

> *“I just feel like I should, like a good little housewife.”* (Participant 9)

Participants were disappointed when their partner failed to acknowledge their pain or its impact on their sexual desire; this was predominately attributed to difficulties understanding the unpredictable level of pain that can accompany physical acts of intimacy. Several participants explained that they made a conscious effort to ‘fake’ interest and enjoyment during sexual activities due to concerns that their partner could interpret their changed sexuality as an indicator of relational dissatisfaction. However, others noted that their partner seemed to have simply accepted the change:

“He never forces, he never nags or moans about it. He just accepts it.” (Participant 7)

Participants reported that sexual activities often had to be planned and many felt that it was their responsibility to instigate such encounters when they felt well enough to do so. Adaptations were required to make the experience as comfortable as possible and descriptions of sexual activity were generally characterised by a lack of passion and spontaneity:

> *“There is a lot of having to get pillows here, there, and everywhere. It’s not a very romantic situation unfortunately ... its ‘let’s make you comfortable’.”* (Participant 12)

Participants noted that their partners can become preoccupied with ensuring that sexual encounters are painless and, at times, may seek reassurance that this is the case. This can have a negative impact on the sexual experience:

> *“It doesn’t really fit with the mood if someone keeps saying ‘are you alright’ ... sometimes I wish he would stop saying that and just enjoy himself, then I would probably enjoy it a lot more too.”* (Participant 17)

However, participants noted that it was possible to maintain an intimate relationship with their partner without engaging in sexual activity. Other forms of intimacy were valued following the onset of fibromyalgia:

> *“I can feel more connected to him by just having a kiss and a cuddle sometimes because we are not worrying about whether I am in pain ... we are just together; we are in each other’s arms.”* (Participant 12)

Unfortunately, factors such as a hypersensitivity to touch and a general sense of frustration also hindered these intimate moments. Participants were concerned that their relationships were devoid of affection, intimacy, and emotional connection. This led to fears that partners could eventually tire of the situation and leave. Although partners provided reassurance in response to these concerns this was difficult for some participants to accept:

> *"He will tell me he's not staying with me out of pity or anything and he is very, very reassuring but sometimes you just hear different words than what they are saying."* (Participant 1)

1.2 A changed shared social life: *"we used to do everything together"*.

Fibromyalgia had a transformative impact on the social life that participants shared with their partner. Valued activities, hobbies, and interests, which previously brought companionship and joy, had become difficult to access:

> *"We don't have date nights anymore ... I don't have the energy, I'm not going to enjoy it, I'm just going to be irritable, I'm going to be jumpy and in pain."* (Participant 7)

Although some participants attempted to maintain their previous social life for the sake of their partner, attempts to do so were typically fraught with difficulty. Social activities generally had to be planned meticulously to account for the challenges presented by fibromyalgia and the resultant lack of spontaneity was a source of frustration for some. Many participants noted that an increasing sense of social isolation accompanied their experience of fibromyalgia:

> *"We used to have the same friendship group, we would be so social. But because of my health that has now been restricted to barely seeing anyone."* (Participant 6)

Participants felt guilty for imposing this changed social life on their partners and were concerned about how they could be perceived. For instance, several participants were concerned that their partner felt that they were 'boring'. It was reported that partners generally struggled to understand the impact of fibromyalgia on social functioning. For instance, one participant was instructed to *"make more of an effort"* (Participant 11) and another was told to conserve their energy for social occasions. However, some participants noted that their partner appeared to have accepted the changed social life brought by fibromyalgia. Factors such as being transparent and honest were noted to facilitate acceptance.

Although participants often encouraged their partners to socialise without them, many were unwilling to do so, which was a source of guilt and frustration for some:

> *"I feel bad because he won't go off and do things on his own if I am not feeling up to it."* (Participant 16)

Others reported that their partners had indeed started to build their own social lives. However, this was typically associated with a growing sense of relational distance, concerns regarding the future, and feelings of abandonment:

> *"I just feel left behind, just sort of stuck on a shelf."* (Participant 7)

Participants generally recounted fond memories of their social lives prior to fibromyalgia. Many appeared to mourn the loss of both the previous shared social life and the envisaged future social life:

> *"We used to say... imagine when the kids have gone and we are on our own but the reality is that I have got to go and have a lie down."* (Participant 9)

Participants emphasized the importance of continuing to spend quality time together to foster an enduring sense of connectedness. Adaptations were valued that allowed participants to maintain their involvement in day-to-day activities and spend time with their partner:

> *"They gave me a perching stool for the kitchen to sit on ... I do that so we can cook together ... It's really important to try and still do things together."* (Participant 10)

1.3 The perceived impact of fibromyalgia on partners: *"I felt like I was a tonne of rocks in a rucksack on his back".*

Participants repeatedly expressed concerns regarding the impact of fibromyalgia on their partner's life. Several participants felt that they had become a different person, in comparison to when their relationship with their partner commenced, and this led some to feel that they had cheated or conned their partner:

> *"I do feel sorry for him, this isn't the person he had a few years ago, this is someone else."* (Participant 13)

Participants sensed that their partners longed for the previous version of themselves, perpetuating feelings of guilt:

> *“He never said ‘you’re not the girl I married’ but he just sometimes says things like ‘where have you gone’ and talks about the olden days.”* (Participant 9)

Participants felt increasingly reliant on their partner for financial assistance, childcare, and support around the home. The majority of participants were concerned that they were a burden that was holding their partner back:

> *“I do feel like I’m a burden, you know I think ‘god I’m not exactly a catch’.”* (Participant 2)

Participants felt that they occupied a different role within their relationship and expressed concerns that this no longer represented an equal partnership. Some felt guilty as they believed that they had let their partner down and others felt unworthy of a relationship. Participants repeatedly reported concerns that they had caused their partner to feel worried, down, stressed, or helpless. Others were fearful that their partner felt trapped in a relationship which they only maintained out of pity.

1.4 Tension and distance: *“it does cause arguments, for sure”.*

Participants generally associated fibromyalgia with a growing sense of isolation and relational distance:

> *“There is this little wedge that’s starting to move in and it's pushing you further and further away from each other.”* (Participant 1)

Partners were pushed away as participants struggled to cope with the intensity of their experiences:

> *“You don’t want to be around anyone, you just want to close everything off.”* (Participant 12)

This distance was noted to be both emotional and physical, as participants often spent their time in a separate room to their partner, causing some to feel that they lived *“totally separate lives”* (Participant 5).

Fibromyalgia was unanimously associated with relational tension, primarily due to disabling symptomology such as pain and fatigue. It was noted that both participants and their partners had become short-tempered and this often led to arguments laden with hurtful comments:

> *"I take that frustration out on the person that I shouldn't be taking it out on ... my husband."* (Participant 13)

Everyday struggles and quarrels were perpetuated by the experience of fibromyalgia. For instance, participants noted that a changed ability to engage with employment or housework resulted in tension:

> *"He thinks he is doing the ladies' jobs ... it does cause arguments for sure."* (Participant 5)

Some noted that even pain expressions could lead to hostility and several participants felt like they were constantly apologising:

> *"Apologising for the fibro and not being able to do stuff ... apologising for existing really."* (Participant 11)

Participants struggled to deal with these relational difficulties, as they had done in the past, as all resources were channeled into coping with fibromyalgia. Eventually, some participants came to resent their partner and all efforts to maintain the relationship were ceased, resulting in relationship breakdown for some.

Theme 2: Factors contributing to relational distress.

2.1 Uncommunicated experiences: ***"I just hide how I am feeling, I have always put on a show".***

Participants generally struggled to articulate and communicate their illness experiences to their significant others. However, some participants actively engaged in attempts to hide their pain and its emotional consequences from their partner:

> *"I put a smile on my face ... and just get on with it. I suppose I wear a mask really, just to hide it all."* (Participant 2)

Participants explained that they did so to ensure that they were not defined by their illness and viewed as sick, weak, or feeble. Others did not want to burden their partner with their worries as they were concerned that they would eventually tire of the situation. Some felt that it was necessary to hide their experiences to avoid their partners displeasure and to maintain a peaceful life. However, it was noted that it is generally only possible to do so temporarily:

> *"I hide everything. Pain, emotions and it just bottles up and bottles up and then you just explode."* (Participant 1)

When participants did *'explode'* some felt that their partner focused on their own difficulties or simply did not listen, making them feel dismissed and unimportant. This lack of communication was often perceived to be reciprocal and many felt that their partners failed to communicate their own thoughts and feelings, despite prompts to do so. Participants generally felt that their partners did so to avoid making them feel worse. However, a lack of communication was reported to be incredibly frustrating for both parties:

> *"He will get angry and say 'why didn't you tell me, why didn't you say how you were feeling instead of me having to guess'."* (Participant 4)

Participants acknowledged that communicating openly and honestly with their partner, and vice versa, would likely resolve doubts and dissolve relational tensions. It was felt that this could lead to increased understanding and strengthened relationships:

> *"If I could give anyone any advice it would be keep talking and be honest with your partner even though it's really hard to."* (Participant 1)

Some participants noted that, with time, they were able to talk openly with their partner about their experiences. Others felt that their partners learnt to recognise when they were fatigued or in pain on the basis of their facial expressions and body language. However, adaptations were necessary to facilitate communication for some. For instance, one participant used numerical rating scales to provide their partner with an insight into their pain levels and mood.

2.2 Searching for understanding: “*if he was an ostrich and could stick his head in the sand he would”*.

The romantic relationships of some participants were marred by a lack of understanding. Participants acknowledged that the juxtaposition between their seemingly healthy appearance and the significance of their physical health difficulties led some partners to misunderstand and doubt the validity of their experiences. Many reported that their partner initially viewed their unusual and variable experiences as exaggerated and/or falsified. Participants felt that their partners expected them to recover and some were told to “*snap out of it”* (Participant 4) when they failed to do so. As a result, some participants felt that they had to convince their partner that they weren’t *“going nuts”* (Participant 2) but were genuinely ill.

Some partners were perceived as trivialising difficulties, which was generally unwelcome as participants wanted their difficulties to be taken seriously:

> *“My husband will laugh and joke about it ... but sometimes you just feel like ‘why am I doing that, what’s wrong with me’.”* (Participant 1)

Participants were hurt when they were met with disbelief or a lack of understanding. Some felt incredibly disappointed that their partner had failed to educate themselves on the experience of living with fibromyalgia:

> *“That hurts me really because I think if you care about someone then you should be worried about them and be reading up on everything that’s wrong with them.”* (Participant 9)

However, participants noted that it is very difficult for partners, who do not experience chronic pain themselves, to truly understand what it is like to live with fibromyalgia:

> *“I would like him to feel what it’s like for an hour and then he could understand what I feel like.”* (Participant 13)

Several participants felt that their partners did understand their experiences, although some doubted the extent to which this was possible or true. It was noted that several partners had also accessed educational resources to increase their understanding of the condition. Participants reported that a combination of education, experience, and time appeared to facilitate understanding.

2.3 A perceived lack of support: *"you're a housewife so you need to look after the house".*

A lack of understanding was often accompanied by a perceived lack of support. Several participants reported that their partners actively ignored their pain or were generally inattentive to their needs:

> *"I do need to vocalize when I am in pain ... I know he hears me ... but he acts as if he hasn't."* (Participant 11)

Others felt that their partner expected them to maintain their previous level of functioning and any failure to do so was said to result in criticism or hostility:

> *"I've let things slip in the house ... and that's what annoys me because he might moan about the state of the place but he won't do anything about it."* (Participant 9)

This caused some participants to feel that their partners were unappreciative, unsympathetic, and uncaring. Partners reportedly struggled to accept the changes brought by fibromyalgia and often failed to provide additional support as a result.

In contrast, several participants expressed gratitude that their partner was supportive, sympathetic, and patient. Although some were concerned that this support could dwindle with time. Partners were noted to mainly provide practical support which involved collecting medication and assisting with personal care. However, one participant felt incredibly grateful that their partner did not allow them to *"sit back ... and become a traditional disabled person" (Participant 8).* Although some partners were described as very emotionally supportive, participants generally found it difficult to access emotional support from their partners:

> *"It was like he was there physically but not emotionally."* (Participant 2)

Nonetheless, several participants noted that they found it difficult to request or accept support from their partner. This was generally attributed to a desire to prevent feelings of burdensomeness, vulnerability, and weakness. However, participants noted that, with time, their support needs became apparent and eventually they learnt to communicate these. Unfortunately, requests for additional support reportedly went unmet for some participants and this left them feeling isolated and alone:

> *"I got no support ... I was living on my own even though I was in a relationship."* (Participant 15)

Conversely, it was noted that partners could become overprotective and discourage any physical activity. This was a source of frustration for participants who felt capable:

> *"I will say to him 'don't wrap me up in cotton wool'."* (Participant 4)

One participant pointed out the importance of maintaining an equal partnership through reciprocal support. However, several participants felt that they did not offer their partner enough support:

> *"I feel like I can't support him with his stuff ... he is a person as well, he has thoughts and feelings."* (Participant 12)

Theme 3: Moving towards the future.

3.1 Adaptation, acceptance, and relational growth: *"you can either change together or change in different directions".*

Ultimately, participants and their partners were required to adapt to their changed circumstances and learn how to live with fibromyalgia. However, this was noted to be an "*uphill struggle"* (Participant 1). Acceptance was a crucial component of the relationships of individuals with fibromyalgia:

> "*It's a lot of acceptance ... a realization of how things are going to be, how things are going to be different."* (Participant 6)

Participants, and their partners, were required to adapt to and accept their changed individual identities and the altered relationship between them. However, this process was said to require significant compromise, learning, and time.

It is important to note that fibromyalgia also highlighted the value and strength of some relationships. Participants were grateful that they had a partner who offered a degree of support and understanding and noted that others were in worse positions than themselves:

> *"I would say that I am really lucky. I think it could have been a lot worse and I am lucky to have someone who is so supportive."* (Participant 7)

The shared illness experience was reported to strengthen some relationships by uniting couples against a common foe:

> *"We are on a journey together. And that togetherness is key, it really is."* (Participant 8)

Nevertheless, for some participants, concerns regarding the stability and future of their relationships persisted. Participants repeatedly expressed concerns that their partner could struggle to cope if they had to provide them with an increasingly significant amount of care in the future.

3.2 Interventions: *"it would be great to have someone to help us stop this gap between us getting wider".*

Participants were aware of the association between fibromyalgia and relational difficulties and recognised the potential value of relational support from health care professionals. However, it was generally felt that this support was either unavailable or inaccessible:

> *"It does affect your relationship and there's nothing there to help really ... unless you've got the money for it and that's sad."* (Participant 1)

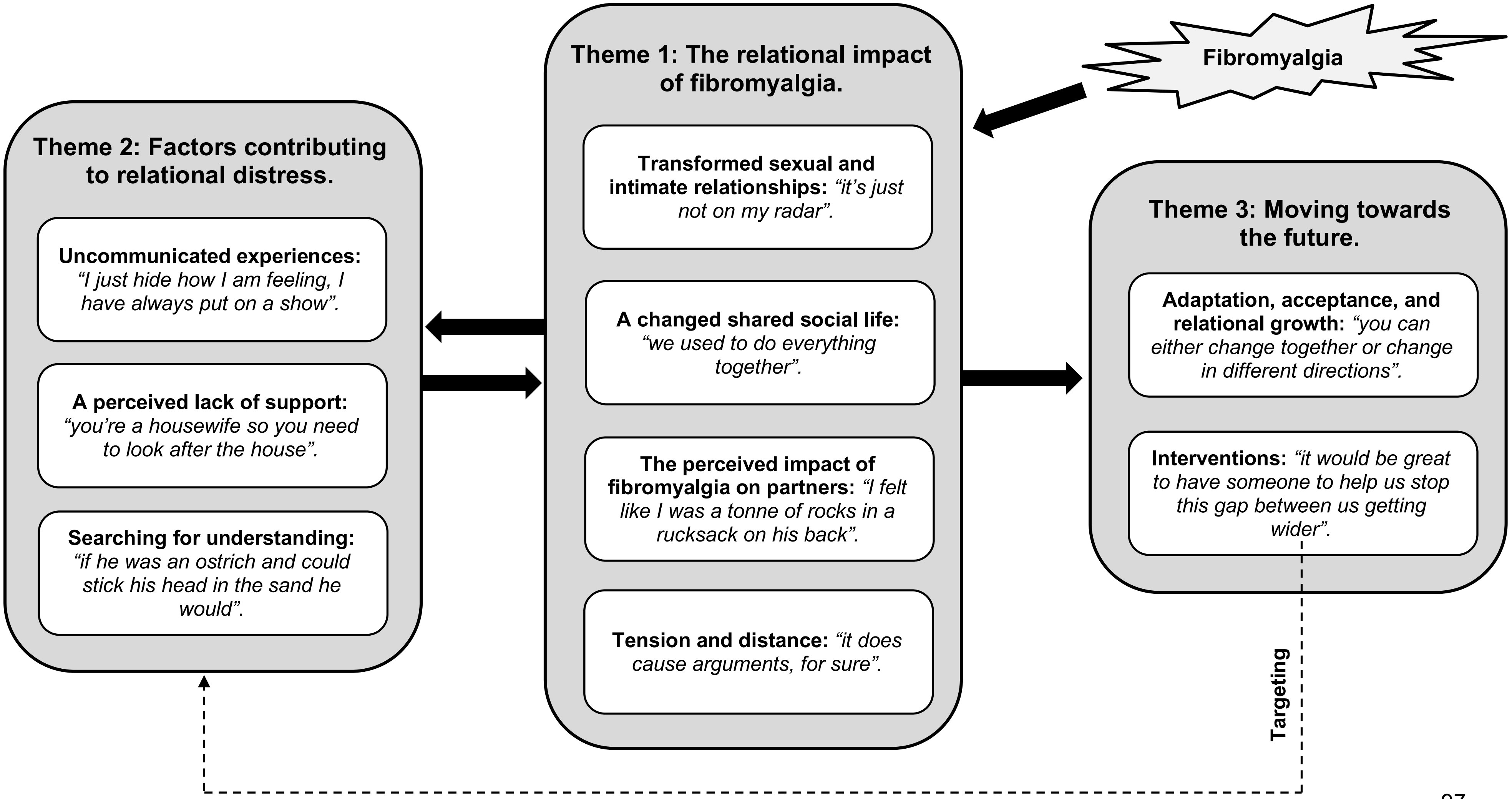
Several participants also spontaneously commented on the lack of support available for their partners. This was perplexing for participants who noted that their partner seemed to have been forgotten about, despite going through fibromyalgia with them:

> *"He may not feel my physical pain but he has felt every fear, every worry, every meltdown, every episode."* (Participant 12)

Some participants reported that their partner had attended a PMP 'friends and family' session, which was generally associated with an increased sense of credibility and understanding. However, several participants noted that they had found it difficult to discuss their intimate relational concerns within a group setting. One participant felt that individual support may be more applicable for couples who are most in need:

> "*It's impossible to say this is what you do within a relationship when you have got fibromyalgia ... what would work for one couple might be an absolute disaster for another"* (Participant 8).

Figure 3: Diagram depicting the proposed thematic structure.



Discussion

To our knowledge this is the first paper to explore the romantic relationships of individuals with fibromyalgia who report ongoing pain-related distress and disability following multidisciplinary tertiary level treatment. The narratives provided by participants were laden with accounts of interpersonal difficulties and changed relationships. These accounts are consistent with existing research demonstrating an association between fibromyalgia, relational difficulties (Collado et al., 2014; Marcus et al., 2013), and pain variables such as symptom intensity and fatigue (Murray et al., 2006; Parrish et al., 2008). Despite the correlational nature of these findings, it appears possible that the interpersonal difficulties reported by participants may contribute to their enduring distress and disability.

Participants noted that the intimate and social aspects of their relationships were particularly affected by fibromyalgia. A general decline in the frequency and quality of sexual relations was reported, consistent with existing research findings (Arnold et al., 2008; Briones-Vozmediano et al., 2016; Sallinen et al., 2011). Other forms of intimacy, such as being *"in each other's arms"*, were valued but inaccessible at times due to disabling symptomology. Nonetheless, some felt obliged to maintain a sexual relationship with their partner, perhaps due to concerns that they could terminate the relationship (Briones-Vozmediano et al., 2016; Granero-Molina et al., 2018). Participants also reported a changed shared social life as they struggled to access previously enjoyed leisure activities and hobbies (Hallberg & Carlsson, 1998; LaChapelle et al., 2008). These changed intimate and social relationships were associated with a perceived lack of understanding, guilt, and concerns regarding potential negative appraisals.

Participants described a growing sense of relational distance and disconnection. These accounts are consistent with research demonstrating that the experience of persistent pain can have a significant impact on an individual's ability to connect emotionally with their significant others (Henne et al., 2015). Fibromyalgia is often associated with reduced social contact which can give rise to feelings of sadness and loneliness (Arnold et al., 2008; Hallberg & Carlsson, 1998; Wuytack & Miller, 2011). Research has found that chronic and transient loneliness is associated with an increased incidence of negative daily social relations and bodily pain among individuals with fibromyalgia (Wolf & Davis, 2014). Negative self-evaluations were scattered throughout participant narratives, which were predominately based on concerns regarding the impact of fibromyalgia on their partner's life. Participants were concerned that they were no longer in an equal partnership or were burdening their partner. Researchers have applied the conceptual framework of the interpersonal theory of suicide to chronic pain populations (Wilson et al., 2017) and have found that interpersonal constructs such as perceived burdensomeness are associated with pain intensity, functional limitations, depressive symptoms, and suicidality (Kowal et al., 2012).

Both here and in previous studies, individuals with fibromyalgia struggled to communicate their illness experiences and thereby obtain the understanding of their partner (Sim & Madden, 2008). Participants in the current study attributed this lack of communication to a range of factors including a desire to avoid being seen as weak or a burden. However, these internalised experiences were associated with building frustrations, an eventual 'explosion' of emotion, and relational tension. It is important to note that this lack of communication appeared to be reciprocal within many relationships, with both partners generally seeking to protect the other. Themes within this study relating to hidden pain experiences and the importance of communication resonate with literature suggesting that communication difficulties in chronic pain can have important implications for family adjustment (Porter et al., 2008).

It is likely that this reported lack of communication perpetuates the lack of understanding reported by many participants. Participants generally felt that their partner did not, and to some extent could not, understand their illness experience. The invisibility of fibromyalgia was noted to lead some partners to misunderstand and question the credibility of participant experiences. This was a hurtful experience that gave rise to feelings of sadness and frustration (Juuso et al., 2011; Juuso et al., 2014). A lack of understanding was commonly associated with a perceived lack of support and several participants noted that expressions of pain were met with displeasure, criticism, or hostility. Research suggests that such responses are associated with increased pain and decreased functioning (Burns et al., 2018), in addition to psychological difficulties such as anxiety and depression (Cano et al., 2004).

In line with previous findings, participants noted that they were ultimately required to adapt to and accept their altered circumstances (LaChapelle et al., 2008). Although the shared illness experience strengthened and highlighted the value of some relationships, previous research has generally noted that factors such as understanding, being needed, and confirmed by others (which were absent for many), are required to live well with chronic illnesses such as fibromyalgia (Juuso et al., 2013; Juuso et al., 2014). Nonetheless, as with the participants in this study, concerns regarding an uncertain and feared future often persist even in the presence of supportive others (Råheim & Håland, 2006; Söderberg & Lundman, 2001).

Relevance to Existing Theoretical Literature

The narratives of the participants in this study are consistent with the theoretical notion that pain can *"infiltrate and affect a person's sense of self"* (Morley, 2010, p. 24). For instance, participants described the distressing impact of pain on their relationship with the past, present, and future social self. The Schema Enmeshment Model (Pincus & Morley, 2001) argues that this distress is the result of pain and illness schemas becoming intertwined with the self-schema and associated cognitive biases towards unattainable goals. The findings of this study suggest that partners may also comment on and emphasise the discrepancy between the past self and the present ill self which may contribute to schema enmeshment.

The importance of partners within the pain experience was initially highlighted through the operant conditioning model of pain (Fordyce, 1976) which argues that interpersonal interactions can influence the expression of pain behaviours and pain management. For instance, pain behaviours may be positively reinforced through solicitous partner responses, which are conceptually similar to the 'overprotective' care reported by participants within this study (Turk et al., 1985). Although these responses may typically be regarded as caring, research indicates that they can also be associated with feelings of helplessness and poorer outcomes (Newton-John & Williams, 2006). This was the case here as participant narratives were loaded with accounts of interpersonal difficulty despite the increased incidence of solicitous partner pain responses reported by the sample. Future research should consider the relationships of individuals who actively report negative pain related responses from their partner. The operant model would predict that such responses should lead to a reduction in expressed pain behaviours and complaints (Fordyce et al., 1985).

This results of this study contribute to the interpersonal model of chronic pain which argues that relational processes influence health processes and outcomes (e.g., Mikail et al., 1994; Romeo et al., 2017). However, the model also emphasises the importance of considering dyadic attachment styles in order to truly understand how interpersonal factors may influence adjustment and functioning within chronic pain populations (Pietromonaco et al., 2013). Future studies should therefore build upon the results of this study through a more explicit consideration of attachment and dyadic processes (e.g., Rodham et al., 2010).

Strengths & Limitations

This study successfully used two streams of recruitment and two interview formats to expand sampling beyond one service and a localised geographical area. This was helpful given that the content of PMPs is highly variable (Wilkinson & Whiteman, 2017). Through this approach we were able to recruit participants from across the lifespan with diverse occupational and social backgrounds. This allowed for a wide range of experiences to be captured.

The lack of gender and sexual diversity within the sample should be considered when interpreting study findings. Given that only one participant identified as male it is likely that a ‘female voice’ may dominate the presented narrative. Nonetheless, the recruited sample could be considered to be representative of individuals typically affected by fibromyalgia, given the disproportionate prevalence in females (Wolfe et al., 2018). Unfortunately, as we were unable recruit additional participants who identified as male, it was not possible to comment on potential gender differences within the data. However, social constructions of gender influence how individuals view themselves, their behaviour and, importantly, their relationships with others (Fillingim, 2000; Saltonstall, 1993). For instance, there are likely to be gender differences relating to the receipt of care and within the roles that males and females expect themselves to fulfil within relationships (Rodham et al., 2010). Thus, it appears likely that males with fibromyalgia may offer a unique perspective on their relational experiences and this could be explored within future research. Additionally, although individuals within same-sex relationships were eligible to participate, the recruited sample was made up of individuals in heterosexual relationships. Further research is necessary to consider if these findings are applicable to non-heterosexual relationships.

Another important limitation of this study is that ethnicity data was not collected. It is acknowledged that the absence of this data may have important implications for the interpretation of the study findings. For instance, it is likely that the presentation of ethnicity data would have facilitated reader decisions regarding the applicability, transferability, and clinical relevance of the findings. It was therefore felt that the decision to not collect ethnicity data was an oversight and, on reflection, this information should have been collected and presented accordingly.

Efforts were made to discourage bias and to ensure the trustworthiness of findings. However, validation techniques such as member checking were not possible due to resource and time constraints. As with all qualitative research, the findings presented above are not generalisable per se. However, they can be transferred to comparable circumstances if they are appropriately recontextualised (Kuper et al., 2008). A detailed description of participant characteristics and the selection procedure have been presented alongside a clear account of data collection and analysis processes to enhance transferability (Graneheim & Lundman, 2004).

Clinical Implications

The participants in this study described changed romantic relationships and associated interpersonal difficulties. However, interpersonal factors are generally not a key focus of PMPs and participants regarded additional relational support as either unavailable or inaccessible. Research has demonstrated that the psychological interventions typically found within pain management programmes, such as CBT and Acceptance and Commitment Therapy, do not lead to ‘clinically significant gains’ for a significant number of patients (Hughes et al., 2017; Morley et al., 2008). Given the relationship between interpersonal difficulties and poor treatment outcomes (e.g., Burns et al., 2018; Parrish et al., 2008), it may be that treatment approaches with an increased interpersonal focus may be necessary to improve outcomes for some patients. For instance, the delivery of cognitive based treatments could be enriched by incorporating skills from Psychodynamic Interpersonal Therapy that allow therapists to better manage difficult interpersonal scenarios (Guthrie et al., 2018). There is also evidence to suggest that standalone interpersonally oriented psychodynamic psychotherapies could be useful for individuals presenting with pain (Fonagy, 2015).

Participants struggled to communicate openly and honestly with their partner. However, they were generally aware that doing so could lead to increased understanding and strengthened relationships. Interventions that aim to improve communication skills and seek to empower individuals with fibromyalgia to educate others about their condition and support needs may therefore be beneficial (Monsivais, 2013). It may also be helpful to provide partners with explicit information regarding the consequences and effects of fibromyalgia to facilitate a shared understanding.

While participants valued the opportunity to temporarily involve their partner in their treatment, most were perplexed by the lack of support available for partners. It is likely that an increased provision of relationally focused care may also be beneficial to partners, who are often a vital source of support for individuals with fibromyalgia (Jiménez et al., 2017) but experience their own relational difficulties, fatigue, and psychological distress (Kuyper & Wester, 1998).

Conclusion

This study investigated the romantic relationships of individuals with fibromyalgia who remained distressed or disabled by their pain despite receiving tertiary level multidisciplinary treatment. Participants described changed relationships which were associated with interpersonal difficulties and relational tension. Participants generally struggled to adapt to and accept their changed circumstances and a range of potential contributing factors such as a lack of communication, understanding, and support were identified. It is possible that interpersonal difficulties may contribute to the ongoing distress and disability experienced by participants, given that research has demonstrated an association between relational difficulties and chronic pain outcomes. However, interpersonal difficulties are not a significant focus of current treatment options, such as the pain management programmes previously attended by participants. It therefore appears that an increased focus on relational difficulties, partner support, and communication skills may enhance therapeutic outcomes for some.

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Paper 3: Critical Reflection

This paper is a reflective piece and is not intended for publication.

Word Count

Complete text *(including references)*: 8,713

Main text *(excluding references but including tables, figures, and footnotes)*: 5,885

Overview

This paper presents a critical appraisal of the work conducted in this thesis and the researcher's personal reflections on the research process. The critical consideration of the work encompasses the overall topic rationale and the planning, methodology, and implementation of the systematic review and empirical study. The implications of the work are also discussed alongside plans for dissemination.

Choice of Research Area

The researcher's interest in the relational experiences of individuals living with chronic pain predominately stems from experience of working therapeutically in health psychology services. Within and across clinical interactions the researcher noted a common and repeated thread: the impact of chronic pain (and chronic health conditions more broadly) on relational factors such as roles and responsibilities, social support, and perceived relationship quality (Kowal et al., 2003). Consistent with empirical evidence (Collado et al., 2014; Marcus et al., 2013), these relational stressors were often accompanied by reports of interpersonal difficulties. The researcher's interest was perpetuated through clinical supervision, informed by relational approaches. Supervision provided a valued space to reflect on the complex interpersonal dynamics observed during clinical assessments and the reported relational implications of chronic pain, such as a changed sense of self and tense family relationships.

Why Fibromyalgia?

The decision to focus specifically on the relational experiences of individuals with fibromyalgia throughout the thesis was informed by a variety of factors:

1. Fibromyalgia has an estimated global prevalence rate of 2.7% (Queiroz, 2013) and represents a significant public health problem (Arnold et al., 2000). This increases the clinical relevance and utility of this thesis.
2. Individuals with fibromyalgia report significant relational difficulties (Collado et al., 2014; Marcus et al., 2013) and divorce rates within the population are reportedly around four times higher than the rates seen within the general population (Dennis et al., 2013). It was felt that additional research to understand these relational difficulties was warranted given that

interpersonal relationships are associated with chronic pain outcomes (Murray et al., 2006; Parrish et al., 2008).

3. The researcher was interested in the relational implications of fibromyalgia as an invisible and contested illness (Barker, 2011) that is often met with a lack of understanding and support, doubt, and stigmatisation (Armentor, 2017; Henriksson, 1995).
4. It has been argued that there are more similarities than differences between fibromyalgia and related conditions such as chronic fatigue syndrome (Wessely, 2002). However, it was felt that recruiting a homogenous sample of individuals with fibromyalgia would allow for more reliable interpretations, as it is argued that the nature and symbolic meaning of the fibromyalgia label are salient issues (Sim & Madden, 2008).
5. Particular attention also had to be paid to the time constraints of the Clinical Psychology Doctorate (ClinPsyD). It was recognised that the heterogeneity of the sample would affect how many interviews were required. It was agreed that a maximum of 20 interviews could be completed within the allocated time frame and thus a relatively homogeneous sample (i.e., with a single type of problem), would likely be required to achieve theoretical saturation (Ando et al., 2014; Guest et al., 2006). The field supervisor also indicated that, as fibromyalgia is a common chronic pain condition (Marcus, 2009), there were a significant number of potential participants on their research registry to support recruitment.

Paper 1: How do women with fibromyalgia experience and understand family relationships? A qualitative systematic review and thematic synthesis.

Topic Selection

Although it was agreed that the thesis would focus on the relational experiences of individuals with fibromyalgia, the researcher found it difficult to select and refine the precise topic and parameters of the review.

An initial scoping exercise informed decisions regarding the type of review to be completed. Although previous quantitative literature has examined the relationship between interpersonal factors and chronic pain variables (e.g., Murray et al., 2006; Parrish et al., 2008), it was felt that a meta-synthesis of qualitative literature had the potential to provide rich and detailed accounts of interpersonal relationships and dynamics (Ganong & Coleman, 2014). The researcher was also aware that the empirical study would take a qualitative approach and thus it was felt that completing a meta-synthesis would be beneficial for a number of reasons. Firstly, it would allow the researcher to become familiar with relevant existing qualitative literature. Secondly, the quality appraisal process would allow the researcher to develop an understanding of high quality qualitative research. Lastly, conducting a meta-synthesis would tie the thesis together as a complete body of qualitative work.

Throughout the scoping exercise the researcher was struck by how frequently the implications of fibromyalgia for family life and relationships appeared as a theme within broader qualitative literature. Although previous meta-syntheses have considered the experiences of individuals with fibromyalgia (e.g., Mengshoel et al., 2018; Sim & Madden, 2008), no previous systematic review had attempted to collate and interpret the relational themes woven throughout existing literature. This was despite the potential clinical utility of these synthesised findings.

The researcher was conscious that the empirical study would not capture the perspectives of family members despite the dyadic nature of relationships. Although there is a paucity of literature in this area, a small number of qualitative studies have considered the impact of fibromyalgia on partners (e.g., Paulson et al., 2003; Söderberg et al., 2003) and the researcher initially considered incorporating these papers within the synthesis. However, it was felt that the scope of this review would be too wide for a ClinPsyD thesis. The researcher was aware that only a small number of papers have considered the experiences of males with fibromyalgia (e.g., Muraleetharan et al., 2018; Sallinen & Mengshoel, 2019), perhaps due to increased female prevalence rates (Wolfe et al., 2018). It was agreed to focus specifically on the relational experiences of women with fibromyalgia within the systematic review, as it was felt that the paucity of qualitative research on men's experiences would not allow for meaningful comparisons.

Search Strategy

An essential prerequisite to thorough and successful information retrieval is the formulation of a systematic search strategy (Smith et al., 2011). The 'Context, How, Issue, Population' Tool (CHIP; Shaw, 2010) facilitated this process by breaking the review question down into its key components. The initial scoping exercise was used to identify a comprehensive range of relevant search terms and the terms used in related reviews (e.g., Mengshoel et al., 2018) were also examined. Truncations were used to account for factors such as spelling and to ensure that all relevant primary studies were identified. It is argued that librarians play a crucial role within systematic reviews (Harris, 2005) and the search strategy[1] was therefore scrutinised by a specialist librarian at the University of Manchester.

Papers were identified for inclusion by searching CINAHL, Embase, MEDLINE, PsycINFO, and Web of Science. No limits were placed on the searches to ensure maximum retrieval. Forward and backward citation searches were conducted for all included papers and reference lists were hand searched. Google Scholar was also used to search for any additional articles. It is argued that these searches have the potential to add significant value to literature reviews (Hinde & Spackman, 2015). These additional searches resulted in the identification of one further paper that was ultimately excluded due to insufficient reference to family relationships.

The titles and abstracts of all identified articles were read. This was crucial as the scoping exercise indicated that relational themes were often located within seemingly irrelevant broader qualitative literature. An independent review of search results by a second researcher is generally recommended (Stoll et al., 2019). Thus, an external reviewer also screened a sample (27.2%) of the identified articles against the inclusion/exclusion criteria and a high level of agreement was reached. The search was repeated in April 2020 to ensure that the review was as up to date as possible.

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[1] See Paper One; Methods (p. 14) for a depiction of the search strategy.

Inclusion & Exclusion Criteria

A potential limitation of the review is that studies which had not been through a peer review process were excluded. This was largely reflective of the stance that ‘grey’ literature can be associated with a lack of scientific rigor, methodological issues, and less valid results (Paez, 2017). There are also difficulties associated with searching grey literature as title and indexing information is often inconsistent (Godin et al., 2015). However, it is acknowledged that grey literature searching can retrieve information from an increased variety of sources, which can moderate the impact of publication bias and enhance systematic review findings (Mahood et al., 2014). To be included within the review studies were required to be published in the English language, predominately due to time and resource restrictions. The researcher was also conscious that the interpretation of meaning is at the core of qualitative research and this meaning can be lost during the translation process (Nes et al., 2010).

Quality Appraisal

It has been argued that a formal quality appraisal process is an essential component of any systematic review (Whiting et al., 2017). Yet there has been significant debate regarding the applicability and utility of quality appraisal processes within the realm of qualitative research (Carroll & Booth, 2014; Garside, 2014). Nevertheless, the researcher is in agreement with the stance that quality should be assessed to avoid drawing unreliable conclusions (Thomas & Harden, 2008).

The Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018) is the most commonly used tool in qualitative evidence syntheses (Noyes et al., 2018). The CASP is recommended for novice researchers’ as it is a short tool that is relatively easy to follow (Majid & Vanstone, 2018). A modified version of the CASP was used within the review which included a ‘somewhat’ response option. This response option was used to indicate when a criterion had been addressed to an extent but lacked some key elements (Long et al., 2019). This approach was taken as it was felt that the divide between response options was potentially arbitrary and traditional descriptive classifications (e.g., ‘good’ and ‘moderate’) were also not assigned for this reason.

The researcher struggled with the subjectivity of the appraisal process and thus a set of guidelines was developed which sought to ensure that decisions regarding quality were consistent across papers. These guidelines were informed by a particularly valuable reflective piece (Newton et al., 2012). An independent reviewer also appraised a sample of the studies (n = 9) to enhance the credibility of the appraisal process and to minimize bias or systematic error. Any areas of uncertainty or discrepancy were resolved through discussion and a high level of inter-rater agreement was reached.

Analysis

The notion of synthesising qualitative research is a contentious issue which is eloquently summed up by Sandelowski et al. (1997):

"Just as it goes against the nature of poetry to attempt to summarize even one poem about love, so it seems both epistemologically and ethically inappropriate to attempt to summarize findings from one or more qualitative studies about human experiences of health and illness" (p. 366).

However, it is increasingly recognised that attempts to synthesise findings are essential to enhance the generalisability of qualitative research and to facilitate effective and appropriate health care (Sandelowski et al., 1997; Thomas & Harden, 2008). When considering the most appropriate analysis, the researcher was overwhelmed by the wide variety of methods that have been developed to conduct qualitative meta-syntheses (Finlayson & Dixon, 2008). Within their critical review, Barnett-Page and Thomas (2009) identify nine discrete methods of qualitative synthesis that vary across a range of factors including epistemological stance and approach to quality appraisal.

Thematic synthesis, which involves the development of descriptive and analytical themes that push beyond the original data, was ultimately chosen as the most appropriate method for a variety of reasons. Firstly, thematic synthesis is particularly suited to experiential review questions (Barnett-Page & Thomas, 2009) and has been used successfully within similar systematic reviews (Fulford & Cobigo et al., 2018; Ridd et al., 2009; Satink et al., 2013). Secondly, consistent with the researcher's own epistemological stance, thematic synthesis is philosophically underpinned by critical realism

(Papadopoulou et al., 2013). Lastly, unlike other methods, thematic synthesis explicitly encourages the use of computer software to complete the coding process (Thomas & Harden, 2008). This was particularly valuable within the current review as a large volume of data had to be processed due to the number of studies included (n = 27). The researcher acknowledges arguments that large samples can impede data analysis (Sandelowski et al., 1997), as at times they struggled to represent the wealth of information included within each study. This reassured the researcher that their choice to limit inclusion to a relatively homogenous sample (i.e., women with fibromyalgia) was appropriate, given the large number of studies included.

Reflexivity

During the quality appraisal process all studies included within the review were screened for evidence of reflexive practice. However, reflexivity statements are rarely included within published qualitative systematic reviews. This is despite the fact that the synthesis process is influenced by researchers' understanding and interpretation of the data, which is also likely to be influenced by their skills and professional background (Mohammed et al., 2016). The researcher therefore recognised the importance of including a reflexivity statement within the current paper to allow readers to consider the complex interaction between data and researcher.

The researcher sought to maintain an awareness of their role within the synthesis process through reflection and a number of factors were identified that were felt to be of particular importance. Firstly, the researcher had their own experiences and views on what may constitute adaptive or maladaptive family relationships. Secondly, the researcher identified as male and it was important to maintain an awareness of their gender-related beliefs and experiences as data were synthesised regarding the relational experiences of women with fibromyalgia (DeVault, 1999). Lastly, the papers within the systematic review explored a similar area as the empirical study, which was running concurrently. It was therefore important that analytical themes and the resultant thematic structure were formulated, refined, and agreed through regular discussions with the wider research team. This process sought to ensure that the meta-synthesis was as bias-free and reflexive as possible.

Trustworthiness, Transparency, & Credibility

The researcher was guided by existing methodological and reporting guidelines throughout the synthesis process. In particular, PRISMA Guidelines (Moher et al., 2015) and the ENTREQ Checklist (Tong et al., 2012). In line with these guidelines a number of steps were taken to ensure that the review process was as transparent, trustworthy, and credible as possible:

1. The systematic review was carefully planned in advance. A protocol was produced and registered on PROSPERO (CRD42020169754).
2. An explicit and systematic literature search was conducted in an attempt to identify all potentially relevant primary studies.
3. An independent reviewer screened a sample of the identified primary studies against the inclusion/exclusion criteria.
4. An independent reviewer quality appraised a third of the included studies.
5. Codes and themes were formulated, refined, and agreed through regular discussions with the wider research team.
6. The synthesis followed existing methodological guidelines (Thomas & Harden, 2008) to allow for future replication.
7. A large number of quotations were presented to increase credibility and transferability (Graneheim & Lundman, 2004).

Appendix 23 presents an ENTREQ checklist for the current review which indicates that all items are present.

Paper 2: Understanding the romantic relationships of people with fibromyalgia who remain distressed or disabled by their pain following treatment.

Topic Selection & Rationale

During the initial stages of this thesis the researcher sought to immerse themselves in existing chronic pain literature with an interpersonal focus. The roots of the empirical study stem from discussions regarding literature stating that a significant number of patients do not achieve ‘clinically significant gains’ from traditional cognitive-behavioural based pain management programmes (PMPs; Morley et al., 2008). This is despite the fact that such programmes are the current treatment of choice for individuals experiencing persistent pain that has a significant impact on physical and psychological functioning (Wilkinson & Whiteman, 2017). As a group of clinical psychologists, the research team immediately started to hypothesise as to why this may be the case and discussions shifted to research that could be conducted to increase our understanding of this group and improve clinical outcomes.

One hypothesis is that these individuals may not derive clinically significant gains from PMPs due to an insufficient focus on interpersonal difficulties. This hypothesis is grounded in literature demonstrating that interpersonal relationships are associated with chronic pain outcomes. For instance, PMPs appear to be less effective for 'interpersonally distressed' individuals with chronic pain (Verra et al., 2011). This sub-group report significantly lower levels of marital satisfaction and higher levels of hostile pain responses from their partners (Broderick et al., 2016)[2].

It was agreed that it could be beneficial to recruit a sample of individuals with fibromyalgia who report ongoing pain-related distress or disability, despite attending a PMP, in order to explore the interpersonal functioning of these individuals in depth. This research was thought to be of particular importance as there is a paucity of literature in the area, despite the apparent clinical need to increase our understanding of this group. The field supervisor, based within an NHS PMP, also felt that this research could have important service-level implications.

The study focused on romantic relationships as research has demonstrated that individuals with fibromyalgia often report difficulties in their relationships with their partner (Collado et al., 2014; Marcus et al., 2013). This may relate to the multiple transitions that occur within such relationships and the significant levels of support that partners are often expected to provide (Jiménez et al., 2017). It has also been found that partners of individuals with chronic illnesses report fatigue and psychological distress due to relational difficulties (Kuyper &

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[2] See Paper Two; Introduction (p. 65) for further discussion.

Wester, 1998). Thus, there was a clinical need to explore these relational problems and to consider how outcomes could be improved for both members of the dyad.

Study Design

Initially, the researcher considered the applicability of qualitative, quantitative, and mixed-method approaches. It was recognised that a quantitative exploratory survey could have been used to gather relational information, perhaps with interwoven free response questions that may have allowed for some brief qualitative analysis. Indeed, such an approach has been used to explore the family relationships of individuals with fibromyalgia (Marcus et al., 2013). The researcher was aware that utilising a quantitative or mixed-methods approach may have conferred a variety of benefits such as the potential for an increased sample size and generalisability. However, the researcher sought to capture rich data that reflected the essence of the participants' relational experiences (Byrne, 2001) and thus a qualitative approach was thought to be most applicable. The researcher was also aware that qualitative approaches are recognised as "*excellent ways to investigate family dynamics and family relationships"* (Ganong & Coleman, 2014, p. 451).

There is a longstanding and enduring focus on spousal relationships within chronic pain literature (e.g., Burns et al., 2018; Cano, 2004; Romano et al., 1991). Initially, the researcher considered continuing this tradition by recruiting a sample of participants who identified as married, co-habiting, or within a civil partnership. However, what constitutes a romantic relationship is a source of debate, partly due to the changing norms of how individuals define their relationships (Kansky, 2018). On reflection, the researcher felt that it would be unwise to exclude potential participants because they had not sought to have their relationship legally recognised or because they did not live with their partner. This was discussed with the wider research team and it was agreed that a sample of individuals who identified as being within a 'committed' and 'long-term' romantic relationship would be recruited.

The researcher also carefully considered how best to identify a sample of individuals experiencing ongoing pain-related distress or disability. Multiple measures of pain-related disability exist; however, many of these are condition specific. Several general disability measures were considered but these are often lengthy and therefore unsuitable for use as a screening measure (e.g., the 32 item Brief Pain Inventory; Cleeland & Ryan, 1994). Eventually, the Pain Interference Scale of the Multi-Dimensional Pain Inventory (Kerns et al., 1985) was chosen as it is a relatively short scale with good psychometric properties (Bernstein et al., 1995). The scale has also been used in multiple studies exploring multidisciplinary treatment outcomes in fibromyalgia (e.g., Hooten et al,. 2007; Thieme et al., 2003). It was agreed that the study would recruit individuals who scored above the mean normative score (≥ 4.3) obtained from a sample of chronic pain patients (Kerns et al., 1985). A single item numerical rating scale captured pain-related distress as these scales are widely used in clinical trials involving patients with chronic pain (Childs et al., 2005). Discussions with the field supervisor indicated that a score of ≥ 5 on this scale would be indicative of significant pain distress within clinical practice.

It is acknowledged that a larger number of descriptive measures (n = 7) were used in the current study compared to traditional qualitative studies. However, the researcher recognised the importance of presenting the physical and psychological characteristics of the sample to facilitate decisions regarding transferability and to allow readers to consider how characteristics may relate to the subsequent interview findings.

Topic Guide

The semi-structured interview format provided an interview template that was containing for the researcher as a novice interviewer and allowed for a flexible approach that was well suited to complex and sensitive discussions (Barriball & While, 1994).

An important stage of the research design process was the development of a bespoke topic guide (Appendix 12). This process was informed by existing literature and discussions with the wider research team. The different dimensions of relationships such as support and communication were formulated within research meetings and incorporated into the topic guide. Questions were designed to be broad and open-ended to encourage in-depth discussions. Probing follow-up questions were also used to generate rich and detailed participant accounts (Charmaz, 2006).

The topic guide was adapted throughout data collection to improve the interview process and to explore emerging concepts in more depth. For instance, the opening question *“can you tell me about your experience of fibromyalgia and your journey to where you are today”* was added to the topic guide after the second interview. This additional question was inspired by the work of Rosenthal (2003) who argued that it is helpful to open interviews with a spontaneous and broad narrative. Although this led to the generation of some irrelevant data, this question was included to build an initial rapport with participants, which was crucial given the sensitive and intimate nature of the discussions that followed.

Public & Patient Involvement

Members of the University of Manchester ClinPsyD Community Liaison Group, with lived experience of chronic pain were consulted during the development of this study. Advice was sought regarding the accessibility and meaningfulness of the questionnaires used in the study (e.g., wording, appropriateness). Group members felt that the sense of safety and privacy offered by the online completion of the eligibility screen could allow participants to be more honest about their relationship with their partner. Group members pointed out that some participants may require support when completing questionnaires and thus the researcher ensured that they were available at all times to assist with queries. With regards the study as a whole, the feedback from group members was positive. It was felt that the study was of importance and could be of benefit to patients and their significant others.

Recruitment

Initially, the researcher planned to solely recruit participants from an NHS PMP in the North West of England. A significant number of potential participants (n = 207) were identified by the field supervisor and contacted via post. However, only 23 individuals went on to commence the online eligibility screen, 10 of whom were recruited into the interview stage of the study. The reasons underlying this moderate response rate (11.1%) are unclear as the researcher was unable to contact potential participants due to ethical constraints.

Eventually, it became apparent that an additional recruitment drive would be necessary to meet the target sample size of 15-20 participants. However, the researcher was unable to recruit further participants from the NHS PMP due to the postage costs involved. Given the short timeframe of the ClinPsyD, the recruitment contingency plan was activated at this point and online fibromyalgia support groups were approached to advertise the study. Additional participants were recruited using this approach (n = 7) and recruitment continued until theoretical saturation was reached (Ando et al., 2014). The final sample size (n = 17) was either consistent with or larger than other qualitative studies conducted with individuals with fibromyalgia (e.g., Ashe et al., 2017; Juuso et al., 2014).

The researcher agrees with the stance that *"the internet is an invaluable resource for recruiting research participants, especially for studies that require recruitment of clinical ... populations"* (Rodham & Gavin, 2006, p. 92). The cost and time investments of online recruitment were minimal and a large number of participants expressed an interest in the study in a short period of time, which came as a welcome surprise for the researcher. The prospect of online recruitment was initially a source of apprehension, however on reflection it was felt that the output of the expanded recruitment strategy was a relative strength of the study. Sampling was extended beyond a localised geographical area (Sweet, 2002) and this allowed for the recruitment of participants with diverse occupational and social backgrounds.

Data Collection Experience

At first the researcher felt rather reliant on the topic guide and noted a desire to ask structured questions. This was reflective of the researcher's lack of experience as an interviewer and concerns that important information could be missed if the researcher strayed from the topic guide. With time, the researcher used the topic guide much more flexibly and, in combination with probing follow-up questions, this produced rich high-quality data (Charmaz, 2006).

It has been argued that fundamental differences exist between clinical and research interviews (Targum, 2011). For instance, in a clinical context the interviewer typically directs an exchange which is streamlined and narrow in focus, whereas in research interviews the interviewer actively seeks to avoid overly directing the interview (Hunt et al., 2011). However, the researcher struggled to disengage from their ‘clinical role’ during interviews, particularly as participants described difficulties that were consistent with the researcher’s concurrent clinical work. Research supervision provided a valued reflective space to discuss these concerns and to receive feedback on interviewing skills; initial interview transcripts were also reviewed to explore emerging concepts in more depth.

Although sensitive personal experiences were discussed within interviews, the researcher was surprised by the level of expressed emotion and trauma reported by participants. This observation is in line with findings suggesting that there may be an association between trauma and fibromyalgia (e.g., Aaron et al., 1997; White et al., 2000). However, these anecdotal observations were not reported within paper two as they were outside of the focus of the study. Discussions regarding relational difficulties were emotive for some and this emphasised the importance of the thorough debrief process (Appendix 24). At the request of the ethics committee, the general practitioners of all participants were contacted and informed of their patients’ participation in the study. Participants were provided with contact details for a number of organisations and were advised to contact their general practitioner or these services to address any distressing feelings that may have arisen during the interview. However, it must be acknowledged that participating in qualitative research is associated with a range of potential benefits including catharsis, empowerment, and healing (Hutchinson et al., 1994).

Depending on participant preference, interviews were either conducted face-to-face or over the telephone. Telephone interviews are often thought of as an inferior alternative to face-to-face interviews (Novick, 2008). However, research has demonstrated that they can produce rich, detailed, and high-quality data (Carr & Worth, 2001; Sturges & Hanrahan, 2004). There is also evidence to suggest that some participants may prefer sensitive interviews (e.g., those relating to their intimate relationships) to take place over the telephone due to the perceived anonymity it provides (Fenig et al., 1993). Although there are limitations of telephone interviews such as a lack of visual cues (Garbett & McCormack, 2001) and the potential for environmental distractions (Novick, 2008), these were not apparent in this study and it was felt that the benefits of this approach (e.g., the ability to expand sampling beyond a localised geographical area) outweighed the potential limitations.

Data Analysis

Selecting the most appropriate analysis method is a key component of the study design process. However, the researcher felt overwhelmed by the broad range of available qualitative methods. Discussions with an experienced research team were therefore an invaluable resource to guide the decision-making process. The researcher initially considered the applicability of a grounded theory approach (Glaser et al., 1968). However, the study did not aim to create a conceptual framework or theory and thus this method was discounted (Charmaz, 1990). Interpretative phenomenological analysis (IPA; Smith, 1996) was a promising potential methodology as this approach is suitable for studies which aim to explore how participants make sense of their personal and social world (Gonzalez et al., 2015). However, IPA studies typically prioritise individual narratives and this has important implications for confidentiality and generalisability (Pringle et al., 2011).

An inductive thematic analysis was carried out, which is a flexible and analytic method used for identifying, analysing, and describing patterns across the data-set (Braun & Clarke, 2013)[3]. The method can be used to report on participants' experiences and to consider how they apply meaning to their reality. Thematic analysis has been referred to as a poorly branded method (Vaismoradi et al., 2013) as there is a lack of available guidance on how to conduct a rigorous analysis (Nowell et al., 2017). On the other hand, it is also argued that thematic analysis is an easily grasped and accessible method which is particularly suited to novice researchers. The researcher's experience was that following the staged approach outlined by Braun and Clark (2006) not only enhanced procedural replicability but also provided a set of clear and easy to follow methodological guidelines. These guidelines were particularly helpful as the analysis was more time consuming than the researcher initially anticipated and at times felt overwhelming.

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[3] See Paper Two; Methods (p. 69) for additional information.

A larger number of interviews (n = 17) were conducted in the present study in comparison to traditional ClinPsyD projects. The researcher transcribed all interviews personally and, although this was a laborious and time-consuming process, the benefits for the analysis were profound. The researcher was able to fully immerse themselves in the data and became familiar with its content and breadth. The transcription process produced a large volume of data (218 pages) and QSR International's *NVivo* (Version 12) was therefore used throughout the analysis process. The software was an invaluable tool and allowed the researcher to manage and organise data throughout the analysis process. Indeed, it has been argued that this *“software greatly reduces manual tasks and gives the researcher more time to discover tendencies, recognize themes, and derive conclusions”* (Hilal & Alabri, 2013, p. 185).

The final stage of thematic analysis is the production of a report which requires researchers’ to select data extracts that illustrate individual themes and provide a concise, coherent, and thought-provoking story of the data (Braun & Clarke, 2006). It is acknowledged that the researcher has included more data extracts throughout their narrative than might traditionally be found within qualitative papers. However, it was felt that this provided a fair and vivid representation of the rich data that participants graciously provided and brought the otherwise analytic narrative to life.

Reflexivity

Qualitative approaches recognise the importance of reflexivity (Finlay, 1998; Guillemin & Gillam, 2004). For instance, Braun and Clarke (2006) note that data is not coded in an epistemological vacuum. Authors are generally encouraged to explore how their actions and role may influence and inform the research process (Nightingale & Cromby, 1999). This exploration should include reflections on the author’s personal experiences and epistemological stance (Willig, 2001).

The researcher is a trainee clinical psychologist with experience of providing psychological support to individuals experiencing physical health conditions and it is acknowledged that an interest in this research area grew from these experiences. Given the researcher’s dual role as a researcher and clinician, it was difficult to not think of the data in clinical terms at times. As a person and a clinical psychologist, the researcher was also conscious that they had their own views on what may constitute a healthy relationship. The researcher therefore recorded reflections on their role within the data collection and analysis process in a reflective diary to maintain an awareness of potential assumptions. To ensure methodological and interpretive rigour the study was evaluated using the CASP (Appendix 25).

A critical realist stance underpinned the study and this influenced how the researcher viewed study findings. This stance is particularly suited to qualitative research as it posits that participant *"experiences and explanations of a phenomenon may in fact prove most accurate in explaining [their] reality"* (Fletcher, 2017, p.188). The researcher viewed the presented findings as one possible interpretation of the data, which was influenced both by how participants explained their reality and the researcher's own experiences, beliefs, and values.

Thesis Implications

The findings of this complete body of work, including the systematic review and empirical study, enhance our understanding of the family relationships of individuals with fibromyalgia and have the potential to inform clinical interventions for this population. It is apparent that fibromyalgia can lead to significant relational changes and difficulties. For instance, both papers highlight that individuals with fibromyalgia can struggle to communicate their experiences to their significant others and this can have implications for the shared pain-related adjustment process.

However, these interpersonal difficulties are often not a specific target of current treatment options, which are typically grounded in cognitive-behavioural principles (Wilson, 2017). It appears that these relational difficulties may be associated with distress and disability and thus treatment approaches with an increased focus on relational difficulties and communication skills may be beneficial for some. Partners, in particular, may benefit from clinical input given that they often constitute a significant source of support for individuals with fibromyalgia.

A number of suggestions for future research have also been made throughout the thesis. For instance, it was noted that relationships often evolve over time yet there is a lack of research that has explored relatedness longitudinally. It may be beneficial to include partners within future samples in order to understand the dyadic relational experiences which occur within the midst of fibromyalgia. Further research should also consider the relational experiences of males with fibromyalgia given that relationships are influenced by social constructions of gender (Fillingim, 2000; Saltonstall, 1993).

Dissemination Plan

The researcher is aware of the importance of sharing psychological knowledge through dissemination. The systematic review and empirical paper have therefore been prepared for submission to ‘Social Science & Medicine’ and ‘Qualitative Health Research’ respectively. The researcher also aims to disseminate findings at relevant conferences such as the British Pain Society Annual Scientific Meeting.

All participants within the empirical study stated that they would like to receive a summary of the findings and this will be distributed in the form of a written lay summary. A poster will also be developed so that findings can be shared with patients and clinicians at the participating NHS trust.

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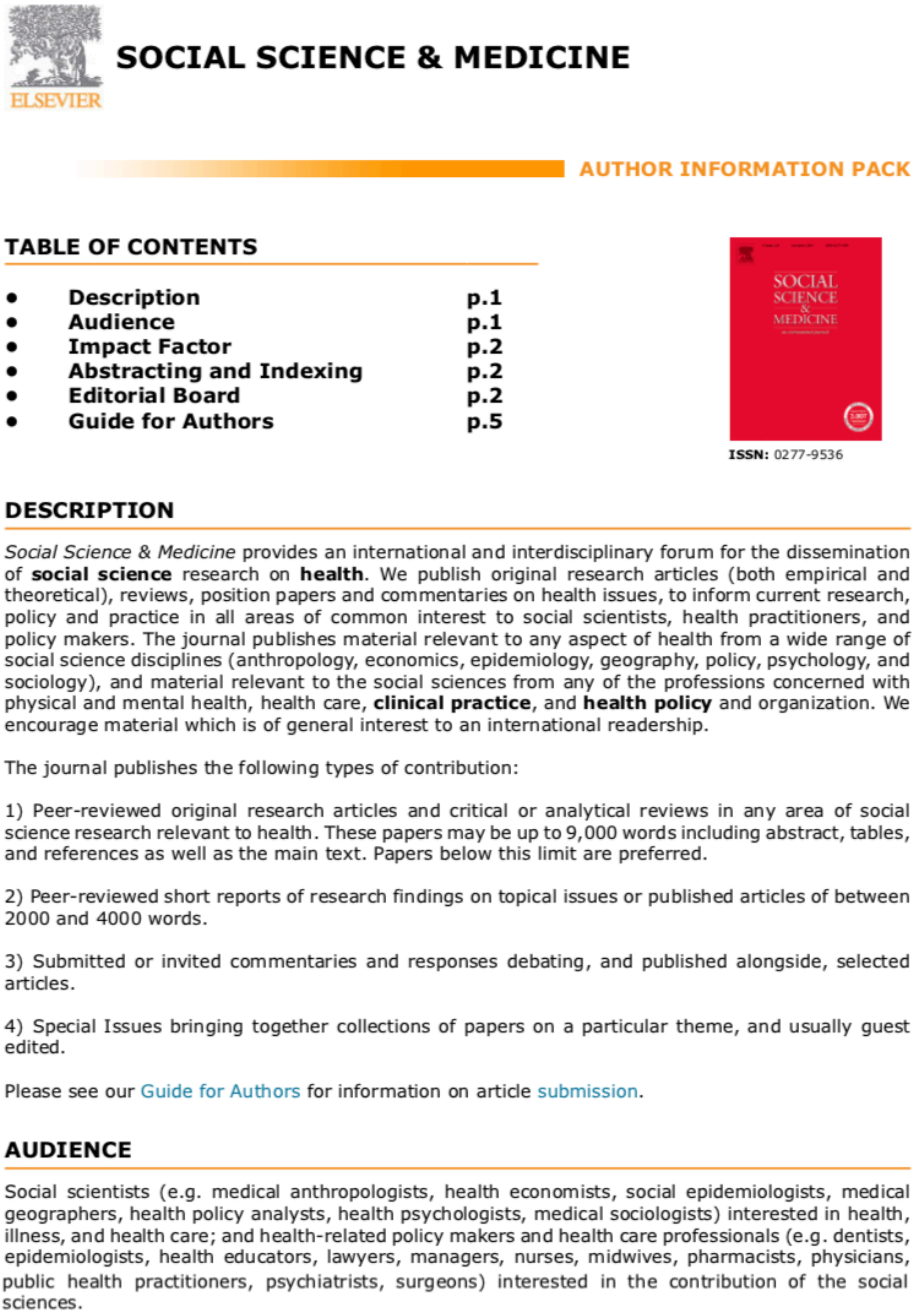
Appendix 1: Social Science & Medicine Publication Guidelines



SOCIAL SCIENCE & MEDICINE

AUTHOR INFORMATION PACK

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DESCRIPTION

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of **social science** research on **health**. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, **clinical practice**, and **health policy** and organization. We encourage material which is of general interest to an international readership.

The journal publishes the following types of contribution:

1) Peer-reviewed original research articles and critical or analytical reviews in any area of social science research relevant to health. These papers may be up to 9,000 words including abstract, tables, and references as well as the main text. Papers below this limit are preferred.

2) Peer-reviewed short reports of research findings on topical issues or published articles of between 2000 and 4000 words.

3) Submitted or invited commentaries and responses debating, and published alongside, selected articles.

4) Special Issues bringing together collections of papers on a particular theme, and usually guest edited.

Please see our Guide for Authors for information on article submission.

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Social scientists (e.g. medical anthropologists, health economists, social epidemiologists, medical geographers, health policy analysts, health psychologists, medical sociologists) interested in health, illness, and health care; and health-related policy makers and health care professionals (e.g. dentists, epidemiologists, health educators, lawyers, managers, nurses, midwives, pharmacists, physicians, public health practitioners, psychiatrists, surgeons) interested in the contribution of the social sciences.

GUIDE FOR AUTHORS

Your Paper Your Way

We now differentiate between the requirements for new and revised submissions. You may choose to submit your manuscript as a single Word or PDF file to be used in the refereeing process. Only when your paper is at the revision stage, will you be requested to put your paper in to a 'correct format' for acceptance and provide the items required for the publication of your article.

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INTRODUCTION

Click here for guidelines on Special Issues.

Click here for guidelines on Qualitative methods.

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health and healthcare from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and the organization of healthcare. We encourage material which is of general interest to an international readership.

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2) Systematic reviews and literature reviews of up to 15000 words including abstract, tables, figures, references and (printed) appendices as well as the main text.

3) Peer-reviewed short communications of findings on topical issues or published articles of between 2000 and 4000 words.

4) Submitted or invited commentaries and responses debating, and published alongside, selected articles (please select the article type 'Discussion' when submitting a Commentary).

5) Special Issues bringing together collections of papers on a particular theme, and usually guest edited.

Due to the high number of submissions received by Social Science & Medicine, Editorial Offices are not able to respond to questions regarding the appropriateness of new papers for the journal. If you are unsure whether or not your paper is within scope, please take some time to review previous issues of the journal and the Aims and Scope at https://www.journals.elsevier.com/social-science-and-medicine/.

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You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
- E-mail address
- Full postal address

Essential cover page information

The Cover Page should **only** include the following information:

- ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible and make clear the article's aim and health relevance.
- ***Author names and affiliations in the correct order.*** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address. Contact details must be kept up to date by the corresponding author.**
- ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Text

In the main body of the submitted manuscript this order should be followed: abstract, main text, references, appendix, figure captions, tables and figures. Author details, keywords and acknowledgements are entered separately during the online submission process, as is the abstract, though this is to be included in the manuscript as well. During submission authors are asked to provide a word count; this is to include ALL text, including that in tables, figures, references etc.

Title

Please consider the title very carefully, as these are often used in information-retrieval systems. Please use a concise and informative title (avoiding abbreviations where possible). Make sure that the health or healthcare focus is clear.

Highlights

Highlights are optional yet highly encouraged for this journal, as they increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

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An abstract of up to 300 words must be included in the submitted manuscript. An abstract is often presented separately from the article, so it must be able to stand alone. It should state briefly and clearly the purpose and setting of the research, the principal findings and major conclusions, and the paper's contribution to knowledge. For empirical papers the country/countries/locations of the study should be clearly stated, as should the methods and nature of the sample, the dates, and a summary of the findings/conclusion. Please note that excessive statistical details should be avoided, abbreviations/acronyms used only if essential or firmly established, and that the abstract should not be structured into subsections. Any references cited in the abstract must be given in full at the end of the abstract.

Keywords

Up to 8 keywords are entered separately into the online editorial system during submission, and should accurately reflect the content of the article. Again abbreviations/acronyms should be used only if essential or firmly established. For empirical papers the country/countries/locations of the research should be included. The keywords will be used for indexing purposes.

Methods

Authors of empirical papers are expected to provide full details of the research methods used, including study location(s), sampling procedures, the date(s) when data were collected, research instruments, and techniques of data analysis. Specific guidance on the reporting of qualitative studies are provided here.

Systematic reviews and meta-analyses must be reported according to PRISMA guidelines.

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There should be no footnotes or endnotes in the manuscript.

Artwork

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Preferred fonts: Arial (or Helvetica), Times New Roman (or Times), Symbol, Courier.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.

- Indicate per figure if it is a single, 1.5 or 2-column fitting image.
- For Word submissions only, you may still provide figures and their captions, and tables within a single file at the revision stage.
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Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full at the end of the abstract. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal (see below) and should include a substitution of the publication date with either "Unpublished results" or "Personal communication" Citation of a reference as "in press" implies that the item has been accepted for publication.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

Reference style

Text: All citations in the text should refer to:

1. *Single author:* the author's name (without initials, unless there is ambiguity) and the year of publication;
2. *Two authors:* both authors' names and the year of publication;
3. *Three or more authors:* first author's name followed by 'et al.' and the year of publication.

Citations may be made directly (or parenthetically). Groups of references can be listed either first alphabetically, then chronologically, or vice versa.

Examples: 'as demonstrated (Allan, 2000a, 2000b, 1999; Allan and Jones, 1999)…. Or, as demonstrated (Jones, 1999; Allan, 2000)… Kramer et al. (2010) have recently shown …'

List: References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Appendix 2: CASP Qualitative Checklist

CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

HINT: Consider

- what was the goal of the research?
- why it was thought important?
- its relevance.

Yes		Somewhat		No		Can’t Tell

Comments:

2. Is a qualitative methodology appropriate?

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.
- Is qualitative research the right methodology for addressing the research goal?
- What is the wording in the aims? Are they using quantitative terms e.g. explain or qualitative terms e.g. experience.

Yes		Somewhat		No		Can’t Tell

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use).
- What philosophical perspective, methodology (e.g. phenomenology, grounded theory) and method (e.g. IPA, TA, Grounded Theory)? Are these appropriate to address the research aims?
- Agreed that 'somewhat' = when the philosophical perspective and methodology are not stated but generally appear to be in line with the methodology.

Yes		Somewhat		No		Can't Tell

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

- If the researcher has explained how the participants were selected.
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.
- If there are any discussions around recruitment (e.g. why some people chose not to take part). This should be given less weight unless people have dropped out or recruitment difficulties are implied. **If all of the other elements above are present but this isn't then this question can still be scored yes.**

Yes		Somewhat		No		Can't Tell

Comments:

5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection (e.g. clinic, charity) has been justified.
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen.
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide).
- If methods were modified during the study. If so, has the researcher explained how and why (if applicable).
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data. It was agreed that this does not have to be present if the sample size is typical. **However, if the sample size appears to be limited then this question should be scored down to somewhat** (providing the other elements above are present).

Yes		Somewhat		No		Can’t Tell

Comments:

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location.
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design (if applicable).
- This includes what their role is (e.g. nurse), how their role could influence their decision making, their interest in research area, their experience of condition, gender etc.
- The relationship between the researcher and participants should definitely be discussed in an IPA study.

Yes		Somewhat		No		Can’t Tell

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- Agreed that if a PIS etc. is mentioned then consent should be assumed.
- Agreed that there should definitely be some mention of an attempt to maintain confidentiality e.g. use pseudonyms.
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee. Agreed that there should be a statement about approval from if ethics committee. **If other elements are present then this item should be marked 'can't tell'.**

Yes		Somewhat		No		Can't Tell

Comments:

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process.
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. **Agreed that this should be given less weight and that If other elements are present then this item should still be marked as 'yes'.**
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account. Agreed this can include different participant views (e.g. one participant said this whilst another said this).
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation. **Agreed that if this is not present but the above elements are then this item should be marked as 'somewhat'.**

Yes		Somewhat		No		Can't Tell

9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?

HINT: Consider

- Agreed that there should be an attempt in results or discussion to sum up findings in a concise manner, this could even be a brief sentence before moving on to discuss individual findings in more detail. **Agreed that if this is not present but the below elements are then this item should be marked as 'somewhat'.**
- If the findings are explicit.
- If there is adequate discussion of the evidence both for and against the researcher's arguments (for = linking to existing research, against = study limitations generally).
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). Agreed that this may be a simple statement anywhere within the paper about several others confirming themes or some evidence of a discussion etc. **Agreed that if this is not present but the above elements are then this item should be marked as 'somewhat'.**
- If the findings are discussed in relation to the original research question.

Yes		Somewhat		No		Can't Tell

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research- based literature.
- If they identify new areas where research is necessary.
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.

Comments:

Appendix 3: Quality Appraisal

Author(s) & Publication Year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?	10. How valuable is the research? (Is the research valuable?)
Armentor (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Arnold et al. (2008)	Yes	Somewhat	No	Somewhat	Somewhat	No	Can’t Tell	Can’t Tell	Somewhat	Somewhat
Briones-Vozmediano et al. (2016)	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Yes
Calsius et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Can’t Tell	Can’t Tell	Yes	Yes
Cuesta et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Somewhat	Somewhat	Yes	Somewhat
Cooper & Gilbert (2017)	Yes	Yes	Somewhat	No	Yes	No	Yes	Can’t Tell	Somewhat	Somewhat
Dennis et al. (2013)	Yes	Yes	No	Somewhat	Yes	No	Somewhat	Can’t Tell	Yes	Yes
Granero-Molina et al. (2) (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes

Author(s) & Publication Year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?	10. How valuable is the research? (Is the research valuable?)
Hallberg & Bergman (2011)	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Somewhat
Hallberg & Carlsson (a) (1998)	Yes	Yes	Somewhat	Somewhat	Somewhat	No	Yes	Somewhat	Somewhat	Somewhat
Hallberg & Carlsson (b) (2000)	Yes	Yes	Somewhat	Somewhat	Somewhat	No	Somewhat	Somewhat	Somewhat	Somewhat
Henriksson (1995)	Yes	Somewhat	Can’t Tell	Can’t Tell	Somewhat	No	Can’t Tell	No	No	No
Jiménez et al. (1) (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Juuso et al. (2011)	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat
Juuso et al. (2013)	Yes	Yes	Yes	Can’t Tell	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat
Juuso et al. (2014)	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat
LaChapelle et al. (2008)	Yes	Yes	Can’t Tell	Somewhat	Somewhat	No	Somewhat	Somewhat	Yes	Yes

Author(s) & Publication Year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?	10. How valuable is the research? (Is the research valuable?)
Löfgren et al. (2006)	Yes	Somewhat	Somewhat	Yes	Somewhat	No	Can’t Tell	No	Somewhat	Yes
Råheim & Håland (2006)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Somewhat	Somewhat
Reibel & Pearson (2017)	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Can’t Tell	Yes	Yes	Somewhat
Sallinen et al. (2011)	Yes	Yes	Yes	Yes	Somewhat	No	Yes	Somewhat	Somewhat	Somewhat
Schaefer (1995)	Yes	Yes	Somewhat	Can’t Tell	Yes	No	Can’t Tell	Somewhat	Somewhat	Somewhat
Schaefer (2005)	Yes	Yes	Somewhat	Yes	Can’t Tell	No	Somewhat	Can’t Tell	Somewhat	Somewhat
Söderberg et al. (1999)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Somewhat	Somewhat	No
Söderberg & Lundman (2001)	Yes	Yes	Can’t Tell	Can’t Tell	Somewhat	No	Somewhat	Somewhat	Somewhat	No
Sturge-Jacobs (2002)	Yes	Yes	Somewhat	Yes	Somewhat	No	Yes	Somewhat	Yes	Somewhat

Author(s) & Publication Year	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?	10. How valuable is the research? (Is the research valuable?)
Wuytack & Miller (2011)	Yes	Yes	Yes	Somewhat	Yes	No	Somewhat	Yes	Yes	Yes

Appendix 4: Qualitative Health Research Publication Guidelines

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

For information and guidance on how to make your article more discoverable, visit our Gateway page on How to Help Readers Find Your Article Online

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Qualitative Health Research*, please ensure you have read the Aims & Scope.

1.2 Article types

Each issue of *Qualitative Health Research* provides readers with a wealth of information —, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.2.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main *QHR* webpage.
- Search the *QHR* journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- *QHR* accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- *QHR* is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in *QHR* provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.
- QHR does NOT publish pilot studies.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals:

- All papers reporting animal and/or human studies **must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval.** Please ensure that you blinded the name and institution of the review committee until such time as your article has been accepted. The Editor will request authors to replace the name and add the approval number once the article review has been completed

- **For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.**

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

4. Preparing your manuscript

4.1 Article Format (see previously published articles in QHR for style):

- Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including othergeographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

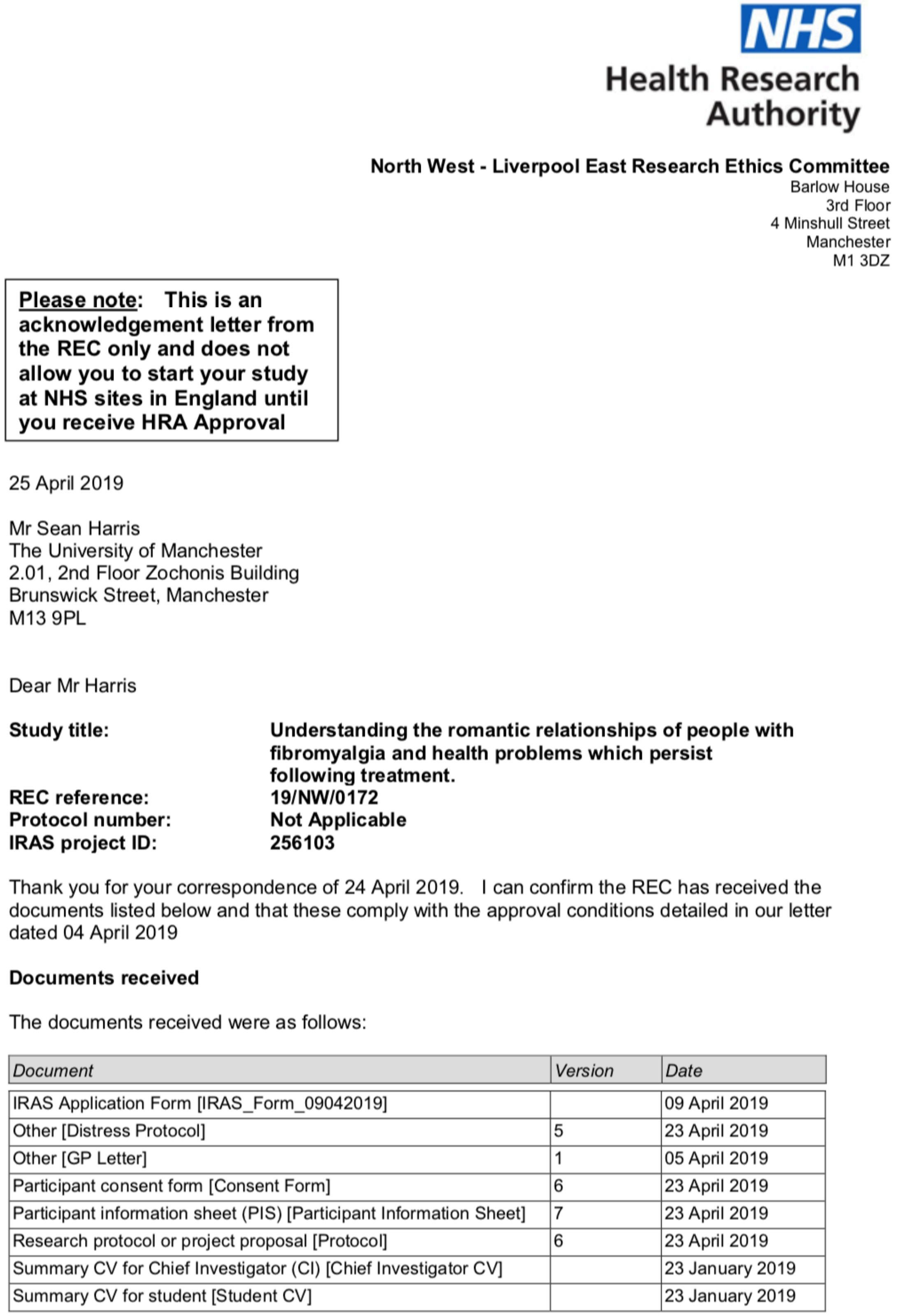
Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

Appendix 5: Research Ethics Committee Approval Letter



NHS
Health Research
Authority

North West - Liverpool East Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

<u>Please note</u>: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

25 April 2019

Mr Sean Harris
The University of Manchester
2.01, 2nd Floor Zochonis Building
Brunswick Street, Manchester
M13 9PL

Dear Mr Harris

Study title:	**Understanding the romantic relationships of people with fibromyalgia and health problems which persist following treatment.**
REC reference:	**19/NW/0172**
Protocol number:	**Not Applicable**
IRAS project ID:	**256103**

Thank you for your correspondence of 24 April 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 04 April 2019

Documents received

The documents received were as follows:

Document	*Version*	*Date*
IRAS Application Form [IRAS_Form_09042019]		09 April 2019
Other [Distress Protocol]	5	23 April 2019
Other [GP Letter]	1	05 April 2019
Participant consent form [Consent Form]	6	23 April 2019
Participant information sheet (PIS) [Participant Information Sheet]	7	23 April 2019
Research protocol or project proposal [Protocol]	6	23 April 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		23 January 2019
Summary CV for student [Student CV]		23 January 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster]	4	18 February 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Document Letter]		25 February 2019
Interview schedules or topic guides for participants [Topic Guide]	2	21 January 2019
IRAS Application Form [IRAS_Form_09042019]		09 April 2019
Letter from sponsor [Letter from Sponsor]		25 February 2019
Letters of invitation to participant [Invite Letter]	4	18 February 2019
Letters of invitation to participant [Charity Invite Letter]	1	18 February 2019
Other [Interview Stage Questionnaire Pack]	3	18 February 2019
Other [Debrief Procedure]	3	21 January 2019
Other [Lone Working Policy]	1	25 February 2019
Other [Risk Disclosure Protocol]	2	21 January 2019
Other [Data Management Plan]	3	22 February 2019
Other [Employers Liability Document]	1	31 May 2018
Other [Employers Liability Certificate]	1	01 June 2018
Other [Combined Liability Confirmation Letter]	1	07 May 2018
Other [University of Manchester Subcommittee Approval Letter]	1	19 November 2018
Other [Social Media Advertisement]	1	12 March 2019
Other [Summary of Participant Information Sheet for Website]	1	12 March 2019
Other [Study Website Screenshots]	2	12 March 2019
Other [GP Letter]	1	05 April 2019
Other [Distress Protocol]	5	23 April 2019
Participant consent form [Consent Form]	6	23 April 2019
Participant information sheet (PIS) [Participant Information Sheet]	7	23 April 2019
Research protocol or project proposal [Protocol]	6	23 April 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		23 January 2019
Summary CV for student [Student CV]		23 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 1 CV]		23 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 2 CV]		23 January 2019
Summary CV for supervisor (student research) [Local Collaborator CV]		23 January 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

19/NW/0172 Please quote this number on all correspondence

Yours sincerely

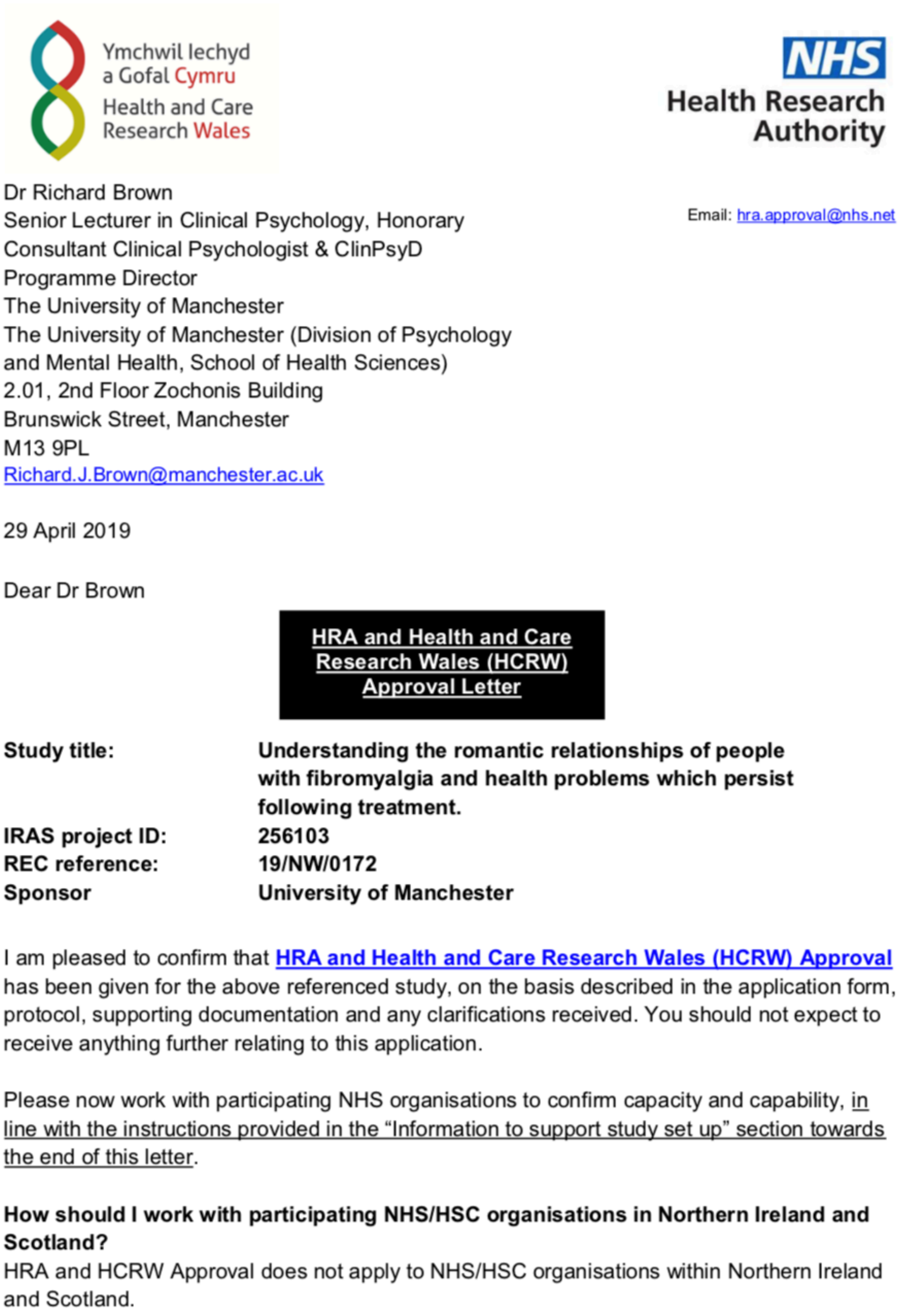
H. wood

Harriet Wood
Approvals Officer

E-mail: nrescommittee.northwest-liverpooleast@nhs.net

Copy to: *Mr Sean Harris*
Mr Dave Watling, The Walton Centre NHS Foundation Trust

Appendix 6: Health Research Authority Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net

Dr Richard Brown
Senior Lecturer in Clinical Psychology, Honorary
Consultant Clinical Psychologist & ClinPsyD
Programme Director
The University of Manchester
The University of Manchester (Division of Psychology
and Mental Health, School of Health Sciences)
2.01, 2nd Floor Zochonis Building
Brunswick Street, Manchester
M13 9PL
Richard.J.Brown@manchester.ac.uk

29 April 2019

Dear Dr Brown

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

Study title:	**Understanding the romantic relationships of people with fibromyalgia and health problems which persist following treatment.**
IRAS project ID:	**256103**
REC reference:	**19/NW/0172**
Sponsor	**University of Manchester**

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 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 **256103**. Please quote this on all correspondence.

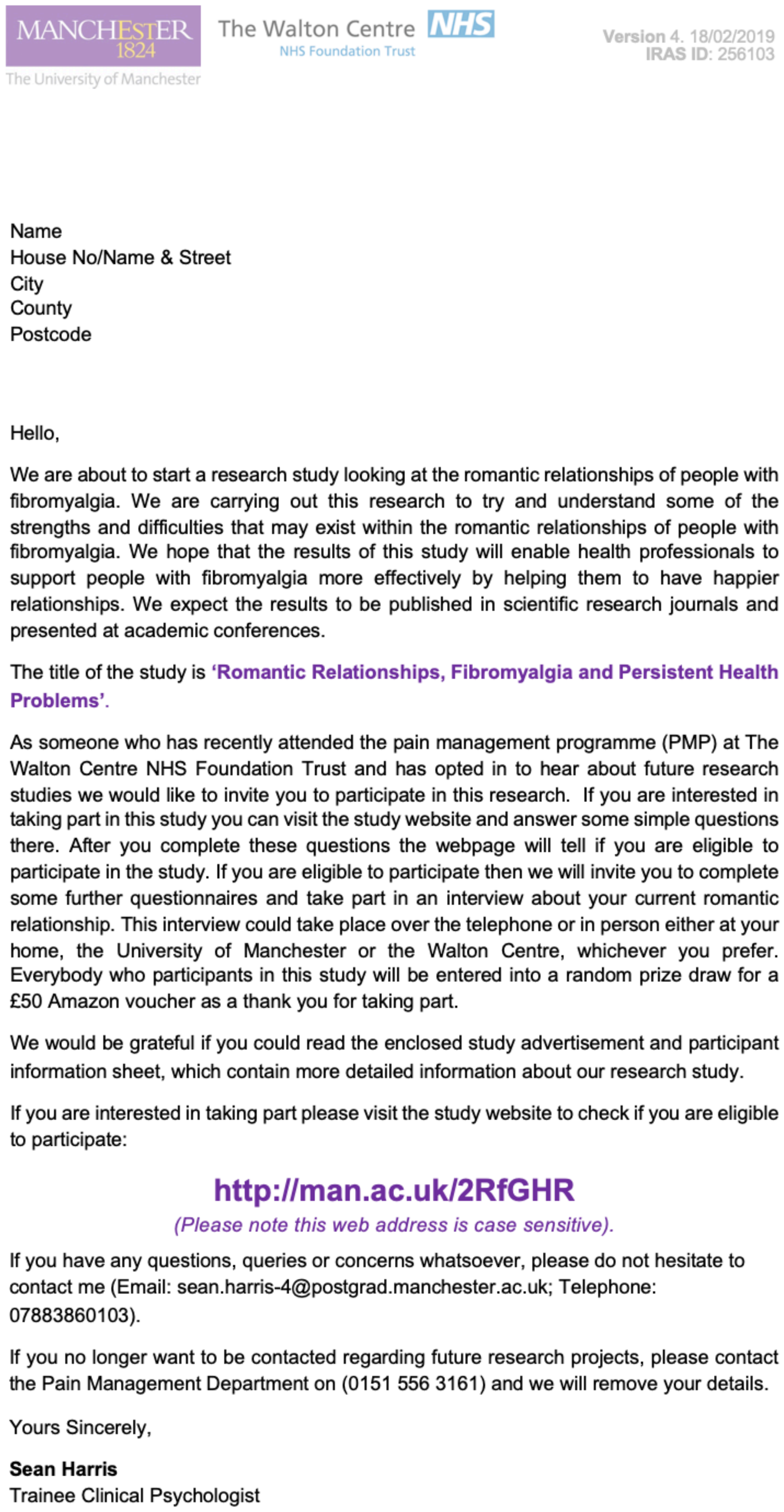
Yours sincerely,
Gemma Oakes

Approvals Specialist

Email: hra.approval@nhs.net

Copy to: *Ms Lynne Macrae, University of Manchester [Sponsor Contact]*
fbmhethics@manchester.ac.uk

Appendix 7: Invitation Letter



MANCHESTER
1824
The University of Manchester

The Walton Centre NHS
NHS Foundation Trust

Version 4. 18/02/2019
IRAS ID: 256103

Name
House No/Name & Street
City
County
Postcode

Hello,

We are about to start a research study looking at the romantic relationships of people with fibromyalgia. We are carrying out this research to try and understand some of the strengths and difficulties that may exist within the romantic relationships of people with fibromyalgia. We hope that the results of this study will enable health professionals to support people with fibromyalgia more effectively by helping them to have happier relationships. We expect the results to be published in scientific research journals and presented at academic conferences.

The title of the study is **'Romantic Relationships, Fibromyalgia and Persistent Health Problems'**.

As someone who has recently attended the pain management programme (PMP) at The Walton Centre NHS Foundation Trust and has opted in to hear about future research studies we would like to invite you to participate in this research. If you are interested in taking part in this study you can visit the study website and answer some simple questions there. After you complete these questions the webpage will tell if you are eligible to participate in the study. If you are eligible to participate then we will invite you to complete some further questionnaires and take part in an interview about your current romantic relationship. This interview could take place over the telephone or in person either at your home, the University of Manchester or the Walton Centre, whichever you prefer. Everybody who participants in this study will be entered into a random prize draw for a £50 Amazon voucher as a thank you for taking part.

We would be grateful if you could read the enclosed study advertisement and participant information sheet, which contain more detailed information about our research study.

If you are interested in taking part please visit the study website to check if you are eligible to participate:

http://man.ac.uk/2RfGHR

(Please note this web address is case sensitive).

If you have any questions, queries or concerns whatsoever, please do not hesitate to contact me (Email: sean.harris-4@postgrad.manchester.ac.uk; Telephone: 07883860103).

If you no longer want to be contacted regarding future research projects, please contact the Pain Management Department on (0151 556 3161) and we will remove your details.

Yours Sincerely,

Sean Harris
Trainee Clinical Psychologist

Appendix 8: Advertisement

MANCHESTER 1824
The University of Manchester

The Walton Centre NHS
NHS Foundation Trust

Version 4. 18/02/2019
IRAS ID: 256103

Do you have fibromyalgia?
Are you in a romantic relationship?

We are conducting a research study and want to hear about **your experiences** of having fibromyalgia and being in a romantic relationship.

Who?

We are looking for English speaking adults with a diagnosis of fibromyalgia who have previously attended an NHS Pain Management Programme and are currently in a romantic relationship.

What?

You will be asked to complete a small number of online questionnaires to check if you are eligible to participate in the study. If you are we will invite you to complete some more questionnaires and participate in an interview. If you participate in this study you will be entered into a random prize draw to win a £50 Amazon voucher as a thank you for taking part.

Why?

We hope that the results of this study will enable health professionals to support people with fibromyalgia more effectively and help them to have happier relationships.

If you are interested in taking part please visit:

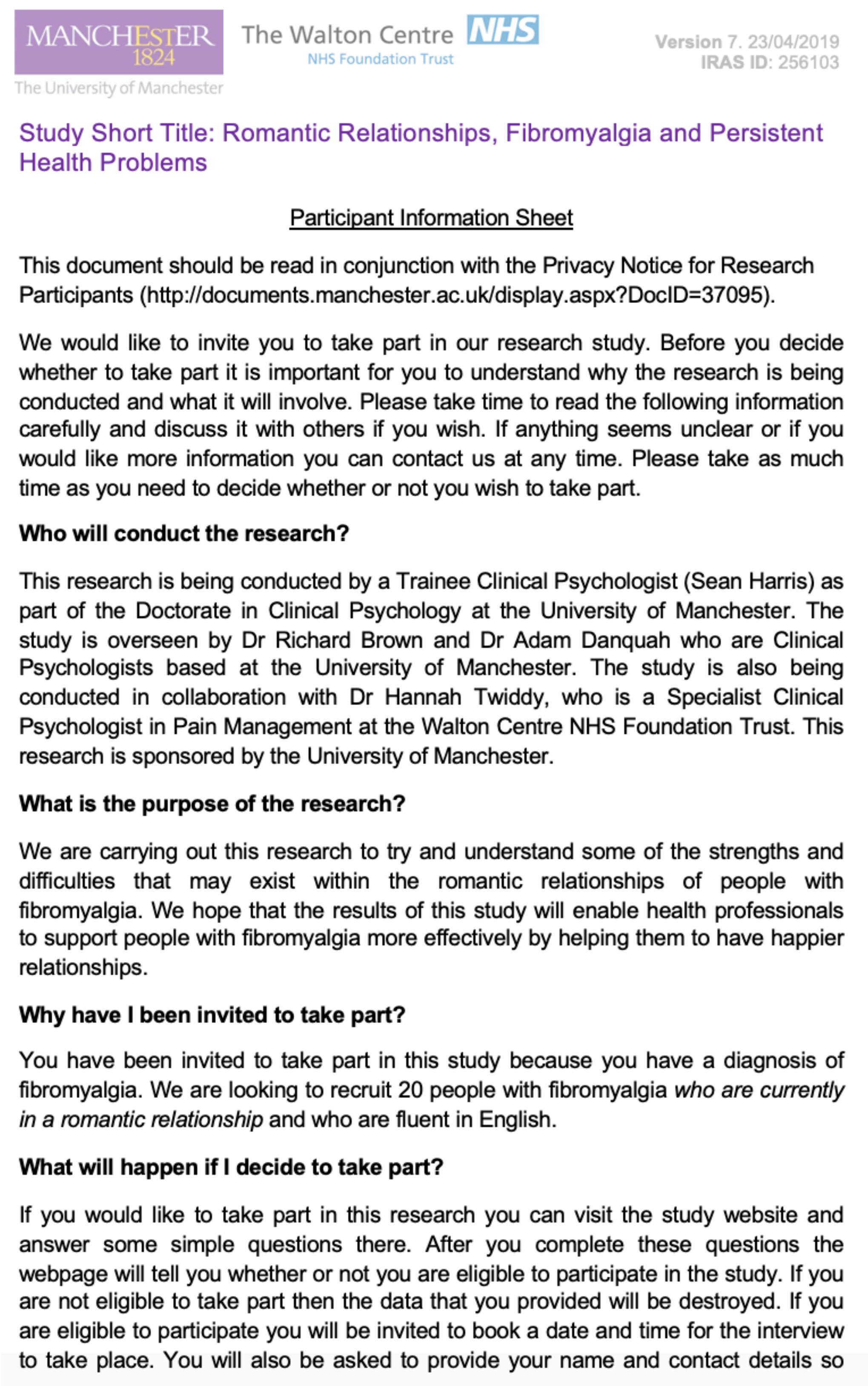
http://man.ac.uk/2RfGHR

(Please note this web address is case sensitive).

Or contact us for more information:

Email: sean.harris-4@postgrad.manchester.ac.uk
Telephone: 07883860103

Appendix 9: Participant Information Sheet



MANCHESTER 1824
The University of Manchester
The Walton Centre NHS
NHS Foundation Trust

Version 7. 23/04/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Participant Information Sheet

This document should be read in conjunction with the Privacy Notice for Research Participants (http://documents.manchester.ac.uk/display.aspx?DocID=37095).

We would like to invite you to take part in our research study. Before you decide whether to take part it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If anything seems unclear or if you would like more information you can contact us at any time. Please take as much time as you need to decide whether or not you wish to take part.

Who will conduct the research?

This research is being conducted by a Trainee Clinical Psychologist (Sean Harris) as part of the Doctorate in Clinical Psychology at the University of Manchester. The study is overseen by Dr Richard Brown and Dr Adam Danquah who are Clinical Psychologists based at the University of Manchester. The study is also being conducted in collaboration with Dr Hannah Twiddy, who is a Specialist Clinical Psychologist in Pain Management at the Walton Centre NHS Foundation Trust. This research is sponsored by the University of Manchester.

What is the purpose of the research?

We are carrying out this research to try and understand some of the strengths and difficulties that may exist within the romantic relationships of people with fibromyalgia. We hope that the results of this study will enable health professionals to support people with fibromyalgia more effectively by helping them to have happier relationships.

Why have I been invited to take part?

You have been invited to take part in this study because you have a diagnosis of fibromyalgia. We are looking to recruit 20 people with fibromyalgia *who are currently in a romantic relationship* and who are fluent in English.

What will happen if I decide to take part?

If you would like to take part in this research you can visit the study website and answer some simple questions there. After you complete these questions the webpage will tell you whether or not you are eligible to participate in the study. If you are not eligible to take part then the data that you provided will be destroyed. If you are eligible to participate you will be invited to book a date and time for the interview to take place. You will also be asked to provide your name and contact details so that a researcher can contact you to confirm the date, time and place of the interview. You can ask the research any questions that you have about participating in the research at this point.

The interview can take place over the telephone or in person either at your home address, the University of Manchester or at the Walton Centre (whichever you prefer). The interview will focus on your relationships with other people, including your current romantic relationship. The interview will be voice recorded using an encrypted audio recorder provided by the University of Manchester to make sure that we do not miss anything. You also be asked to complete some short questionnaires about your background and your health. All of the information you provide will be held confidentially, and neither you nor your partner will be identifiable in any reports we write about the research.

How long will it take?

It should take no more than 15 minutes to answer the initial questions on the Internet to find out if you are eligible to part. If you do participate in the study, the research meeting will last for up to 2 hours. This includes time to discuss the study and for you to ask questions, and time to compete the questionnaires. We expect the interview itself to take about an hour.

What are the possible disadvantages and risks of taking part?

For some people, talking about their relationships can be difficult because this topic can be sensitive and personal. There is a possibility that talking about your relationship may be upsetting. You are free to have a break or end the interview at any time should you feel upset or distressed, and if there are any questions you do not wish to answer you can leave them unanswered.

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or The Walton Centre NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you

What will happen to my personal information?

In order to undertake the research project we will need to collect the following personal information/data about you:

- Demographic information (e.g. your age, gender, employment status)
- Contact details (e.g. name, telephone number, email address)
- Information about your health (e.g. how long you have had fibromyalgia for)
- Information about your relationships (e.g. how long you have been in a relationship for and what your current relationship is like)

The main way that we will collect information about your relationships is by interviewing you. The interview will be recorded using an encrypted audio recorder provided by the University of Manchester and only your voice will be captured on the recording. Your interview will be typed up as soon as practical in a way that makes it impossible to identify you or anyone you spoke about. We will then destroy the recording of the interview. When we publish the findings of this study, we may use direct quotes, but these will be used in such a way that they will not reveal your identity.

Only the research team will have access to any personal information that you provide. We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is "public interest task" and "for research purposes" if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our Privacy Notice for Research Participants (http://documents.manchester.ac.uk/display.aspx?DocID=37095).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

- The study team at the University of Manchester will have access to your personal identifiable information, that is data which could identify you, but they will anonymise it as soon as practical. However, we will retain a copy of your consent form for five years after we publish the research, as this is the standard retention period. Consent forms will be stored in a locked filing cabinet at the University of Manchester. Any other data that you provide to us on paper (e.g. through completing questionnaires) will also be temporarily stored securely in a locked filing cabinet at the University, digitised as soon as possible and destroyed. This data will be stored on a computer database which will be password protected and stored on a secure network at the University of Manchester

- Your contact details will be kept in a separate database to any other data that you provide in this study. We will need to retain your contact details if you would like to receive a summary of our findings, however these will be deleted once the summary has been sent to you. If you do not want to receive this summary then your contact details will be deleted after the interview.

- Any data that you provide online (via the study website) will be stored on a secure server hosted by the University of Manchester. If you are not eligible to participate in the study your data will be deleted as soon as is practical.
- As per University of Manchester protocol, your anonymised data will be stored for 5 years after the last publication of the data or for 10 years, whichever is greater. After this period, all data will be destroyed.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our privacy notice for research (http://documents.manchester.ac.uk/display.aspx?DocID=37095) and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights. You also have a right to complain to the Information Commissioner's Office, Tel: 0303 123 1113.

Will my participation in the study be confidential?

To maintain your confidentiality you will be assigned a random participant identification number, any data that you provide will be linked to this number and you will therefore be unidentifiable.

All of the information that you provide will be treated with strict confidentiality. The interview will be recorded using an encrypted audio recorder provided by the University of Manchester. Your interview will be typed up as soon as practical in a way that makes it impossible to identify you or anyone you spoke about. In some instances, interviews may be transcribed by the Clinical Psychology Doctorate Departmental Secretary, who is employed by The University of Manchester. As an employee of the University, the secretary is professionally bound by University policies on confidentiality and data protection. The secretary will also sign a confidentiality agreement before being given access to any of your information.

Confidentiality may be broken if you tell us anything that makes us think that you or anyone else is at risk of harm. We will have to share this information, for example, with your GP. For monitoring and auditing purposes, study data and materials may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust. All will have a duty of confidentiality to you as a participant.

Will anyone know that I am taking part?

As mentioned above we would need to inform someone if you tell us something that makes us believe there is an immediate risk to either yourself or others and this would include your GP. We will therefore inform your GP that you have taken part in this research study. However, they will not be told about what you said during the interview and they will not have access to any of the questionnaires that you complete.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you are eligible to participate in the study and decide to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights.

Due to the nature of the research it would not be possible to take part in this study unless you are willing to have your voice recorded during an interview. However, the researcher will seek to ensure that you feel comfortable with the recording process at all times. You are also free to stop the recording at any time.

Will my data be used for future research?

When you agree to take part in a research study, information about you may be provided to researchers running other research studies in this organisation. The future research should not be incompatible with this research project. These organisations may be universities, NHS organisations or companies involved in specific relevant research in this country or abroad. Where your information relates to your health and care it will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research (https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-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 regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

Will I be paid for participating in the research?

No, you will not receive any payment for taking part. However, all participants will be entered into a random prize draw for a £50 Amazon voucher as a thank you for taking part.

If you attend an interview with a researcher and incur any travel costs (e.g. taxis, trains) these will be reimbursed by the researcher on the day of the interview. Please note that you will be required to produce a receipt for expenses purposes.

Will the outcomes of the research be published?

Yes, once all the information has been collected and analysed, the research findings will be written up as part of Sean Harris' doctoral thesis and the findings will may be published in an academic journal. We will also share the results with other people with fibromyalgia, health care professions and researchers. This may be through presentations at conferences, charity newsletters or social media platforms etc. In all cases, any information you provide will be anonymous and used in such a way so they will not identify a particular participant.

A summary of the findings will be written for participants. If you would like a copy of this summary, please tell us and we will ensure that you will receive it when the study has finished. We will need to retain your contact details in order to send this to you. However, we will destroy your name and contact details once we have sent the summary to you.

Disclosure and Barring Service (DBS) Check

The researcher in this study has undergone a satisfactory DBS check.

Who has reviewed the research project?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the North West (Liverpool East) Research Ethics Committee and was given a favourable opinion on 29/04/2019. The REC reference number is 19/NW/0172. This study also has HRA and Health and Care Research Wales (HCRW) Approval.

What if I want to make a complaint?

If you have a minor complaint then please contact the researcher(s) in the first instance. Contact details for Sean Harris and Dr Richard Brown are provided at the end of this information sheet.

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you receive care from the Walton Centre you could also contact the Patient Experience Team to discuss any queries. They can be reached by telephoning 0151 556 3090 or by emailing PatientExperienceTeam@thewaltoncentre.nhs.uk.

What do I do now?

If you would like to discuss the study or have any questions or concerns, please do not hesitate to contact a member of our research team using the contact details below.

If you would like to take part then please complete the screening stage of the study online at:

http://man.ac.uk/2RfGHR

(Please note this web address is case sensitive).

Thank you for considering taking part in this study.

Contacts for further information:

Sean Harris
Researcher

Trainee Clinical Psychologist,
The University of Manchester
(Faculty of Biology, Medicine and Health)
2.01, 2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL

Email:
sean.harris-4@postgrad.manchester.ac.uk

Telephone: 07883860103

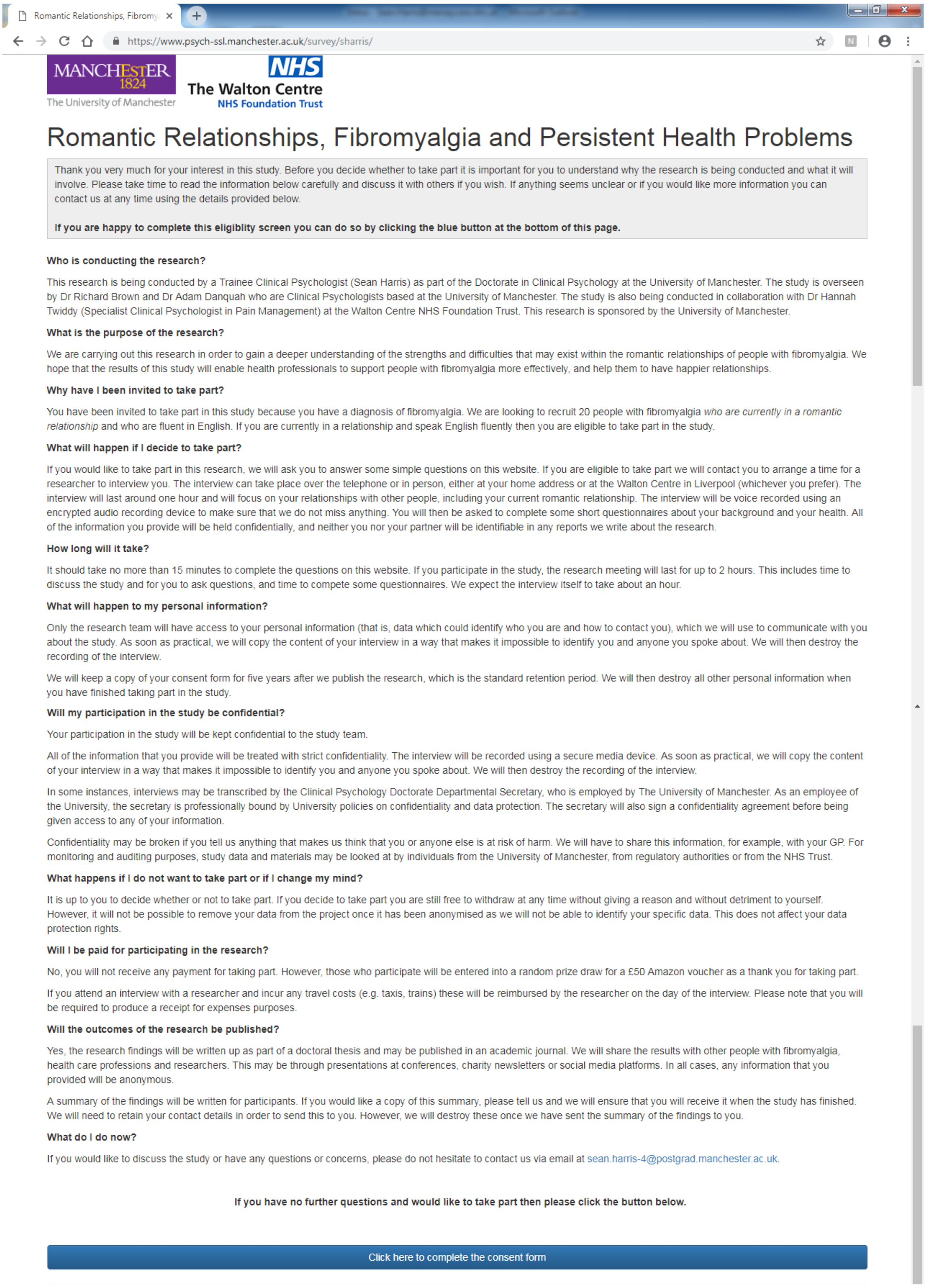
Dr Richard Brown
Chief Investigator

The University of Manchester
(Faculty of Biology, Medicine and Health)
2.01, 2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL

Email:
richard.j.brown@manchester.ac.uk

Appendix 10: Online Eligibility Screen

Summary of Participant Information Sheet



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Thank you very much for your interest in this study. Before you decide whether to take part it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the information below carefully and discuss it with others if you wish. If anything seems unclear or if you would like more information you can contact us at any time using the details provided below.

If you are happy to complete this eligiblity screen you can do so by clicking the blue button at the bottom of this page.

Who is conducting the research?

This research is being conducted by a Trainee Clinical Psychologist (Sean Harris) as part of the Doctorate in Clinical Psychology at the University of Manchester. The study is overseen by Dr Richard Brown and Dr Adam Danquah who are Clinical Psychologists based at the University of Manchester. The study is also being conducted in collaboration with Dr Hannah Twiddy (Specialist Clinical Psychologist in Pain Management) at the Walton Centre NHS Foundation Trust. This research is sponsored by the University of Manchester.

What is the purpose of the research?

We are carrying out this research in order to gain a deeper understanding of the strengths and difficulties that may exist within the romantic relationships of people with fibromyalgia. We hope that the results of this study will enable health professionals to support people with fibromyalgia more effectively, and help them to have happier relationships.

Why have I been invited to take part?

You have been invited to take part in this study because you have a diagnosis of fibromyalgia. We are looking to recruit 20 people with fibromyalgia *who are currently in a romantic relationship* and who are fluent in English. If you are currently in a relationship and speak English fluently then you are eligible to take part in the study.

What will happen if I decide to take part?

If you would like to take part in this research, we will ask you to answer some simple questions on this website. If you are eligible to take part we will contact you to arrange a time for a researcher to interview you. The interview can take place over the telephone or in person, either at your home address or at the Walton Centre in Liverpool (whichever you prefer). The interview will last around one hour and will focus on your relationships with other people, including your current romantic relationship. The interview will be voice recorded using an encrypted audio recording device to make sure that we do not miss anything. You will then be asked to complete some short questionnaires about your background and your health. All of the information you provide will be held confidentially, and neither you nor your partner will be identifiable in any reports we write about the research.

How long will it take?

It should take no more than 15 minutes to complete the questions on this website. If you participate in the study, the research meeting will last for up to 2 hours. This includes time to discuss the study and for you to ask questions, and time to compete some questionnaires. We expect the interview itself to take about an hour.

What will happen to my personal information?

Only the research team will have access to your personal information (that is, data which could identify who you are and how to contact you), which we will use to communicate with you about the study. As soon as practical, we will copy the content of your interview in a way that makes it impossible to identify you and anyone you spoke about. We will then destroy the recording of the interview.

We will keep a copy of your consent form for five years after we publish the research, which is the standard retention period. We will then destroy all other personal information when you have finished taking part in the study.

Will my participation in the study be confidential?

Your participation in the study will be kept confidential to the study team.

All of the information that you provide will be treated with strict confidentiality. The interview will be recorded using a secure media device. As soon as practical, we will copy the content of your interview in a way that makes it impossible to identify you and anyone you spoke about. We will then destroy the recording of the interview.

In some instances, interviews may be transcribed by the Clinical Psychology Doctorate Departmental Secretary, who is employed by The University of Manchester. As an employee of the University, the secretary is professionally bound by University policies on confidentiality and data protection. The secretary will also sign a confidentiality agreement before being given access to any of your information.

Confidentiality may be broken if you tell us anything that makes us think that you or anyone else is at risk of harm. We will have to share this information, for example, with your GP. For monitoring and auditing purposes, study data and materials may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights.

Will I be paid for participating in the research?

No, you will not receive any payment for taking part. However, those who participate will be entered into a random prize draw for a £50 Amazon voucher as a thank you for taking part.

If you attend an interview with a researcher and incur any travel costs (e.g. taxis, trains) these will be reimbursed by the researcher on the day of the interview. Please note that you will be required to produce a receipt for expenses purposes.

Will the outcomes of the research be published?

Yes, the research findings will be written up as part of a doctoral thesis and may be published in an academic journal. We will share the results with other people with fibromyalgia, health care professions and researchers. This may be through presentations at conferences, charity newsletters or social media platforms. In all cases, any information that you provided will be anonymous.

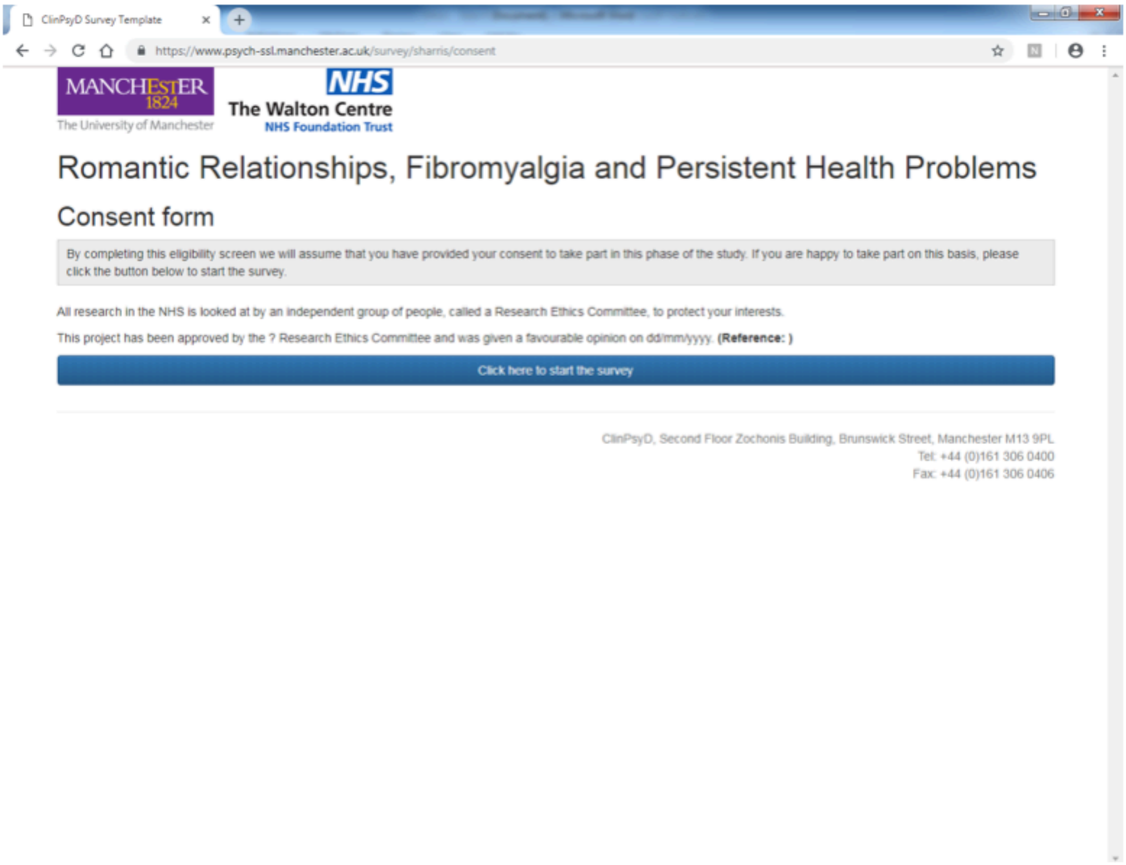
A summary of the findings will be written for participants. If you would like a copy of this summary, please tell us and we will ensure that you will receive it when the study has finished. We will need to retain your contact details in order to send this to you. However, we will destroy these once we have sent the summary of the findings to you.

What do I do now?

If you would like to discuss the study or have any questions or concerns, please do not hesitate to contact us via email at sean.harris-4@postgrad.manchester.ac.uk.

If you have no further questions and would like to take part then please click the button below.

Consent Page



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Consent form

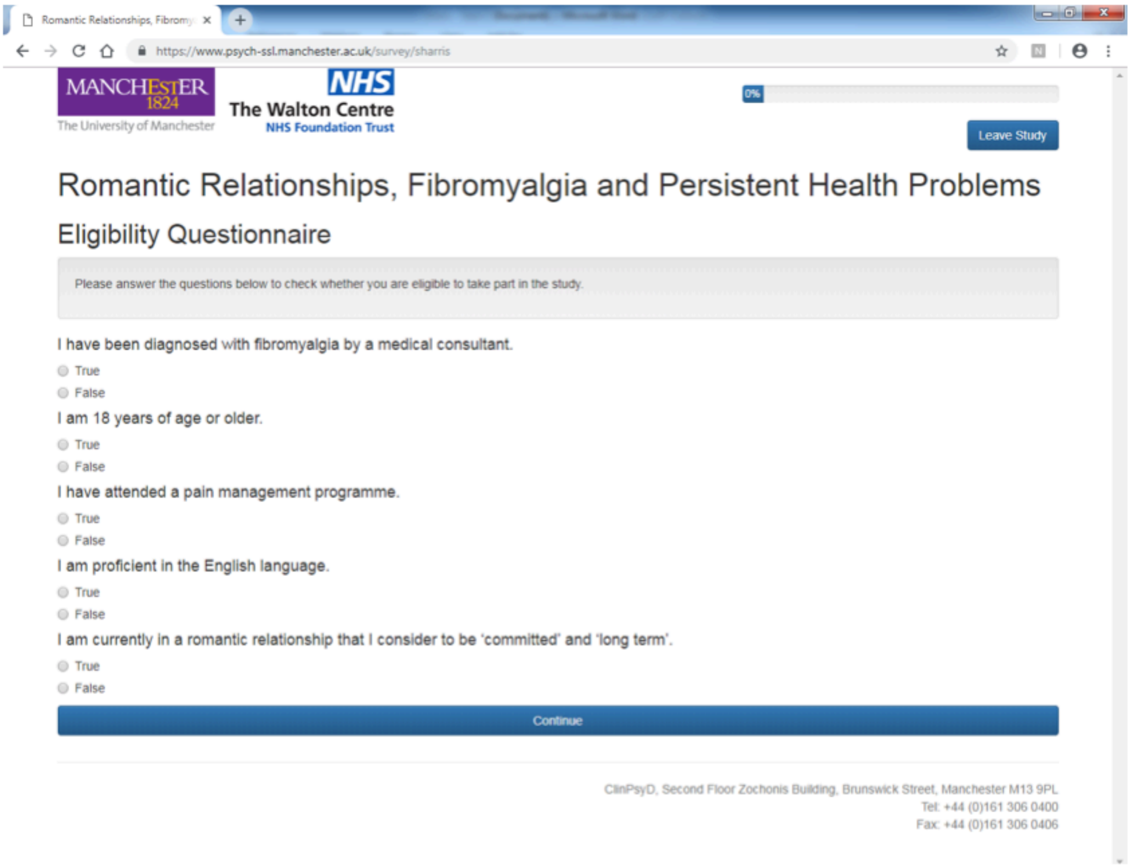
By completing this eligibility screen we will assume that you have provided your consent to take part in this phase of the study. If you are happy to take part on this basis, please click the button below to start the survey.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

This project has been approved by the ? Research Ethics Committee and was given a favourable opinion on dd/mm/yyyy. **(Reference:)**

ClinPsyD, Second Floor Zochonis Building, Brunswick Street, Manchester M13 9PL
Tel: +44 (0)161 306 0400
Fax: +44 (0)161 306 0406

Eligibility Questionnaire



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Eligibility Questionnaire

Please answer the questions below to check whether you are eligible to take part in the study.

I have been diagnosed with fibromyalgia by a medical consultant.
○ True
○ False

I am 18 years of age or older.
○ True
○ False

I have attended a pain management programme.
○ True
○ False

I am proficient in the English language.
○ True
○ False

I am currently in a romantic relationship that I consider to be ‘committed’ and ‘long term’.
○ True
○ False

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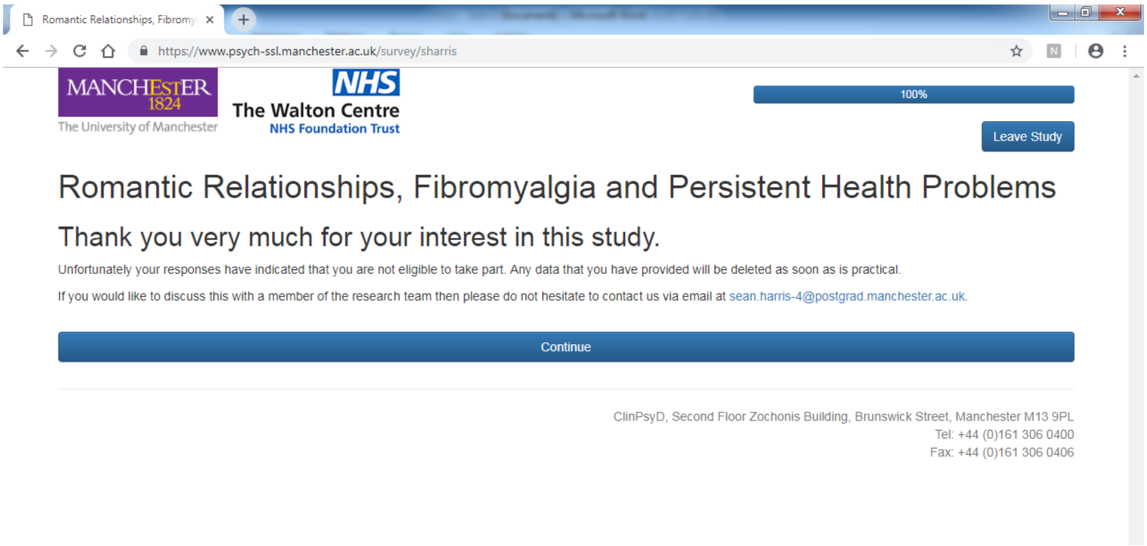
Fax: +44 (0)161 306 0406

If participants answer **‘false’** to one or more of the eligibility questionnaire items they will be directed to this page. Participants will not be able to progress to any of the measures below and their participation will end at this point.



Romantic Relationships, Fibromyalgia and Persistent Health Problems

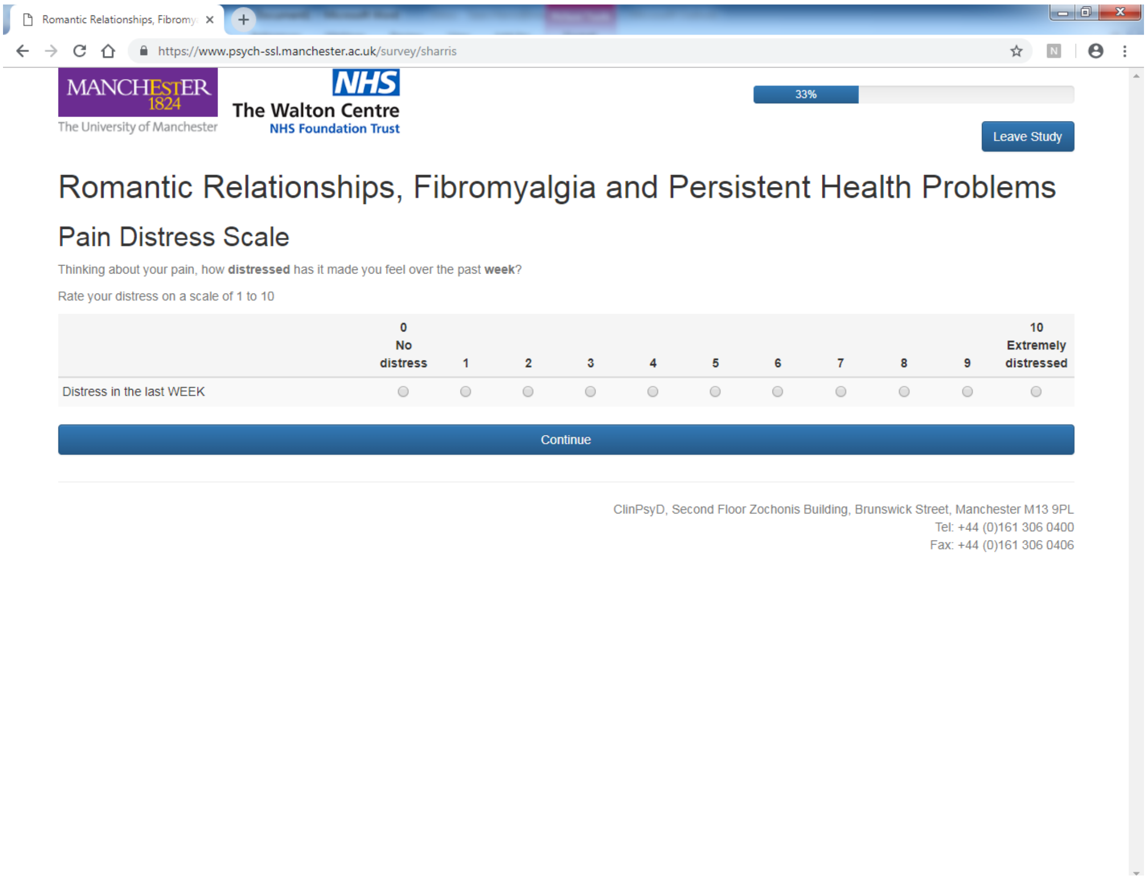
Thank you very much for your interest in this study.

Unfortunately your responses have indicated that you are not eligible to take part. Any data that you have provided will be deleted as soon as is practical.

If you would like to discuss this with a member of the research team then please do not hesitate to contact us via email at sean.harris-4@postgrad.manchester.ac.uk.

ClinPsyD, Second Floor Zochonis Building, Brunswick Street, Manchester M13 9PL
Tel: +44 (0)161 306 0400
Fax: +44 (0)161 306 0406

If participants answer **‘true’** to all items on the eligibility questionnaire they will be directed to this page and the one that follows to complete both the ‘Pain Distress Scale’ and the ‘Pain Scale’



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Pain Distress Scale

Thinking about your pain, how **distressed** has it made you feel over the past **week**?

Rate your distress on a scale of 1 to 10

	0 No distress	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10 Extremely distressed**
Distress in the last WEEK	○	○	○	○	○	○	○	○	○	○	○

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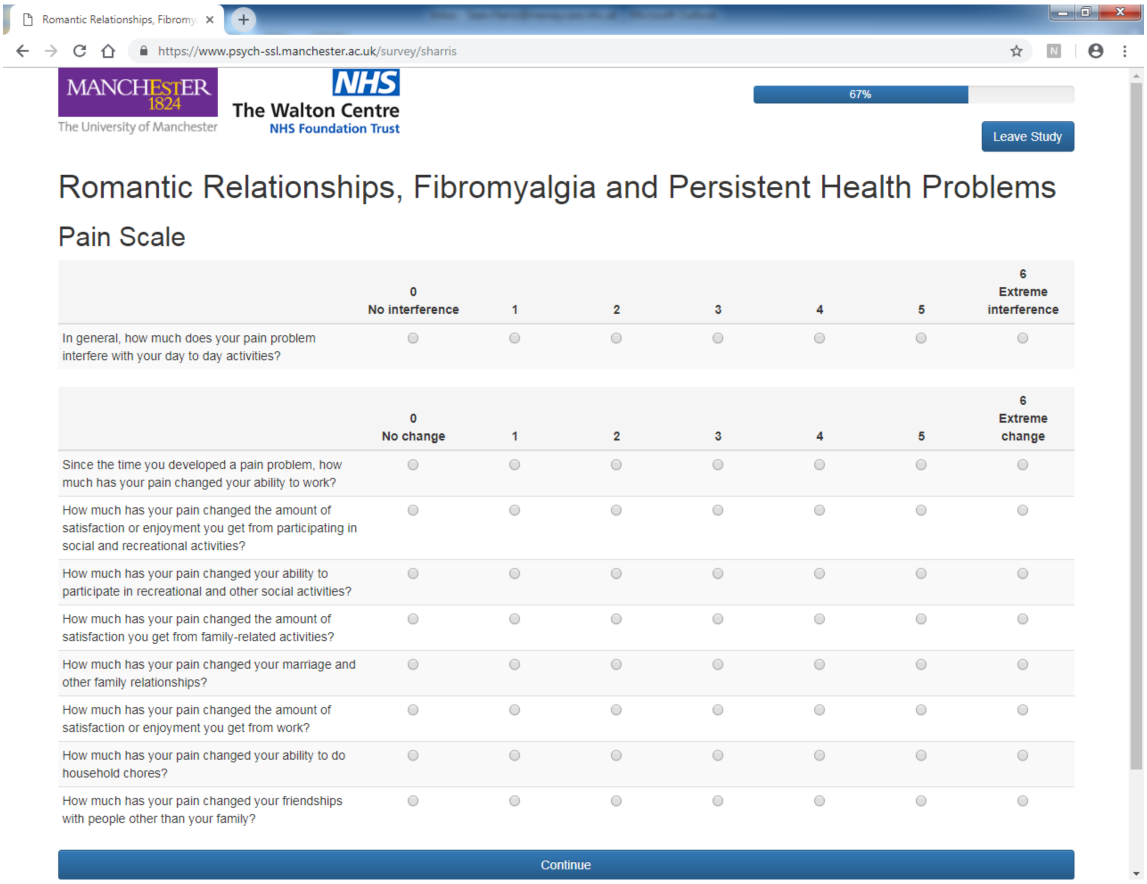
Tel: +44 (0)161 306 0400
Fax: +44 (0)161 306 0406



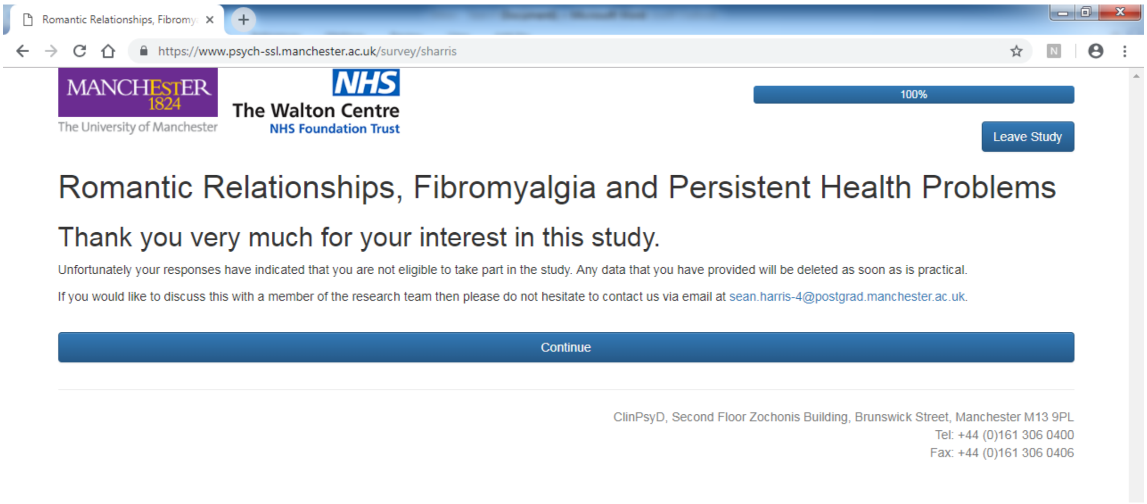
Romantic Relationships, Fibromyalgia and Persistent Health Problems

Pain Scale

	0 No interference	1	2	3	4	5	6 Extreme interference
In general, how much does your pain problem interfere with your day to day activities?	○	○	○	○	○	○	○

	0 No change	1	2	3	4	5	6 Extreme change
Since the time you developed a pain problem, how much has your pain changed your ability to work?	○	○	○	○	○	○	○
How much has your pain changed the amount of satisfaction or enjoyment you get from participating in social and recreational activities?	○	○	○	○	○	○	○
How much has your pain changed your ability to participate in recreational and other social activities?	○	○	○	○	○	○	○
How much has your pain changed the amount of satisfaction you get from family-related activities?	○	○	○	○	○	○	○
How much has your pain changed your marriage and other family relationships?	○	○	○	○	○	○	○
How much has your pain changed the amount of satisfaction or enjoyment you get from work?	○	○	○	○	○	○	○
How much has your pain changed your ability to do household chores?	○	○	○	○	○	○	○
How much has your pain changed your friendships with people other than your family?	○	○	○	○	○	○	○

If participants **do not** meet the study eligibility criteria *'Score ≥ 5 on an 11 point pain distress numerical rating scale or score ≥ 4.3 (the mean normative score) on the Pain Interference Scale of the Multi-Dimensional Pain Inventory (Kerns et al., 1985)'* they will be directed to this page. Participants will not be able to progress to the appointment booking page below and their participation will end at this point.



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Thank you very much for your interest in this study.

Unfortunately your responses have indicated that you are not eligible to take part in the study. Any data that you have provided will be deleted as soon as is practical.

If you would like to discuss this with a member of the research team then please do not hesitate to contact us via email at sean.harris-4@postgrad.manchester.ac.uk.

ClinPsyD, Second Floor Zochonis Building, Brunswick Street, Manchester M13 9PL
Tel: +44 (0)161 306 0400
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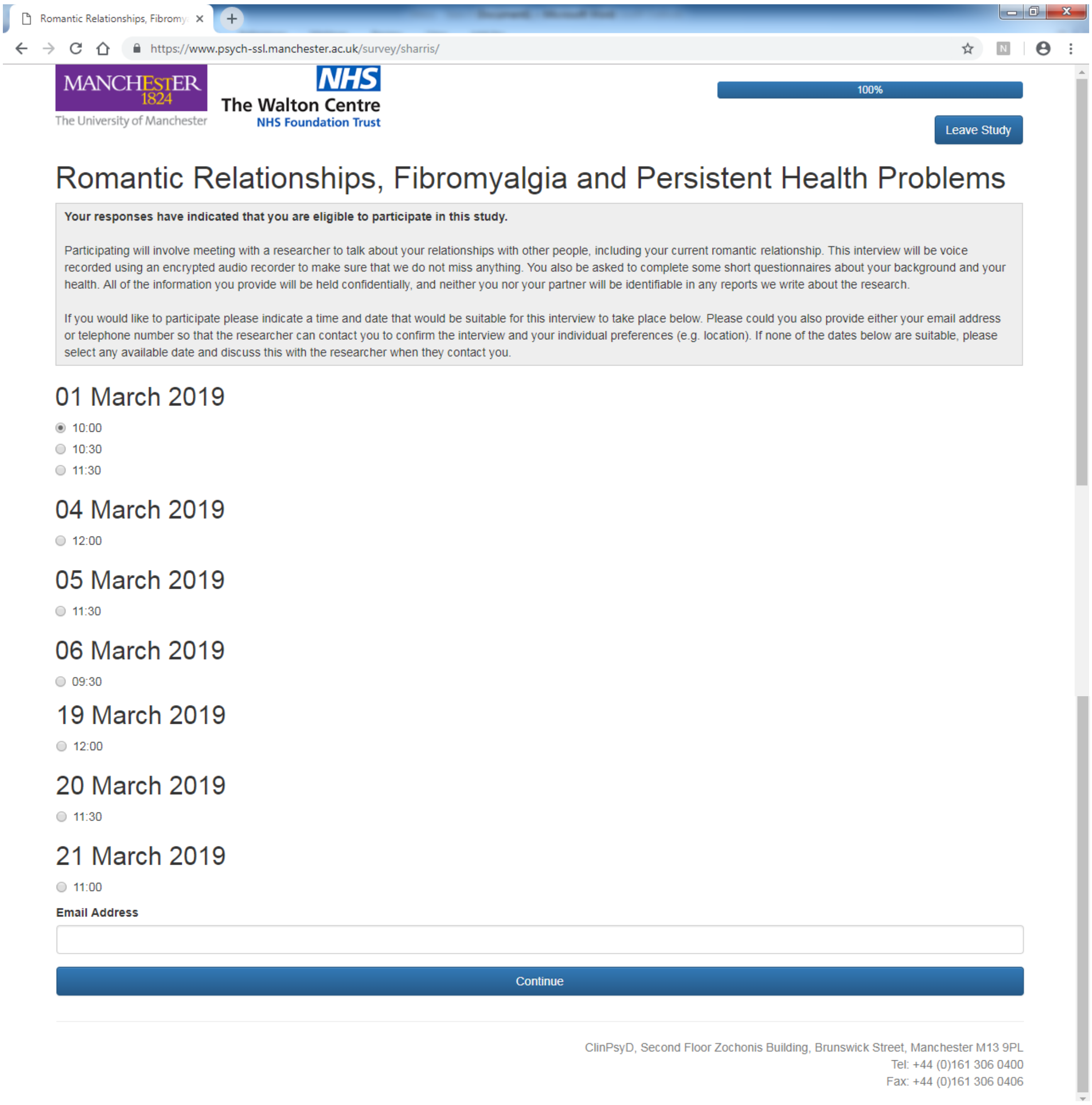
If participants **do** meet the study eligibility criteria *'Score ≥ 5 on an 11 point pain distress numerical rating scale or score ≥ 4.3 (the mean normative score) on the Pain Interference Scale of the Multi-Dimensional Pain Inventory (Kerns et al., 1985)'* they will be directed to this page. Participants can indicate a suitable date and time for them to participate in the research.



Romantic Relationships, Fibromyalgia and Persistent Health Problems

Your responses have indicated that you are eligible to participate in this study.

Participating will involve meeting with a researcher to talk about your relationships with other people, including your current romantic relationship. This interview will be voice recorded using an encrypted audio recorder to make sure that we do not miss anything. You also be asked to complete some short questionnaires about your background and your health. All of the information you provide will be held confidentially, and neither you nor your partner will be identifiable in any reports we write about the research.

If you would like to participate please indicate a time and date that would be suitable for this interview to take place below. Please could you also provide either your email address or telephone number so that the researcher can contact you to confirm the interview and your individual preferences (e.g. location). If none of the dates below are suitable, please select any available date and discuss this with the researcher when they contact you.

01 March 2019

● 10:00
○ 10:30
○ 11:30

04 March 2019

○ 12:00

05 March 2019

○ 11:30

06 March 2019

○ 09:30

19 March 2019

○ 12:00

20 March 2019

○ 11:30

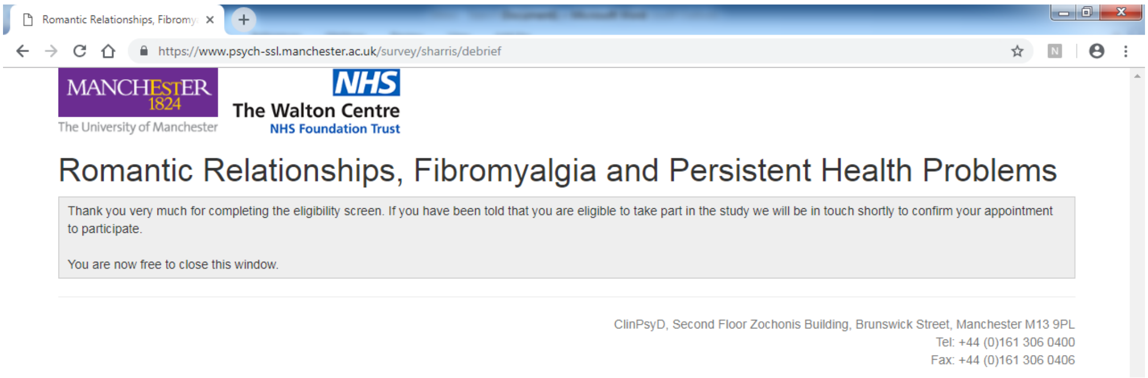
21 March 2019

○ 11:00

Email Address

ClinPsyD, Second Floor Zochonis Building, Brunswick Street, Manchester M13 9PL
Tel: +44 (0)161 306 0400
Fax: +44 (0)161 306 0406

Final page of the eligibility screen.



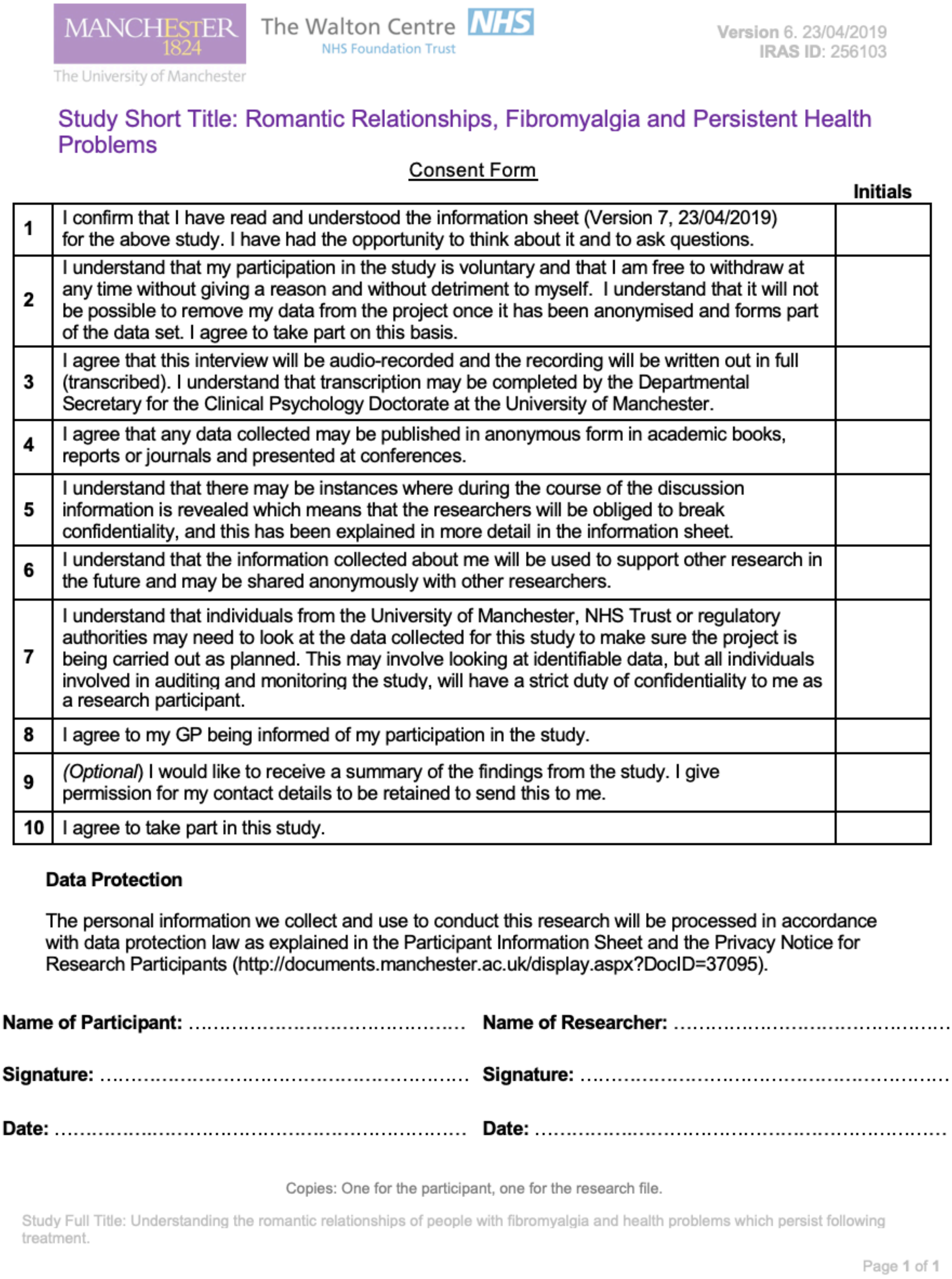
Romantic Relationships, Fibromyalgia and Persistent Health Problems

Thank you very much for completing the eligibility screen. If you have been told that you are eligible to take part in the study we will be in touch shortly to confirm your appointment to participate.

You are now free to close this window.

ClinPsyD, Second Floor Zochonis Building, Brunswick Street, Manchester M13 9PL
Tel: +44 (0)161 306 0400
Fax: +44 (0)161 306 0406

Appendix 11: Consent Form



Version 6. 23/04/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Consent Form

		Initials
1	I confirm that I have read and understood the information sheet (Version 7, 23/04/2019) for the above study. I have had the opportunity to think about it and to ask questions.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis.	
3	I agree that this interview will be audio-recorded and the recording will be written out in full (transcribed). I understand that transcription may be completed by the Departmental Secretary for the Clinical Psychology Doctorate at the University of Manchester.	
4	I agree that any data collected may be published in anonymous form in academic books, reports or journals and presented at conferences.	
5	I understand that there may be instances where during the course of the discussion information is revealed which means that the researchers will be obliged to break confidentiality, and this has been explained in more detail in the information sheet.	
6	I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.	
7	I understand that individuals from the University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data, but all individuals involved in auditing and monitoring the study, will have a strict duty of confidentiality to me as a research participant.	
8	I agree to my GP being informed of my participation in the study.	
9	*(Optional)* I would like to receive a summary of the findings from the study. I give permission for my contact details to be retained to send this to me.	
10	I agree to take part in this study.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants (http://documents.manchester.ac.uk/display.aspx?DocID=37095).

Name of Participant: ……………………………………… **Name of Researcher:** ………………………………………

Signature: …………………………………………………… **Signature:** ……………………………………………………

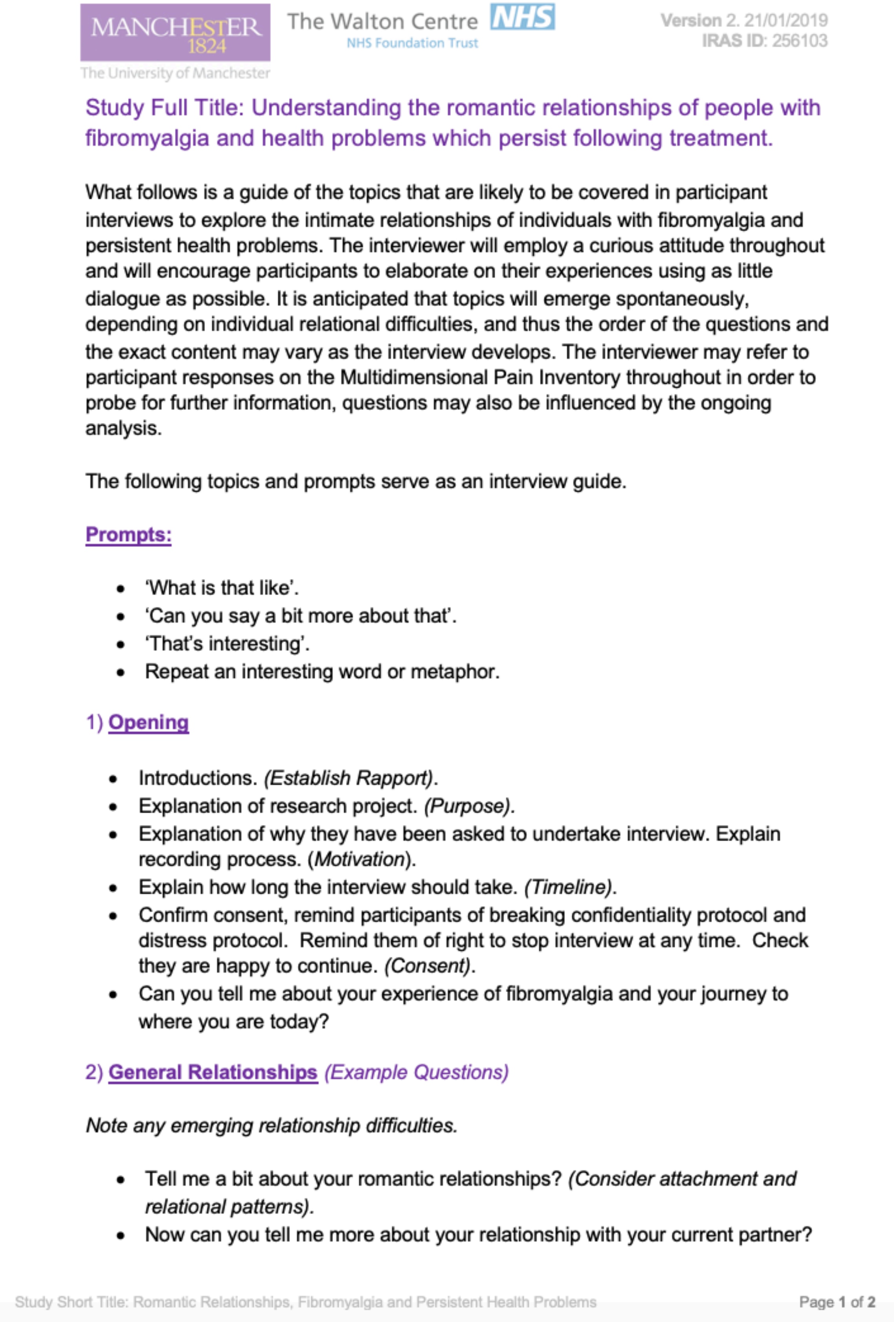
Date: ……………………………………………………… **Date:** ………………………………………………………

Copies: One for the participant, one for the research file.

Study Full Title: Understanding the romantic relationships of people with fibromyalgia and health problems which persist following treatment.

Page 1 of 1

Appendix 12: Topic Guide



MANCHESTER 1824 The University of Manchester

The Walton Centre NHS Foundation Trust

Version 2. 21/01/2019
IRAS ID: 256103

Study Full Title: Understanding the romantic relationships of people with fibromyalgia and health problems which persist following treatment.

What follows is a guide of the topics that are likely to be covered in participant interviews to explore the intimate relationships of individuals with fibromyalgia and persistent health problems. The interviewer will employ a curious attitude throughout and will encourage participants to elaborate on their experiences using as little dialogue as possible. It is anticipated that topics will emerge spontaneously, depending on individual relational difficulties, and thus the order of the questions and the exact content may vary as the interview develops. The interviewer may refer to participant responses on the Multidimensional Pain Inventory throughout in order to probe for further information, questions may also be influenced by the ongoing analysis.

The following topics and prompts serve as an interview guide.

Prompts:

- 'What is that like'.
- 'Can you say a bit more about that'.
- 'That's interesting'.
- Repeat an interesting word or metaphor.

1) Opening

- Introductions. *(Establish Rapport)*.
- Explanation of research project. *(Purpose)*.
- Explanation of why they have been asked to undertake interview. Explain recording process. (*Motivation*).
- Explain how long the interview should take. *(Timeline)*.
- Confirm consent, remind participants of breaking confidentiality protocol and distress protocol. Remind them of right to stop interview at any time. Check they are happy to continue. *(Consent)*.
- Can you tell me about your experience of fibromyalgia and your journey to where you are today?

2) General Relationships *(Example Questions)*

Note any emerging relationship difficulties.

- Tell me a bit about your romantic relationships? *(Consider attachment and relational patterns)*.
- Now can you tell me more about your relationship with your current partner?

- How does fibromyalgia affect your relationship with your partner?

Interviewer Note: Only progress to the questions below once sufficient phenomenological information has been acquired.

3) **Partner Responses** *(Example Questions)*

- How does your partner react to your pain?
- *If necessary.* Does your partner ever react negatively to your pain?
- Do you talk about your pain?
- Does your partner support you with your pain? If so, how?

4) **Patient Responses** *(Example Questions)*

- How do you react to your partner?
- How do you feel about your partners responses to your pain?
- Do you share with your partner how they are making you feel?

5) **The Future** *(Example Questions)*

Why do the relational difficulties persist? What are the barriers to change?

- What would need to change to improve your relationship with your partner?
- How able do you feel able to make changes to your relationship?
- *If applicable.* Can you think of anything that would help you to feel more able to make changes to your relationship?

6) **Summary**

- Do you have any further points that you would like to make?
- Can you think of any other questions that could be asked in future interviews?
- Do you have any questions?

Appendix 13: Demographic Questionnaire

MANCHESTER 1824
The University of Manchester
The Walton Centre NHS
NHS Foundation Trust

Version 3. 18/02/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Demographic Questionnaire

Participant ID	
Date of Interview	

This questionnaire is designed to gather some more information about you and your relationship. Please ask the researcher if you would like anything explained further.

1) Date of Birth: ______________________

2) Gender (please circle one): Male Female

3) How long have you had fibromyalgia? ______ Years ______ Months

4) Please circle one of the following statements which best describes you.

1. Full time paid employment
2. Part time paid employment
3. Not working due to pain
4. Not working for other reasons
5. Not working due to other health condition
6. Homemaker
7. Student / vocational training
8. Retired
9. Voluntary work
10. Actively seeking work/planning to return to work

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

5) Are you currently in a romantic relationship that you would consider to be 'committed' and 'long term'? (please circle one).

Yes No

6) How long have you been in this relationship? ________ Years ________ Months

7) Please circle one or more of the following statements which best describe your relationship status.

1. Married
2. Civil Partnership
3. Cohabiting
4. Engaged
5. Other (Please Specify) ______________________

8) Please provide contact details for your GP so that we can inform them that you have participated in this study.

GP Name: ____

GP Practice Name & Address: ____

____

____

GP Postcode: ____

Appendix 14: Numerical Rating Scales

Version 3. 18/02/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Pain Intensity & Pain Distress

Thinking about your pain, how would you rate its intensity over the past week?

	Rate its intensity on a scale of 1 to 10										
	0 (No pain)						**10 (The most intense pain imaginable)**				
Intensity in the last WEEK	0	1	2	3	4	5	6	7	8	9	10

Thinking about your pain, how distressed has it made you feel over the past week?

	Rate your distress on a scale of 1 to 10										
	0 (No distress)								**10 (Extremely Distressed)**		
Distress in the last WEEK	0	1	2	3	4	5	6	7	8	9	10

Appendix 15: The Patient Health Questionnaire-9

Version 3. 18/02/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

(PHQ-9)

Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems?	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

Appendix 16: The Generalised Anxiety Disorder-7

MANCHESTER 1824
The University of Manchester
The Walton Centre NHS
NHS Foundation Trust

Version 3. 18/02/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Appendix 17: The Multidimensional Pain Inventory

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

West Haven-Yale Multidimensional Pain Inventory

BEFORE YOU BEGIN, PLEASE ANSWER 2 PRE-EVALUATION QUESTIONS BELOW:

1. Some of the questions in this questionnaire refer to your "significant other". A significant other is *a person with whom you feel closest.* This includes anyone that you relate to on a regular or infrequent basis. It is very important that you identify someone as your "significant other". For this study please select either **husband/wife or partner.**

[ ] Husband/Wife [ ] Partner

2. Do you currently live with this person? [ ] YES [ ] NO

When you answer questions in the following pages about "your significant other", always respond in reference to the specific person you just indicated above.

A.

In the following 20 questions, you will be asked to describe your pain and how it affects your life. Under each question is a scale to record your answer. Read each question carefully and then <u>circle</u> a number on the scale under that question to indicate how that specific question applies to you.

1.Rate the level of your pain at the present moment.

0	1	2	3	4	5	6
No pain						Very intense pain

2.In general, how much does your pain problem interfere with your day to day activities?

0	1	2	3	4	5	6
No intereference						Extreme interference

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

3.Since the time you developed a pain problem, how much has your pain changed your ability to work?

0 1 2 3 4 5 6

No change Extreme change

___ Check here, if you have retired for reasons other than your pain problem

4. How much has your pain changed the amount of satisfaction or enjoyment you get from participating in social and recreational activities?

0 1 2 3 4 5 6

No change Extreme change

5. How supportive or helpful is your spouse (significant other) to you in relation to your pain?

0 1 2 3 4 5 6

Not at all supportive Extremely supportive

6. Rate your overall mood during the past week.

0 1 2 3 4 5 6

Extremely low mood Extremely high mood

7. On the average, how severe has your pain been during the last week?

0 1 2 3 4 5 6

Not at all
severe

Extremely severe

8. How much has your pain changed your ability to participate in recreational and other social activities?

0 1 2 3 4 5 6

No change

Extreme change

9. How much has your pain changed the amount of satisfaction you get from family-related activities?

0 1 2 3 4 5 6

No change

Extreme change

10. How worried is your spouse (significant other) about you in relation to your pain problem?

0 1 2 3 4 5 6

Not at all worried

Extremely worried

11. During the past week, how much control do you feel that you have had over your life?

0 1 2 3 4 5 6

Not at all in control — Extremely in control

12. How much suffering do you experience because of your pain?

0 1 2 3 4 5 6

No suffering — Extreme suffering

13. How much has your pain changed your marriage and other family relationships?

0 1 2 3 4 5 6

No change — Extreme change

14. How much has your pain changed the amount of satisfaction or enjoyment you get from work?

0 1 2 3 4 5 6

No change — Extreme change

__ Check here, if you are not presently working.

15. How attentive is your spouse (significant other) to your pain problem?

0 1 2 3 4 5 6

Not at all attentive Extremely attentive

16. During the past week, how much do you feel that you've been able to deal with your problems?

0 1 2 3 4 5 6

Not at all Extremely well

17. How much has your pain changed your ability to do household chores?

0 1 2 3 4 5 6

No change Extreme change

18. During the past week, how irritable have you been?

0 1 2 3 4 5 6

Not at all irritable Extremely irritable

19. How much has your pain changed your friendships with people other than your family?

0 1 2 3 4 5 6

No change Extreme change

20. During the past week, how tense or anxious have you been?

0 1 2 3 4 5 6

Not at all tense or anxious Extremely tense or anxious

In this section, we are interested in knowing how your significant other (this refers to the person you indicated above) responds to you when he or she knows that you are in pain. On the scale listed below each question, **circle a number** to indicate how often your significant other generally responds to you in that particular way when you are in pain.

1. Ignores me.

0 1 2 3 4 5 6

Never Very often

2. Asks me what he/she can do to help.

0 1 2 3 4 5 6

Never Very often

3. Reads to me.

0	1	2	3	4	5	6
Never						Very often

4. Expresses irritation at me.

0	1	2	3	4	5	6
Never						Very often

5. Takes over my jobs or duties.

0	1	2	3	4	5	6
Never						Very often

6. Talks to me about something else to take my mind off the pain.

0	1	2	3	4	5	6
Never						Very often

7. Expresses frustration at me.

0	1	2	3	4	5	6
Never						Very often

8. Tries to get me to rest.

0	1	2	3	4	5	6
Never						Very often

9. Tries to involve me in some activity

0	1	2	3	4	5	6
Never						Very often

10. Expresses anger at me.

0	1	2	3	4	5	6
Never						Very often

11. Gets me some pain medications.

0	1	2	3	4	5	6
Never						Very often

12. Encourages me to work on a hobby.

0	1	2	3	4	5	6
Never						Very often

13. Gets me something to eat or drink.

0	1	2	3	4	5	6
Never						Very often

14. Turns on the T.V. to take my mind off my pain

0	1	2	3	4	5	6
Never						Very often

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Listed below are 18 common daily activities. Please indicate how often you do each of these activities by circling a number on the scale listed below each activity. Please complete all 18 questions.

1. Wash dishes.

0 1 2 3 4 5 6

Never Very often

2. Mow the lawn.

0 1 2 3 4 5 6

Never Very often

3. Go out to eat.

0 1 2 3 4 5 6

Never Very often

4. Play cards or other games.

0 1 2 3 4 5 6

Very often

Never

5. Go grocery shopping.

0 1 2 3 4 5 6

Never Very often

6. Work in the garden.

0 1 2 3 4 5 6

Never Very often

7. Go to a movie.

0 1 2 3 4 5 6

Never Very often

8. Visit friends.

0 1 2 3 4 5 6

Never Very often

9. Help with the house cleaning.

0 1 2 3 4 5 6

Never Very often

10. Work on the car.

0 1 2 3 4 5 6

Never Very often

11. Take a ride in a car.

0 1 2 3 4 5 6

Never Very often

12. Visit relatives.

0 1 2 3 4 5 6

Never Very often

13. Prepare a meal.

0 1 2 3 4 5 6

Never Very often

14. Wash the car.

0 1 2 3 4 5 6

Never Very often

15. Take a trip.

0 1 2 3 4 5 6

Never Very often

16. Go to a park or beach.

0 1 2 3 4 5 6

Never Very often

17. Do a load of laundry.

0 1 2 3 4 5 6

Never Very often

18. Work on a needed house repair.

0 1 2 3 4 5 6

Never Very often

Appendix 18: The Pain Self Efficacy Questionnaire

MANCHESTER 1824
The University of Manchester
The Walton Centre NHS
NHS Foundation Trust

Version 2. 21/01/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Self-Efficacy Questionnaire

Please rate how confident you are that you can do the following at present, DESPITE YOUR PAIN. Circle a number for each item where **0 = Not at all confident and 6 = completely confident.**

	Circle a number where						
	0 = Not Confident					**6 = Completely Confident**	
1. I can enjoy things despite the pain	0	1	2	3	4	5	6
2. I can do most of the household chores (tidying up, washing dishes) despite the pain	0	1	2	3	4	5	6
3. I can socialise with my friends or family as often as I used to despite the pain	0	1	2	3	4	5	6
4. I can cope with my pain in most situations	0	1	2	3	4	5	6
5. I can do some form of work (including housework, paid and unpaid work) despite the pain	0	1	2	3	4	5	6
6. I can still do most of the things I enjoy, such as hobbies or leisure activities despite the pain	0	1	2	3	4	5	6
7. I can cope with my pain without medication	0	1	2	3	4	5	6
8. I can accomplish most of my goals in life despite the pain	0	1	2	3	4	5	6
9. I can lead a normal lifestyle despite the pain	0	1	2	3	4	5	6
10. I can gradually become more active despite the pain	0	1	2	3	4	5	6

Appendix 19: The Pain Catastrophizing Scale

MANCHESTER 1824
The University of Manchester

The Walton Centre NHS
NHS Foundation Trust

Version 2. 21/01/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

PCS

Everyone experiences painful situations at some point in their lives. Such experiences may include headaches, tooth pain, joint or muscle pain. People are often exposed to situations that may cause pain such as illness, injury, dental procedures or surgery.

We are interested in the types of thoughts and feelings that you have when you are in pain.

Listed below are thirteen statements describing different thoughts and feelings that may be associated with pain. Using the following scale, please indicate the degree to which you have these thoughts and feelings when you are experiencing pain.

		Not at all	**To a slight degree**	**To a moderate degree**	**To a great degree**	**All the time**
1.	I worry all the time about whether the pain will end	0	1	2	3	4
2.	I feel I can't go on	0	1	2	3	4
3.	It's terrible and I think it's never going to end	0	1	2	3	4
4.	It's awful and I feel it overwhelms me	0	1	2	3	4
5.	I feel I can't stand it anymore	0	1	2	3	4
6.	I become afraid that the pain will get worse	0	1	2	3	4
7.	I keep thinking of other painful events	0	1	2	3	4
8.	I anxiously want the pain to go away	0	1	2	3	4
9.	I can't seem to keep it out of my mind	0	1	2	3	4
10.	I keep thinking about how much it hurts	0	1	2	3	4
11.	I keep thinking about how badly I want the pain to stop	0	1	2	3	4
12.	There's nothing I can do to reduce the intensity of the pain	0	1	2	3	4
13.	I wonder whether something serious may happen	0	1	2	3	4

Appendix 20: Transcript Extract

Interview with Participant 20040

R=Researcher **P**=Participant

R: Awful?

P: It really is. You know we used to just lay on the sofa, cuddled up, watching a film. You can't do things like that just off the cuff. It's that spontaneity, it's gone. I can't cook him a meal, like we used to do, he'd do one week and then I'd do the next. Can't sit at a table for too long and eat a meal. But yeah it's those sorts of things. Because I'm on the walker we can't hold hands when we are walking down the road. All those imitate times that you take for granted and then one day they are just not there. Or they are but just not as much. I mean I would say that it's less than a third of what we used to do. It's all the little thoughtful things that mean so much now, like he will always ring me before he goes to sleep if he's working away, but sometimes when you haven't got the intimacy of each other it's just really hard.

R: Can you tell me more?

P: Well I just think that until all the little things are taken away from you, you just don't realise what you've got. It's such a change.

R: What's that change been like?

P: It's been hard and we both feel, and we have spoken about this, we both have that sense of 'well don't you want me anymore', 'don't you find me attractive any more'. And he goes 'it's not that' or he'll go 'can't we even cuddle tonight' and I'll go 'no I just can't stand to be anywhere near you at the minute'. And it feels like you've been so close but then there is this little wedge that's starting to move in and it's pushing you further and further away from each other.

R: What is that little wedge?

P: Well it's the fibromyalgia I'd say.

R: Okay.

P: You know sometimes he will be walking down the street with our son, who is a teenager, and he'll go 'oh look at her'. And I'm thinking you know that's someone that can walk around and do things. That's again where it comes in, he'd be better off without me, he wouldn't have all this stress, intimate time. It's just so, you take it for granted in a relationship. Being one, being together and being one. Intimacy is that one link that holds you two together and it's like fibromyalgia comes along and that link is broke a bit, you know what I mean?

R: Why?

P: Just by the pain and the illness, my mood swings. I'm going through the menopause as well so with everything on top it's sort of one of them and I think there could be this really lovely tall blonde that goes past and you see him look and you're thinking 'oh are you wishing you could have someone like her'. And it's daft as well because I've always been big, so we've had this big change now because I've gone from a 26 down to a 16 sort of 3 years ago. Because my appearance has changed, my husband will tell you he's a boob man anyway, and I'll go 'oh my god I've lost all that weight now, they've gone they've shrunk' and he goes 'well I still love you, and I still want you and I still fancy you'. But that's not what's going on in your head. It doesn't matter how much you're reassured by someone, especially when you've been told as a child that you're no good. You just feel worthless and then the intimacy starts going ... I mean sometimes it could be 3 or 4 months before we have any intimacy at all, you know intercourse and stuff, the loving, physically. When you don't have that for such a long period of time ... it does make you feel that you're not good enough anymore. He'll tell me he's not staying with me out of pity or anything and he is very, very reassuring but sometimes you just hear different words than what they are saying and it just puts that more of a wedge between you.

R: I see. I'm just aware of the time, have we not talked about anything important?

P: Probably socialising. We always were social. Even when our son was little we would still go out and go into beer gardens or go to friends' houses. We don't do that half as much. I mean he took me out for a meal, we went out the day before my birthday for a meal but again that was just after my son got home from school so it was like 4 o'clock. So instead of going out like 8 or 9 o'clock when most couples go out, we go out so much earlier. And where most couples would go out for 3 or 4 hours, I can do an hour and a half tops and then I want to be home or I need my medication so you know it's planning everything, everything has to be planned and again spontaneity goes out of the window. And I think we always had that and not to have it, it's like something else has been taken away from you. But I'm just thankful that we are a strong couple. And we are, because we have gone through some really tough times, fibromyalgia and that, it's been really tough. Erm but yeah you miss all those bits, the intimacy, the going out.

Appendix 21: Coding Example

R: What is that little wedge?

P: Well it's the fibromyalgia I'd say.

R: Okay.

P: You know sometimes he will be walking down the street with our son, who is a teenager, and he'll go 'oh look at her'. And I'm thinking you know that's someone that can walk around and do things. That's again where it comes in, he'd be better off without me, he wouldn't have all this stress, intimate time. It's just so, you take it for granted in a relationship. Being one, being together and being one. Intimacy is that one link that holds you two together and it's like fibromyalgia comes along and that link is broke a bit, you know what I mean?
R: Why?

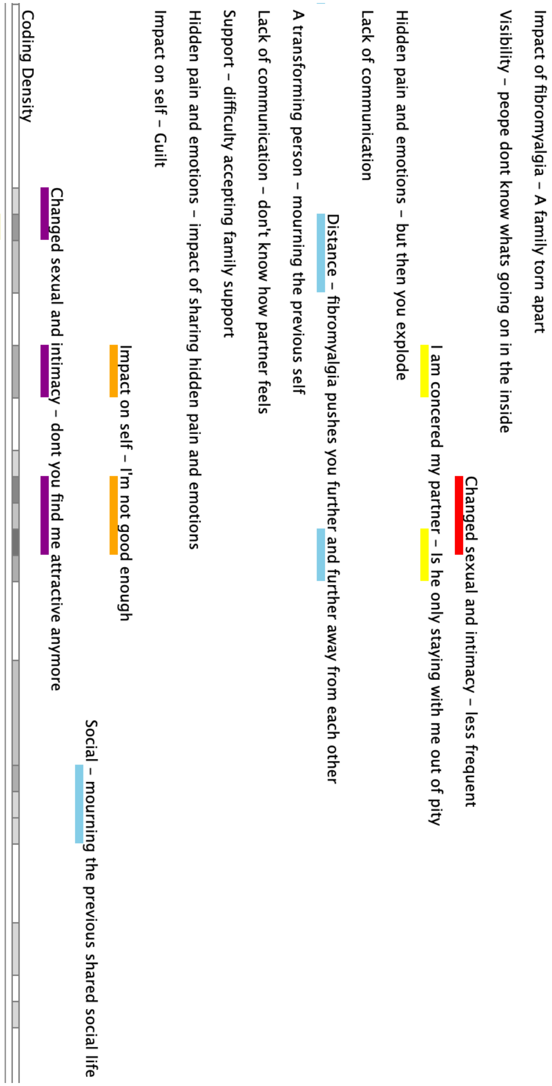
P: Just by the pain and the illness, my mood swings. I'm going through the menopause as well so with everything on top it's sort of one of them and I think there could be this really lovely tall blonde that goes past and you see him look and you're thinking 'oh are you wishing you could have someone like her'. And it's daft as well because I've always been big, so we've had this big change now because I've gone from a 26 down to a 16 sort of 3 years ago. Because my appearance has changed, my husband will tell you he's a boob man anyway, and I'll go 'oh my god I've lost all that weight now, they've gone they've shrunk' and he goes 'well I still love you, and I still want you and I still fancy you'. But that's not what's going on in your head. It doesn't matter how much you're reassured by someone, especially when you've been told as a child that you're no good. You just feel worthless and then the intimacy starts going ... I mean sometimes it could be 3 or 4 months before we have any intimacy at all, you know intercourse and stuff, the loving, physically. When you don't have that for such a long period of time ... it does make you feel that you're not good enough anymore. He'll tell me he's not staying with me out of pity or anything and he is very, very reassuring but sometimes you just hear different words than what they are saying and it just puts that more of a wedge between you.

R: I see. I'm just aware of the time, have we not talked about anything important?

P: Probably socialising. We always were social. Even when our son was little we would still go out and go into beer gardens or go to friends' houses. We don't do that half as much. I mean he took me out for a meal, we went out the day before my birthday for a meal but again that was just after my son got home from school so it was like 4 o'clock. So instead of going out like 8 or 9 o'clock when most couples go out, we go out so much earlier. And where most couples would go out for 3 or 4 hours, I can do an hour and a half tops and then I want to be home or I need my medication so you know it's planning everything, everything has to be planned and again spontaneity goes out of the window. And I think we always had that and not to have it, it's like something else has been taken away from you. But I'm just thankful that we are a strong couple. And we are, because we have gone through some really tough times, with the fibromyalgia and that, it's been really tough. Erm but yeah you miss all those bits, the intimacy, the going out.

R: Yeah.

P: Just even watching a film together you know curled up on the sofa or even up in bed just curled up in bed watching a film. The little kisses, the cuddles. We can't do that because I'm just too sensitive or the pain is too bad. You know if we are in bed watching a film I'm shuffling trying to get comfortable, trying to prod myself up with pillows, so you don't enjoy the film then because there is that much movement where you can't get comfortable or you're in pain and you don't really want to say you're in pain but then they notice you're in pain. So yeah there's a lot of things you miss and it's the little things that have a big impact on the relationship over time.



Appendix 22: Example Thematic Map

Appendix 23: Completed ENTREQ Checklist for Systematic Review (Tong et al., 2012)

No	Item	Guide & Description	Present (Yes/No)
1	Aim	State the research question the synthesis addresses.	Yes
2	Synthesis Methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g., meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	Yes
3	Approach to Searching	Indicate whether the search was pre-planned *(comprehensive search strategies to seek all available studies)* or iterative *(to seek all available concepts until they theoretical saturation is achieved).*	Yes
4	Inclusion Criteria	Specify the inclusion/exclusion criteria *(e.g., in terms of population, language, year limits, type of publication, study type).*	Yes
5	Data Sources	Describe the information sources used *(e.g., electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	Yes

No	Item	Guide & Description	Present (Yes/No)
6	Electronic Search Strategy	Describe the literature search *(e.g., provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).*	Yes
7	Study Screening Methods	Describe the process of study screening and sifting *(e.g., title, abstract and full text review, number of independent reviewers who screened studies).*	Yes
8	Study Characteristics	Present the characteristics of the included studies *(e.g., year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	Yes
9	Study Selection Results	Identify the number of studies screened and provide reasons for study exclusion *(e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).*	Yes
10	Rationale for Appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	Yes
11	Appraisal Items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g., existing tools: CASP, QARI, COREQ, Mays and Pope; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	Yes

No	**Item**	**Guide & Description**	**Present (Yes/No)**
12	Appraisal Process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	Yes
13	Appraisal Results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Yes
14	Data Extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g,. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).*	Yes
15	Software	State the computer software used, if any.	Yes
16	Number of Reviewers	Identify who was involved in coding and analysis.	Yes
17	Coding	Describe the process for coding of data *(e.g., line by line coding to search for concepts).*	Yes
18	Study Comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	Yes

No	Item	Guide & Description	Present (Yes/No)
19	Derivation of Themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Yes
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.	Yes
21	Synthesis Output	Present rich, compelling and useful results that go beyond a summary of the primary studies *(e.g., new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	Yes

Appendix 24: Debrief Information

MANCHESTER 1824
The University of Manchester

The Walton Centre NHS
NHS Foundation Trust

Version 3. 21/01/2019
IRAS ID: 256103

Study Short Title: Romantic Relationships, Fibromyalgia and Persistent Health Problems

Thank you for your participation in the study**.** We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing, please contact the researcher, Sean Harris (Email: sean.harris-4@postgrad.manchester.ac.uk; Telephone: 07883860103), who will help you to think about where you might be able to get appropriate support and advice.

There are also a number of organisations listed below that you can contact.

- **Samaritans.** Samaritans are open 24 hours a day, 365 days a year, to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of suicide and self-harm. Their national freephone number is 116 123, or you can email jo@samaritans.org.

- **SANEline.** SANEline offers emotional support and information from 6pm–11pm, 365 days a year. Their national number is 0300 304 7000.

- **CALM.** If you're a man experiencing distressing thoughts and feelings, the Campaign Against Living Miserably (CALM) is there to support you. They're open from 5pm–midnight, 365 days a year. Their national number is 0800 58 58 58, and they also have a webchat service if you're not comfortable talking on the phone.

- **RELATE.** Relate is the UK's largest provider of relationship support. Please visit www.relate.org.uk to find your local relate. The number for Cheshire & Merseyside Relate Centre is – **0300 330 5793** or visit www.relatecm.org.uk for information specific to this area.

- **For 24-hour medical advice:** in England and Scotland dial 111.

If you remain distressed or are worried about your physical or mental health, **please contact your GP.**

Thank you again for taking part in the study, if you opted in to receive a summary of the findings you will receive these in due course.

Appendix 25: Empirical Study CASP Evaluation

CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

HINT: Consider

- what was the goal of the research?
- why it was thought important?
- its relevance.

Yes	X	Somewhat		No		Can’t Tell

Comments: The author states that they sought to “enhance understanding of the romantic relationships of people with fibromyalgia who remain distressed or disabled by pain after receiving tertiary-level treatment in a multidisciplinary PMP”. The introduction presents the background literature and the potential clinical relevance of the findings.

2. Is a qualitative methodology appropriate?

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.
- Is qualitative research the right methodology for addressing the research goal?
- What is the wording in the aims? Are they using quantitative terms e.g. explain or qualitative terms e.g. experience.

Yes	X	Somewhat		No		Can’t Tell

Comments: The author was interested in the subjective experiences of participants. They also note that “qualitative methods are excellent for investigating interpersonal relationships and dynamics”.

Is it worth continuing? Yes

3. Was the research design appropriate to address the aims of the research?

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use).
- What philosophical perspective, methodology (e.g. phenomenology, grounded theory) and method (e.g. IPA, TA, Grounded Theory)? Are these appropriate to address the research aims?
- Agreed that 'somewhat' = when the philosophical perspective and methodology are not stated but generally appear to be in line with the methodology.

Yes	X	Somewhat		No		Can't Tell

Comments: There is discussion around the use of thematic analysis and the author states that the ontological and epistemological position underpinning the study is critical realism.

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

- If the researcher has explained how the participants were selected.
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.
- If there are any discussions around recruitment (e.g. why some people chose not to take part). This should be given less weight unless people have dropped out or recruitment difficulties are implied. **If all of the other elements above are present but this isn't then this question can still be scored yes.**

Yes	X	Somewhat		No		Can't Tell

Comments: The author explains the purposive sampling strategy and presents inclusion/exclusion criteria. There is discussion around the streams of the recruitment and the author presents the number of participants at various stages.

5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection (e.g. clinic, charity) has been justified.
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen.
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide).
- If methods were modified during the study. If so, has the researcher explained how and why (if applicable).
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data. It was agreed that this does not have to be present if the sample size is typical. **However, if the sample size appears to be limited then this question should be scored down to somewhat** (providing the other elements above are present).

Yes	X	Somewhat		No		Can't Tell

Comments: The author states that data were collected through semi-structured interviews, the location of interviews is presented. The author makes reference to recording interviews with an "encrypted audio recorder", the concept of data saturation is also discussed.

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location.
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design (if applicable).
- This includes what their role is (e.g. nurse), how their role could influence their decision making, their interest in research area, their experience of condition, gender etc.
- The relationship between the researcher and participants should definitely be discussed in an IPA study.

Yes	X	Somewhat		No		Can't Tell

Comments: A reflexivity statement is included. The author reflects on their professional background and gender, there is also reference to the use of a reflective diary.

Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- Agreed that if a PIS etc. is mentioned then consent should be assumed.
- Agreed that there should definitely be some mention of an attempt to maintain confidentiality e.g. use pseudonyms.
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee. Agreed that there should be a statement about approval from if ethics committee. **If other elements are present then this item should be marked 'can't tell'.**

Yes	X	Somewhat		No		Can't Tell

Comments: The author states that potential participants were presented with an invitation letter, advertisement and participant information sheet. There is reference to a consent process and how this was managed given the two forms of interview. The author states that interview transcripts were pseudonymised to protect participant anonymity. There is reference to receiving ethical approval.

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process.
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. **Agreed that this should be given less weight and that If other elements are present then this item should still be marked as 'yes'.**
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account. Agreed this can include different participant views (e.g. one participant said this whilst another said this).
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation. **Agreed that if this is not present but the above elements are then this item should be marked as 'somewhat'.**

Yes	X	Somewhat		No		Can't Tell

Comments: The author provides an in-depth description of the analysis process and makes reference to the inductive approach taken. Data is presented throughout the results section and conflicting views are presented. There is a reflexivity section in which the researcher considers their own role in analysis process.

9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?

HINT: Consider

- Agreed that there should be an attempt in results or discussion to sum up findings in a concise manner, this could even be a brief sentence before moving on to discuss individual findings in more detail. **Agreed that if this is not present but the below elements are then this item should be marked as 'somewhat'.**
- If the findings are explicit.
- If there is adequate discussion of the evidence both for and against the researcher's arguments (for = linking to existing research, against = study limitations generally).
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). Agreed that this may be a simple statement anywhere within the paper about several others confirming themes or some evidence of a discussion etc. **Agreed that if this is not present but the above elements are then this item should be marked as 'somewhat'.**
- If the findings are discussed in relation to the original research question.

Yes	X	Somewhat		No		Can't Tell

Comments: The author sums up the findings in the discussion section and relates these to existing literature. There is discussion around the strengths and limitations of the findings. Attempts to discourage bias and ensure the trustworthiness of findings are also discussed.

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research- based literature.
- If they identify new areas where research is necessary.
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.

Comments: The author discusses the implications of the findings for clinical work and future research. The findings are discussed in the context of the current evidence base and current clinical practice, there is also some reference to the transferability of the findings.