Haig, Caroline (2013) Experiences of relating with the self and others amidst living with fibromyalgia. D.Clin.Psych. thesis, Canterbury Christ Church University.

CAROLINE HAIG, BA Hons, MSc

EXPERIENCES OF RELATING WITH THE SELF AND OTHERS AMIDST LIVING WITH FIBROMYALGIA

Section A: The role of stress in Fibromyalgia: The interconnection between childhood, affective-cognitive factors and relationships.

Word Count: 5172 (plus 331 additional words)

Section B: What are people's experiences of relating with the self and others amidst living with Fibromyalgia?

Word Count: 7999 (plus 472 additional words)

Section C: Critical Appraisal

Word Count: 2000 (plus 43 additional words)

Overall Word Count: 15,171 (plus 846 additional words)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

September 2013

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements Page

I would like to give sincere thanks to the people who agreed to participate in my study. I was humbled by the honesty and openness of all who were interviewed. I was often touched by what you shared with me and I know that I will continue to be influenced and learn from you in many ways.

I would like to give an enormous thank you to both my supervisors. I wish to thank Monika Tuite for her unwavering enthusiasm, wisdom and guidance. Michael, thank you, I always felt contained and completely supported. I feel like you guided me through this process with genuine interest and kindness – for that I am really grateful.

Finally, I would like to thank my mum, Kay Haig. I am so hugely grateful for the time, love and patience you have given to me throughout this process. You have always inspired me with your keenness to learn and understand – I have got here because of you.

Summary of the MRP portfolio

Section A is a literature review that functions to critically evaluate evidence pertaining to the role of stress and fibromyalgia (FMS). The paper begins with an introduction to FMS and various key terms. The review goes on to explore the following stress-related areas in the context of FMS: childhood abuse, affective-cognitive factors and relationships. Methodological drawbacks and gaps in research are highlighted. Considerations for future research are discussed.

Section B presents a qualitative study whereby the experiences of 10 participants with FMS are detailed. Interpretative Phenomenological Analysis was employed to analyse the interviewees' experiences. Three superordinate themes emerged from the analysis: “The power of painful childhood experiences”, “the connection between stress and relating to others” and “interpersonal stress is wedded to illness”. The results are discussed in relation to existing research. Limitations, directions for future research and clinical implications are outlined.

Section C is a critical appraisal of the qualitative study. The appraisal is organised around four key questions, which explore the following areas: The learning of research skills, reflections on what changes would be made if the project could be repeated, how the project has led to working differently in a clinical context, and possibilities for future research.

List of contents

List of Tables and Figures

Section A

Section B

Section D

List of appendices

Section A

Section B

SECTION A: LITERATURE REVIEW PAPER

The role of stress in Fibromyalgia: The interconnection between childhood, affective-cognitive factors and relationships.

Accurate Word Count: 5172 (plus 331 words)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

SEPTEMBER 2013

DEPARTMENT OF APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

It has been increasingly recognised that stress plays a central role in the development and maintenance of fibromyalgia (FMS) (Luyten & Van Houdenhove, 2013). Reviews have explored the relationship between stress and chronic pain, yet a review that is specific to FMS has yet to be completed. The review specifically explored three key areas whilst keeping the concept of stress in mind: The connection between childhood abuse and FMS, the influence of affective-cognitive factors and the role of relationships. Using a range of terms, ASSIA, Psychinfo, Ovid and Web of Knowledge databases were searched. The literature suggests that childhood abuse may play a causal role in the development of FMS and insecure attachment is implicated. In adulthood, people with FMS have been found to have a disrupted ability to understand feelings – this is likely to negatively affect how adversity is coped with. People with FMS have been found to have increased levels of loneliness and invalidation. Quality of social support was found to be a more effective stress buffer than quantity of support in people with FMS. Further findings and the interconnections between these studies are discussed. A critique of the evidence is provided and gaps in the literature are identified. A rationale for future research concludes the review.

1. Introduction

In recent years, it has become increasingly recognised that stress is a central concept in fibromyalgia (FMS) and can relate to almost every aspect of the condition. In their review of fatigue disorders and chronic widespread pain, Van Houdenhove, Luyten and Egle (2009) noted a link between these conditions and a number of different stressors. A review that focuses exclusively on FMS and the role of stress is yet to be completed.

Stress is a very broad concept and could relate to many areas of enquiry. Due to the brevity of this review, the present paper will focus on specific areas that have been highlighted as important in Van Houdenhove et al.'s (2009) review - stress in childhood and its impact on adult functioning, and the impact of other people on stress. This review was carried out by examining a number of databases including, ASSIA, Cochrane database of systematic reviews, Psychinfo, and Web of Knowledge. References were also followed up (see appendix 1 for literature search methodology).

The review will begin by outlining the condition and explaining key terms. A key predisposing stressor associated with FMS will then be explored: childhood abuse. Specifically, the first question that the review will explore is: What is the relationship between childhood abuse and FMS? The review will then focus on the possible impact of childhood adversity on adult functioning. Hence, the second question to be considered is: What impact do childhood experiences have on adult functioning in people with FMS? The review will include studies that attend to both affective and perceptual-cognitive capacities. Considering the impact of social factors on stress, the review will ask a final, third question: What does the literature tell us about the role of social support and how people with FMS relate to others, and how do these factors interact with stress? The final section of the review will consider directions for future research.

1.1. Outlining the condition - Fibromyalgia

FMS is a common syndrome characterised by musculoskeletal pain – it is considered to affect two to four percent of the worldwide population (Wolfe, Ross, Anderson, Russell, & Hebert, 1995). Within clinical settings, onset of symptoms most frequently occurs during middle-age and women are more likely to be affected (Gran, 2003). Symptoms include tenderness around specific points, fatigue, sleep difficulties and stiffness. Chronic musculoskeletal pain is the overwhelming feature (Wolfe et al., 1990). It is a long-lasting syndrome and most individuals do not recover after a five to ten year period (Olin & Schenkmanis, 1996). Cognitive difficulties are also a common feature (Henriksson, 1995). Pain linked to FMS is considered to be more debilitating, more emotionally complex and more severe than the experiences of other chronic pain conditions (Boissevain & McCain, 1991). Bengtsson, Henriksson, and Larsson (1986) observed that intense feelings of illness are more highly reported in individuals with FMS than individuals with Rheumatoid Arthritis (RA).

In addition to physical impairment, FMS has been found to have a psychological impact – increased rates of current and lifetime depression, hypochondriasis and anxiety have been documented (Epstein et al., 1999). Many sufferers report additional psychological and somatic difficulties (Häuser, Zimmer, Felde, & Kollner, 2008). Indeed, compared to individuals who experience other forms of chronic pain, individuals with FMS report higher frequencies of psychological problems (Ahles, Yunus, Gaulier, Riley, & Masi, 1985; Wolfe et al., 1984).

FMS is complex in terms of causation; the precise aetiology is unknown, however, research increasingly indicates that both biological and psychological factors are linked to the development and maintenance of the condition (Van Houdenhove & Luyten, 2007). It has been proposed that FMS may arise when the Hypothalamic Pituitary Adrenal (HPA) axis system switches to a state of "over-drive" from "under-drive", following an intense psychosocial or physical stress (Van Houdenhove & Luyten, 2007). The HPA axis dysfunction may exacerbate inflammatory activity – pro-inflammatory cytokines can result in fatigue, lethargia, decreased concentration, light fever and sensitivity to mental and physical stressors (Dantzer, O'Connor, Freund, Johnson, & Kelley, 2008). Hence, it may be appropriate to refer to FMS as a "stress-related pain syndrome" (Luyten & Van Houdenhove, 2013).

1.2. Key Terms

Attachment: According to the theoretical position of attachment, representations of one's self in relation to others are developed and sustained from early experiences with the caregiver (Bowlby, 1969). Bowlby's (1988) theory proposes that there are three types of attachment style: "secure", "anxious-avoidant" and "anxious-resistant". An individual's formative attachment experiences create a template for all subsequent interpersonal interactions.

Attachment and stress: A body of research suggests that experiences of secure attachment during early life are crucial for developing resilience against adversity (Gunner & Quevedo, 2007). If attachment is secure, a child internalises the caregiver's self-soothing function (Tolpin, 1971). Consequently, arousal and stress can be regulated in later life. On the other hand, Bowlby (1988) postulated that early psychosocial traumatic events could lead to an impaired ability to cope with stress in later life. In support of Bowlby's theory, early life stressors can lead to a series of neurodevelopmental occurrences that determine how the individual copes with future stress (Maunder & Hunter, 2001).

Attachment, Mentalisation and Reflective Functioning (RF): RF lies behind the capacity to mentalize (Fonagy, 1991). Mentalization refers to the skill of holding “minds in mind” (Fonagy, Gergely, Jurist, & Target, 2002). When attachment relationships are secure, regulatory neurological systems that moderate internal stress are developed. In turn, adequate mentalization can be fostered (Fonagy & Target, 1997). However, experiences of invalidating or abusive parenting can lead to fragmented cognitive, behavioural and affective abilities (Dillon, Johnstone, & Longden, 2012). In turn, mentalization and RF skills can be disturbed. Mentalization plays a central part in buffering the impact of adversity or stress (Fonagy & Luyten, 2009).

2. Question 1: What is the relationship between childhood abuse and FMS?

For more than fifteen years, noxious life experiences in childhood (emotional, sexual and physical) have been cited as possible causal factors in FMS (Hudson & Pope, 1995). The “trauma hypothesis” postulates that these experiences of abuse are linked to disturbances in the HPA axis system (Weissbecker, Floyd, Dedert, Salmon, & Sephton, 2006). However, various other pathways have been put forward as to why childhood adversities may increase one’s vulnerability to FMS including low self-esteem, inadequate ability to cope with stress due to negative affect, personality disorders and depression proneness (Van Houdenhove, Luyten, & Egle, 2009).

Häuser, Kosseva, Üceyler, Klose, and Sommer (2011) conducted a systematic review and meta-analysis on 18 case-control studies with 13,095 participants. Five studies were conducted in Europe, 12 in North America and one in Central America. Seven studies recruited FMS participants from tertiary care, eight from secondary care, one from primary care and two from the general population.

Odds ratios (OR) were gleaned from each study. Taking into account confidence intervals, an OR of more than 1.0 indicates that exposure to abuse leads to a more likely outcome of FMS. The meta-analysis found a significant association between FMS and physical abuse (OR 2.49, $p < 0.0001$) and sexual abuse (OR 1.94, $p = 0.0002$), sexual as well as physical abuse (OR 2.02, $p = 0.03$), and physical and/or sexual abuse (OR 1.78, $p = 0.03$) in childhood. Interestingly, childhood emotional abuse was not found to be associated with FMS (OR 1.65, $p = 0.11$). However, operationalising emotional abuse can be difficult and it can be a subtle occurrence; the studies used different definitions for this concept and therefore the authors argued that the association between emotional abuse and FMS may not have been accurately captured.

After performing sensitivity and subgroup analyses, the robustness of the studies did not alter. An inspection of funnel plots did not reveal a publication bias effect. A meta-regression discovered a correlation between the childhood sexual abuse outcome and low methodologic quality. However, low study quality was not associated with childhood physical abuse outcomes.

Häuser et al.'s review is commendable in that it is extremely thorough and engages in careful criticism of each study that it reviews. Some of the key limitations of the studies will now be outlined. The authors argue that a primary flaw of most studies is that they utilise self-report measures and are therefore prone to response and recall biases. It is possible that a clinical interview may have been a more reliable assessment tool, as this technique can reduce recall bias (Goodman et al., 2003).

The authors noted that the studies were susceptible to bias. For example, many studies did not account for variables that may confound the correlations between abuse and FMS. Socioeconomic status, sex of the participant, and mental-health co-morbidities were not matched between the control group and the experimental group. Only half of the studies recruited controls from the same population as the FMS participants. Both emotional and physical abuse had different definitions across studies. In contrast, sexual abuse had a clear, agreed definition, yet rape was not separately assessed.

Hauser et al. objected that none of the studies used legal or medical documentation to confirm incidences of abuse. The authors also noted that no studies employed a second clinician to corroborate histories of abuse. To some extent, the above criticisms are valid. However, it is arguable that that the above requirements are neither realistic nor ethical; repeating stories of abuse or seeking out supportive documents are likely to be a highly distressing experiences for the participant.

Overall, Häuser et al. concluded that there appears to be a robust correlation between FMS and some forms of abuse. However, it is important that prospective studies are developed to explore how childhood adversities may link to FMS and to consider potential mediators.

The relationship between traumatic childhoods and FMS has been explored via qualitative research. Using a grounded theory approach, Hallberg and Carlsson (1998) noted the experiences of women with FMS “as they themselves tell it”. Participants were found to have a preoccupation with pain, to be overactive and voiced psychosocial trauma. It was noted that two higher-order concepts prevailed – psychosocial vulnerability and maintaining forces. Psychosocial vulnerability linked to the categories of traumatic life history, pessimistic view of life, over-compensatory perseverance and an unsatisfactory work life. Maintaining forces linked to medicalised reinforcement of the “sick-role” and secondary gains.

The authors extend the conclusions of previous quantitative studies; Hallberg and Carlsson (1998) argued that high reports of early loss, inflated responsibility in childhood and familial social problems may have been associated with insecure attachment in people with FMS (Bowlby, 1988).

Wentz, Lindberg, and Hallberg (2004) built upon the previous study by using grounded theory to shed light on the psychological processes of women with FMS. This study also referred to the role of childhood stress. A theoretical model emerged, which suggested that a sense of an “unprotected self” as a child led to “compensating strategies” (for example, adopting a large sense of responsibility and attempts to be highly active). Later on in life, an “increase in mental load” occurred. This over-stimulation was linked to the onset of FMS symptoms and cognitive disintegration.

The authors linked their findings to an existing theory, which notes that females appear to react differently to stress than males. Whereas early life stress may lead to antisocial behaviour in boys, girls are more likely to develop an inflated sense of responsibility (Page, 2001). Hence, “tending and befriending” is a recognised female response to stress (Taylor et al., 2000).

Overall, these findings imply that many individuals with FMS experienced a childhood that involved chaotic or threatening relationships. Both biological and attachment-based theories have been put forward to explain the link between childhood abuse and FMS, however, more evidence is needed before firm conclusions are drawn. More qualitative research is needed to give a richer insight into these childhood experiences. It would be useful to consider how childhood experiences affect how stress is managed both in the past and present.

3. Question 2: What impact do childhood experiences have on adult functioning in people with FMS? An investigation of affective and perceptual-cognitive capacities.

It has been well established that attachment difficulties in early childhood can lead to psychological disturbances in later life (Dillon et al., 2012) and can affect how one relates to others during adulthood (Bartholomew & Horowicz, 1991). Unresponsiveness and poor empathy in parents has been associated with alexithymia (Kooiman, Spinhoven, Trijsberg & Rooijmans, 1998) and mentalization (or RF) deficits in adulthood (Fonagy et al., 2002). As these factors affect how others are related to, they seem particularly relevant to this review (Choi-Kain & Gunderson, 2008).

Given that alexithymia has been frequently cited in the literature as being associated with FMS, the empirical evidence pertaining to FMS and alexithymia will first be outlined. Theories that explain the relationship between childhood experiences and alexithymia will then be discussed. Mentalization deficits have been repeatedly associated with childhood adversity and insecure attachment (Fonagy & Bateman, 2006). Therefore, this section will explore evidence that explores mentalization in relation to FMS.

The meaning of alexithymia is “absence of words for emotion”, which was coined by Sifneos (1973); the term refers to an inability to identify and describe feelings and a lack of fantasies. It can involve a reliance on an analytic, externally-focussed cognitive style (Pedrosa et al., 2008).

Alexithymia can be considered to be a strategy for regulating emotions such as anger or sadness. Whereas some individuals manage emotions by approaching them (for example, emotional expression or processing), others rely on strategies that may involve avoidance (i.e., alexithymia). It has been hypothesised that the latter strategy may cause, maintain or worsen symptoms of FMS (Van Middendorp et al., 2008).

Research indicates that alexithymia is a common characteristic associated with FMS. Brosschot and Aarse (2001) found that FMS participants have increased alexithymia scores compared to healthy controls. The two groups had differing attributional patterns; the experimental group reported increased physical symptoms whilst attributing them less to psychological causes.

Sayar, Gulec and Topbas (2004) confirmed these results; it was found that compared to participants with RA and healthy controls, those with FMS were found to be significantly more alexithymic. The authors noted that the “difficulties with identifying feelings” dimension correlated particularly with FMS. Tuzer et al. (2011) built upon the above research; these authors compared people with FMS, chronic lower back pain (CLBP) and healthy controls with 75 participants in each group. Again, it was found that people with FMS were found to have significantly elevated scores of alexithymia, as well as heightened scores of anxiety, depression, hostility and somatisation. It was also found that anxiety positively correlated with an inability to describe emotions in people with FMS. Linking to the above research, Steinweg, Dallas, and Rea (2011) observed a strong association between moderate to severe depression and alexithymia in people with FMS. This study also observed increased alexithymia scores in the experimental group compared to the general population and RA participants. Importantly, when depression was controlled for, group differences in alexithymia scores disappeared. This suggests that alexithymia is correlated with depression in participants with FMS. However, a causal relationship was not established.

Pedrosa et al. (2008) added to alexithymia research by considering whether parental characteristics predicted alexithymia in 40 female participants with FMS. 15 percent of participants presented with clinically significant alexithymia scores. Alexithymia was found to positively correlate with “paternal indifference” and “maternal abuse”.

These results appear to support the hypothesis that a lack of parental responsiveness and empathy can disturb emotional development, which may lead to alexithymia in adult life. A drawback of this study is that it involves reports of emotional characteristics of significant others. Given that the involved participants have been found to have impaired abilities to report on emotions, the accuracy of these reports may be questionable. Although the aim of this study was to explore correlations, it would have been useful to compare the experimental group to a control group. In turn, it would have been possible to observe whether these correlations were unique to people with FMS or whether they applied to a wider population.

Using a heterogeneous experimental sample of 403 participants, Van Middendorp et al. (2008) aimed to investigate the link between emotional avoidance strategies used by participants with FMS and symptoms. Confirming the results of previous studies, these authors found that FMS participants tended to utilise an emotional-avoidant strategy. Again, participants scored particularly high on a “difficulty identifying feelings scale”. It was also found that positive emotions were lower compared to a control group. In the experimental sample, higher rates of negative affect, in particular mental distress, were correlated with alexithymia and were slightly correlated with increased pain and fatigue. Delineating the results, the authors found that negative affect only had a relationship with pain severity when combined with an inability to verbalise or process information.

The above studies have all investigated alexithymia by utilising self-report measures. Arguably, using self-report measures is abstract, as participants are not required to reflect on their emotions in relation to a specific incident and therefore accuracy is questionable. Moreover, they rely on assessing oneself retrospectively. Given that FMS is associated with memory deficits (Grace, Nielson & Hopkins, 1999), the latter drawback seems particularly pertinent.

The exact nature of the relationship between alexithymia and FMS has not been confirmed in the literature. However, various theories have been put forward. For example, the "restricted emotional processing" theory (REP) postulates that FMS involves a dissociation between affective responses and physiological responses. Hence, physiological arousal caused by emotional distress can be misconstrued as a symptom of an illness (Brosschott & Bouman, 1994). This theory, however, is unsubstantiated. Moreover, it does not explain why other psychological disorders that are associated with alexithymia (for example, borderline personality disorder) are not linked to experiences of pain or why pain occurs at common tender points in those with FMS.

In the theoretical literature, it has been suggested that alexithymia may be a product of disrupted attachment. Van Houdenhove and Luyten (2007) postulated that individuals with FMS are frequently characterised by "attachment deactivating strategies". Those who utilise such strategies can attempt to manage stress by denying the need for attachment and asserting their own strength and autonomy. This converges with McEwen' s (2007) "allostatic load" model, which claims that such individuals portray themselves as resilient, independent and emotionally-unaffected, however, underneath this presentation, high levels of distress are experienced. This strategy is considered to be associated with feelings of loneliness and isolation (Mikulincer & Shaver, 2007).

It is arguable that mentalization plays a central part in buffering the impact of adversity or stress (Fonagy & Luyten, 2009). Hence, it seems possible that mentalization abilities are impaired in people with FMS and this may contribute to the heightened experience of stress in day to day life (Dailey, Bishop, Russell, & Fletcher, 1990). At present, no quantitative studies have evaluated the mentalization abilities of those with FMS. A case report, authored by Griffies (2010) appears to be the only published study that directly explored FMS and mentalization. Although generalisations from this case report cannot be made, Griffies (2010) noted that insecure attachment in the participant under discussion appeared to lead to mentalization deficits. This was evidenced by an incapacity to self-reflect. The ability to self-soothe when experiencing pain was also limited.

Mentalization involves the ability to hold in mind both other’s and one’s own mind. An element of mentalization is consciousness of affect (Choi-Kain & Gunderson, 2008). Hence, alexithymia is at least one facet of mentalization that has been shown in the literature to be disturbed in people with FMS. Despite these considerations, research has not directly investigated whether mentalization deficits are present in people with FMS. Therefore, no firm conclusions can be made regarding the relationship of FMS and mentalization.

4. Question 3: What does the literature tell us about the role of social support and how people with FMS relate to others, and how do these factors interact with stress?

It is possible that childhood adversity and the adult consequences of such experiences may impact upon how others are related to. Moreover, there is a strong body of literature demonstrating that social support can moderate the outcomes of stressful experiences (Pengilly & Dowd, 2000). Hence, the next section will review evidence that sheds light on the quantity and quality of social support in those with FMS. Studies that provide insights into how social support plays a role in the lives of people with FMS will also be reviewed. In the literature, social support can refer to a number of related ideas including societal or community integration, supportive relationships and perception of support (Pierce, Sarason, & Sarason, 1996).

Several studies have investigated the levels of social support in people with FMS. Bergman (2005) found that compared to people with regional chronic pain and no pain, people with FMS and people with widespread chronic pain were more likely to have lower social support. These results contrast with earlier studies; Amir et al. (2000), demonstrated that social support did not differ between people with FMS, normal controls and other pain conditions. Bolwijn, Van Santen-Hoeufft, Baars and Van der Linden’s (1996) also disagreed with Bergman’s results; these authors found that people with FMS in fact had more intimate friendships and heightened family contact than controls.

Due to the methodological shortcomings associated with the above three studies, these results should be viewed with particular caution; the three studies all employed a sample of 51 participants or fewer in each group, hence these studies lack sufficient statistical power. Therefore, these results may be demonstrative of a type two error. These studies also relied on self-reports of social characteristics. It may have been useful if studies had also included reports from significant others in order to reduce the possibility of bias. Terminology was not discussed with each participant. Hence, it is unclear as to whether terms such as “intimate friendship” had the same meaning for each participant. In order to draw confident conclusions regarding the social status of people with FMS, it is crucial that future research aims to overcome these limitations.

Comparing 78 women with FMS and 28 female controls, Shuster, McCormack, Pillai Riddell, and Toplack (2009) also found no difference between the two groups in terms of social support from friends. However, the authors did observe that participants from the control condition reported significantly higher support from their family. Within the experimental group, lower family support was found to be a significant predictor of depression. Hence, it may be the case that sub-types of social support are disrupted in people with FMS.

Research has also aimed to shed light on concepts of invalidation and loneliness in FMS. Kool and Geenan (2012) completed a large-scale study that compared FMS participants to those with four other rheumatic conditions. Using online questionnaires, it was found that participants with FMS reported significantly higher rates of loneliness compared to all other groups. Taking into account unemployment, age, low education and poor social support, perceived invalidation (not acknowledging pain, lecturing and denial) from others was found to correlate with loneliness in the FMS condition. Overall, in terms of evidence pertaining to how people with FMS relate to others, experiences of invalidation and loneliness appear to be frequent and interlinked.

Franks, Cronan, and Oliver (2004) added to the understanding of social support and FMS. In contrast to former research, this study did not compare levels of social support between FMS and other groups. Rather, Franks et al. investigated the correlation between social support and wellbeing in a sample of 568 participants with FMS. Both quantity and quality of support were examined. The authors criticised previous studies for failing to delineate between these two categories.

In terms of "quantity", it was found that small social networks were associated with lower self-efficacy and poor management of symptoms. Better "quality" of support correlated with lower levels of mood disturbance, impact of pain, helplessness and depression. Quality of support also predicted increased wellbeing, self-efficacy and improved symptom management. The authors concluded that although quantity of social support is important, quality of support seemed to be more beneficial. It appears, therefore, that specific factors related to the concept of "social support" are crucial for understanding how people with FMS relate to others; namely loneliness, invalidation and quality of support.

A limitation of some of the discussed research is that "social support" is not fully operationalised. Even studies that have explored sub-sections of people's social world may have delineated this category further. For instance although Shuster et al. (2009) considered the impact of peer and family support, they did not investigate the specific areas of familial support. It is therefore useful that several studies have explored familial support more specifically, focusing on the role of the sufferer's marital relationship.

With the aim of investigating partner support, Reich, Olmsted and Van Puymbroeck (2006) compared 51 people with FMS to 32 people with osteoarthritis (OA). Functional ability, pain, illness uncertainty, relationship satisfaction and partner support were assessed. Partner support considered the availability of the partner as well as instrumental and emotional support. Caregiver burden was also measured in the partners of the participants. Illness uncertainty refers to the possibility of treatment success and how much is known about aetiology and illness progression.

The key findings were that partner burden correlated with lower levels of partner support, lower levels of functioning and increased pain in the FMS group only. In contrast, increased disability led to increased support in the OA group. Furthermore, poor relationship satisfaction predicted increased pain and lower functioning in the FMS condition. Low levels of supportiveness only predicted relationship dissatisfaction when uncertainty was high. Illness uncertainty was found to be significantly higher in the FMS group. The authors argue that this is unsurprising, given that OA is a reasonably well understood condition compared to FMS.

It is possible that illness uncertainty at least partly accounts for the differences found between the two groups. It would be useful if future research explored relationship support and quality in people with FMS before the onset of illness symptoms, perhaps by investigating relationships in people who are at high risk of developing FMS. In turn, one may better understand whether reduced relationship dissatisfaction was due to illness uncertainty or other factors.

Drawing conclusions from the above quantitative research is somewhat problematic, as several of the studies did not employ a control group from a healthy population. Therefore, in some domains, it is unclear as to whether people with FMS differ from the normal population. The above studies did not clearly outline the relationship between social support and FMS; longitudinal studies are needed to consider whether FMS leads to reduced social support or whether the stress of having poor social support contributes to the development of FMS.

A further drawback of the above studies is that they do not provide rich insights into how poor social support may lead to psychological distress. Qualitative studies have shed light on how social factors may cause distress. For example, research has explored how people with FMS are affected by societal attitudes; Soderberg, Lundman and Norberg (1999) interviewed women with FMS about meaning gleaned from living with the condition. Interlinked themes were identified; the struggle to attain relief when living in an unwell body, the struggle to achieve understanding from others and a feared loss of integrity (for example, through negative societal attitudes).

In Arnold et al.'s (2008) study, the social lives of people with FMS were explored via focus groups. Using grounded theory, it was found that FMS diminished peoples' ability to develop and maintain physical and emotional contact with others. This was largely attributed to the unpredictability of the condition in that illness rendered them unreliable. Friends also doubted the veracity of the participants' condition. This study also touched upon the experience of relating to a partner amidst living with FMS; participants expressed guilt at feeling burdensome on loved ones. Constant pain had a negative impact on sexual intimacy. This experience was connected to common feelings of self-loathing and guilt.

Wuytack and Miller (2011) were also interested in gaining a wider understanding of the relational impact of FMS. All participants highlighted that family support was important. However, some expressed that the absence of support is what made them come to this realisation. The husband was often cited as the most intimate and assisting figure. The presence or absence of support was associated with a corresponding "strengthening" or "shattering" of the relationship.

The above qualitative research is useful in that it gives some insight into why poor social support may lead to psychological distress; it appears that fearing judgement, a lack of understanding or support and feeling burdensome or unreliable are key difficulties of people with FMS when relating to others.

The above studies implicitly consider how stress is exacerbated by social and relationship circumstances. For instance, it appears that common experiences of invalidation, loneliness, poor relationship quality, limited familial support and relationship dissatisfaction are likely to affect one's ability to cope with stress. However, given that FMS has been considered to be a "stress-related pain syndrome" (Van Houdenhove & Luyten, 2006), it seems striking that the studies have not explicitly considered how stress may play a part in the relationship between FMS and social support.

The following questions are yet to be addressed in relation to FMS: Does stress hinder one's ability to relate to others? How have others impacted upon the person's ability to cope with stress? Some of these answers may come to light if research more thoroughly explores how relationships with others and stressful life events are experienced.

5. Future Research

The above literature review suggests that future research could be conducted in a number of areas.

5.1 Quantitative Studies

Clear conclusions regarding the link between childhood adversity and FMS have not been established. It is important that prospective studies assess this association as well as potential mediators. Given that a causal link between childhood adversity and FMS seems possible, it would be useful if future clinical trials assessed abuse-related psychological treatment in the context of FMS management. This seems particularly pertinent, as it has been suggested that disclosing experiences of abuse during therapy may alleviate psychological and somatic symptoms (Paras et al., 2009).

Greater attention to the role of alexithymia in FMS would be of benefit in future research. A possible research question could be whether interventions that aimed to enhance emotional expression or processing could lead to improved mental or physical health in those with FMS. Research has demonstrated that targeting alexithymia in other conditions can lead to clinical benefits (Beresnevaite, 2000; Graugaard, Holgerson, & Finset, 2004; Lumley, 2004).

Little is known about the thinking styles of people with FMS. Other conditions associated with abusive or invalidating parenting, such as borderline personality disorder (BPD) or anorexia nervosa (AN), have been associated with concrete thinking styles (e.g., Skårderud, 2007) and theory of mind deficits (e.g., Fonagy et al., in press). Identifying the abilities of FMS participants in these domains would increase understanding of the condition and could lead to widening considerations of clinical treatment of FMS.

Deficits in RF or mentalization have also been strongly linked to early life adversity (for example, Fonagy, 2005; Fonagy et al., 2002). The summarised current body of literature seems to tentatively suggest that deficits in mentalization skills may be found in those with FMS. It has also been theorised that insecure attachment may play a role in the aetiology of FMS (Hallberg & Carlsson, 1998). Studies that determine mentalization skills (or RF) and attachment styles in people with FMS are required, exploring whether insecure attachment or deficits in mentalization are associated with FMS. It would also be important to consider how alexithymia links in with attachment style. For example, does alexithymia mediate the relationship between attachment style and FMS?

5.2. Qualitative Research

Concepts such as stress, early experiences and relating with others and the self have not been combined with inductive qualitative methodology. People living with FMS are subject to personal and intense experiences; these cannot be fully examined without the perspective of the individual and without context.

Although the aetiology of FMS remains vague, how others were related to in childhood and early stressful experiences are likely key factors in the development of FMS. These experiences and the meanings gleaned from them are yet to be explored via qualitative research. Specifically, the following research questions are yet to be answered: How were childhood relationships and stressful events experienced by individuals with FMS and what meanings were drawn from them? How are relationships and stress experienced presently? Have early life experiences affected how others are related to in the present?

Research suggests that when experiencing stress, it is common for individuals to seek out attachment figures if the individual has a secure attachment style. On the other hand, if one has an insecure attachment style, others may be avoided or an ambivalent relationship with others may manifest (Bowlby, 1988). Qualitative research is yet to answer the following question – how do people with FMS experience relating to others? An inductive study that focussed on the latter question whilst keeping in mind experiences of stress would explore novel and clinically relevant research territory.

6. References

Ahles, T., Yunus, M., Gaulier, B., Riley, S., & Masi, A. (1985). The use of contemporary MMPI norms in the study of chronic pain patients. *Pain, 24*, 159-163.

Amir, M., Neumann, L., Bor, O., Shir, Y., Rubinow, A., & Buskila, D. (2000). Coping styles, anger, social support, and suicide risk of women with fibromyalgia syndrome. *Journal of Musculoskeletal Pain, 8,* 7-20.

Arnold, L., Crofford, L., Mease, P., Burgess, S., Palmer, S., Abetz, L., & Martin, S. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counselling, 73,* 114-120.

Bartholomew, K., & Horowicz, L. (1991). Attachment styles among young adults: A test of a four-category model. *Journal of Personality and Social Psychology, 61,* 226-244.

Bengtsson, A., Henriksson, K., & Larsson, J. (1986). Reduced high-energy phosphate levels in the painful muscles of patients with primary fibromyalgia. *Arthritis and Rheumatology, 29,* 817-821.

Beresnevaite, M. (2000). Exploring the benefits of group psychotherapy in reducing alexithymia in coronary heart disease patients: a preliminary study. *Psychotherapy and Psychosomatics, 69*, 117-122.

Bergman, S. (2005). Psychosocial aspects of chronic widespread pain and fibromyalgia. *Disability and Rehabilitation, 27,* 675–683.

Boissevain, M.D., & McCain, G.A. (1991). Toward an integrated understanding of fibromyalgia syndrome: Medical and pathophysiological aspects. *Pain, 45*, 227-238.

Bolwijn, P., Van Santen-Hoeufft, M., Baars, H., Kaplan, C., & Van der Linden, S. (1996). The social network characteristics of fibromyalgia patients compared with healthy controls. *Arthritis Care Research, 9*, 18-26.

Bowlby, J. (1969). *Attachment and Loss.* New York: Basic Books.

Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. London: Routledge.

Brosschot, J. F., & Aarsse, H. R. (2001). Restricted emotional processing and somatic attribution in fibromyalgia. *International Journal of Psychiatry in Medicine, 31*, 127-146.

Brosschot, J.F., & Bouman, T. H. (1994). Somatization revisited: Old wine in new bottles. *Netherland Journal of Psychology, 49*, 247-254.

Choi-Kain, L.W, & Gunderson J.G. (2008). Mentalization: Ontogeny, assessment, and application in the treatment of borderline personality disorder. *American Journal Psychiatry, 165*, 1127–1135.

Dailey, P., Bishop, G., Russell. A., & Fletcher, E. (1990). Psychological stress and the fibrositis/ fibromyalgia syndrome. *Journal of Rheumatology, 17*, 1380-1385.

Dantzer, R., O'Connor, J., Freund, G., Johnson, R., & Kelley, K. (2008). From inflammation to sickness and depression: When the immune system subjugates the brain. *Nature Reviews Neuroscience, 9,* 46-56.

Davis, D., Leucken, L., & Zautra, A. (2005). Are reports of childhood abuse related to the experience of chronic pain in adulthood? A meta-analytic review of the literature. *Clinical Journal of Pain, 2,* 398–405.

Dillon, J., Johnstone, L., & Longden, E. (2012). Trauma, dissociation, attachment and neuroscience: A new paradigm for understanding mental illness. *The Journal of Critical Psychology, Counselling and Psychotherapy, 12,* 145-155.

Epstein, S., Clauw, D., Klein, D., Kuck, J., Masur, D., & Waid, R. (1999). Psychiatric disorders in patients with fibromyalgia. *Psychosomatics, 40,* 57-63.

Evren, B., Evren, C., & Guler, M. (2006). An open clinical trial of venlafaxine in the treatment of pain, depressive and anxiety symptoms in fibromyalgia. *The Pain Clinic, 18,* 167–173.

Fonagy, P. (2001). *Attachment Theory and Psychoanalysis.* New York: Other Press.

Fonagy, P. (2005, April). *Eating disorders and dysfunctional attachment: a focus on mentalization*. Paper presented at the 7th London International Conference on Eating Disorders, London.

Fonagy, P., & Bateman, A. (2006). Mechanisms of change in mentalization based treatment on patients with a borderline personality disorder: Mentalization based treatment of BPD. *Journal of Clinical Psychology, 62*, 411-430.

Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect regulation, Mentalization, and the Development of the Self.* New York: Other Press.

Fonagy, P., & Luyten, P. (2009). A developmental, mentalization-based approach to the understanding and treatment of borderline personality disorder. *Development and Psychopathology, 21*, 1355-1381.

Fonagy, P., Stein, H., Allen, D., Chen, C. F., Allen, J. G., & Vrouva, I. (in press). The relationship of childhood and adolescent adversity to impairment of mentalizing capacity and psychological disorder. *Journal of Personality Disorder*.

Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in self-organization. *Development and Psychopathology, 9*, 679-700.

Franks, H. M., Cronan, T. A., & Oliver, K. (2004). Social support in women with fibromyalgia: Is quality more important than quantity? *Journal of Community Psychology, 32*, 425-438.

Goodman, G., Ghetti, S., Quas, J., Edelstein, R., Alexander, K., Redlich, A., Cordon, I., & Jones, D. (2003). A prospective study of memory for child sexual abuse: New findings relevant to the repressed-memory controversy. *Psychological Science, 14*, 113-118.

Grace, G., Nielson, W., & Hopkins, M. (1999). Concentration and memory deficits in patients with fibromyalgia syndrome. *Journal of Clinical and Experimental Neuropsychology, 21*, 477-487.

Gran, J. T. (2003). The epidemiology of chronic generalized musculoskeletal pain. *Best Practice and Research: Clinical Rheumatology, 17*, 547-561.

Graugaard, P., Holgerson, K., & Finset, A. (2004). Communicating with alexithymic and non-alexithymic patients: An experimental study of the effect of psychosocial communication and empathy on patient satisfaction. *Psychotherapy and Psychosomatics, 73,* 92-100.

Griffies, W. S. (2010). Believing in the patient's capacity to know his mind: A psychoanalytic case study of fibromyalgia. *Psychoanalytic Inquiry, 30*, 390-404.

Gunner, M., & Quevedo, K. (2007). The neurobiology of stress and development. *Annual Review of Psychology, 58,* 145-173.

Hallberg L. R. M., & Carlsson S. G. (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Sciences, 12*, 95–103.

Häuser, W., Kosseva, M., Üceyler, N., Klose, P., & Sommer, C. (2011). Emotional, physical, and sexual abuse in fibromyalgia syndrome: A systematic review with meta-analysis. *Arthritis Care & Research, 63*, 808–820.

Häuser, W., Zimmer, C., Felde, E., & Kollner, V. (2008). What are the key symptoms of fibromyalgia? Results of a survey of the German Fibromyalgia Association. *Schmerz, 22,* 176-183.

Henriksson, C. M. (1995). *Living with fibromyalgia. A study of the consequences for daily activities.* Unpublished doctoral dissertation, Linköping University, Linköping, Sweden.

Hudson, J., & Pope, H. (1995). Does childhood sexual abuse cause fibromyalgia? *Arthritis and Rheumatology, 38*, 161-163.

Imbierowics, K., & Egle, U. (2003). Childhood adversities in patients with fibromyalgia and somatoform pain disorder. *European Journal of Pain, 7*, 113-119.

Kooiman, C., Spinhoven, P., & Trijsberg, W., & Rooijmans, H. (1998). Perceived parental attitude, alexithymia, and defence style in psychiatric outpatients. *Psychotherapy and Psychosomatics. 67*, 81-87.

Kool, M., & Geenen, R. (2012). Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *Journal of Psychology, 146*, 229-241.

Lumley, M. (2004). Alexithymia, emotional disclosure, and health: a program of research. *Journal of Personality, 72,* 1271-1300.

Luyten, P., & Van Houdenhove, B. (2013). Common and specific factors in the psychotherapeutic treatments of patients suffering from chronic fatigue and pain. *Journal of Psychotherapy Integration, 23,* 14-27.

Maunder, R.G., & Hunter, J.J. (2001). Attachment and psychosomatic medicine: Developmental contributions to stress and disease. *Psychosomatic Medicine, 63,* 556-567.

McEwen, B. (2007). Physiology and neurobiology of stress and adaptation: Central role of the brain. *Physiological Reviews, 87,* 873-904.

Mikulincer, M., & Shaver, P. (2007). *Attachment in adulthood: Structure, dynamic and change*. New York: Guilford Publications.

Olin, R., & Schenkmanis, U. (1996). *Fibromyalgia: Symptoms, diagnosis, treatment*. Sweden: Sveriges Radios Forlag.

Page, T. (2001). Attachment themes in the family narratives of pre-school children: A qualitative analysis. *Child and Adolescent Social Work Journal, 18,* 353-375.

Paras, M., Hassan, M., Chen, L., Goranson, B., Sattler, A., Colbenson, K., et al. (2009). Sexual abuse and lifetime diagnosis of somatic disorders: A systematic review and meta-analysis. *The Journal of the American Medical Association, 302,* 550-561.

Pedrosa, F., Weigl, M., Wessels, T., Irnich, D., Baumuller, E., & Winkelmann, M. (2008). Parental bonding and alexithymia in adults with fibromyalgia. *Psychosomatics*, *49*, 115-122.

Pengilly, J.W., & Dowd, E.T. (2000). Hardiness and social support as moderators of stress. *Journal of Clinical Psychology, 56,* 813-820.

Pierce, G. R., Sarason, I. G., & Sarason, B. R. (1996). Coping and social support. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 434-451). New York: Wiley.

Raphael, K, G., Chandler, H. K., & Ciccone, D, S. (2004). Is childhood abuse a risk factor for chronic pain in adulthood? *Current Pain and Headache Reports, 8,* 99-110.

Reich, J., Olmsted, M., & Van Puymbroeck, C. (2006). Illness uncertainty, partner caregiver burden and support, and relationship satisfaction in fibromyalgia and osteoarthritis patients. *Arthritis and Rheumatology, 55,* 86-93.

Sayar, K., Gulec, H., Topbas, M. (2004). Alexithymia and anger in patients with fibromyalgia. *Clinical Rheumatology, 23,* 441-448.

Shuster, J., McCormack, J., Pillai Riddell, R., & Toplak, M.E. (2009). Understanding the psychosocial profile of women with fibromyalgia. *Pain Research and Management, 14,* 239-245.

Sifneos, P. (1973). The prevalence of “alexithymic” characteristics in psychosomatic patients. *Psychotherapy and Psychosomatics, 22*, 255-262.

Skårderud, F. (2007). Eating one's words: Part I. 'Concretised metaphors' and reflective function in anorexia nervosa-an interview study. *European Eating Disorders Review, 15,* 163-174.

Söderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity: The meaning of women´s experiences of living with fibromyalgia. *Qualitative Health Research, 9,* 575–587

Steinweg, D., Dallas, A., & Rea, W. (2011). Fibromyalgia: Unspeakable suffering, a prevalence study of alexithymia. *Psychosomatics, 52,* 255-262.

Stormorken, H., & Brosstad, F. (1992). Fibromyalgia: family clustering and sensory urgency with early onset indicate genetic predisposition and thus a "true" disease. *Scandinavian Journal of Rheumatology, 21*, 207-208.

Taylor, S., Klein, L., Lewis, B., Gruenwald, T., Gurung R., & Updegraff, J. (2000). Bio-behavioural responses to stress in females: Tend-and-befriend not fight-and-flight. *Psychological Review, 107,* 411-429.

Tolpin, M. (1971). On the beginnings of a cohesive self. *The Psychoanalytic Study of the Child, 26*, 316-351.

Tuzer, V., Dogan Bulut, S., Bastug, B., Kayalar, G., Goka, E., & Bestepe, E. (2011). Causal attributions and alexithymia in female patients with fibromyalgia or chronic low back pain. *Nordic Journal of Psychiatry, 65*, 138-144.

Van Houdenhove, B. & Luyten, P. (2006). Stress, depression and fibromyalgia. *Acta Neurologica Belgica, 106*, 149-156.

Van Houdenhove, B., & Luyten, P. (2007). Fibromyalgia and related syndromes characterised by stress intolerance and pain hypersensitivity: Do we need a new nosology? *Current Rheumatology Reviews, 3,* 304-308.

Van Houdenhove, B., Luyten, P., & Egle, U. (2009). Stress as a key concept in chronic widespread pain and fatigue disorders. *Journal of Musculoskeletal Pain, 17,* 390-399.

Van Middendorp, H., Lumley, M., Jacobs, J., Van Doornen, L., Bijlsma, J., & Geenen, R. (2008). Emotions, emotional approach and avoidance strategies in fibromyalgia. *Journal of Psychosomatic Research, 64,* 159-167.

Weissbecker, I., Floyd, A., Dedert, E., Salmon, P., & Sephton, S. (2006). Childhood trauma and diurnal disruption in fibromyalgia syndrome. *Psychoneuroendocrinology, 31*, 312-324.

Wentz, K., Lindberg, C., & Hallberg, L. (2004). Psychological functioning in women with fibromyalgia: a grounded theory study. *Health Care for Women International, 25,* 702-729.

Wieseler-Frank, J., Maier, S., & Watkins, L. (2005). Central proinflammatory cytokines and pain enhancement. *Neurosignals, 14*, 166-174.

Wuytack, F., & Miller, P. (2011). The lived experience of fibromyalgia in female patients: A phenomenological study. *Chiropractic and Manual Therapies, 19*, 1-9.

Wolfe, F., Catley, M., Kleinheksel, S., Amos, S., Hoffman, R., & Young, D. (1984). Psychological functioning in primary fibrositis and fibrositis associated with rheumatoid arthritis. *Journal of Rheumatology, 11,* 500-506.

Wolfe, F., Ross, K., Anderson, J., Russell, I., & Hebert, L. (1995). The prevalence and characteristics of fibromyalgia in the general population. *Arthritis and Rheumatism, 38,* 19-28.

Wolfe, F., Smythe, H., Yunus, M., Bennett, R., Bombarier, C., Goldenberg, D. et al. (1990). The American College of Rheumatology 1990 criteria for the classification of Fibromyalgia: Report of the multicenter committee. *Arthritis and Rheumatism, 33,* 160-172.

7. Appendix 1: Literature search methodology for section A

Three searches took place for each question within section A. Different search terms were used for the three research questions. The searches will be organised around three sub-headings.

Databases searched: Applied Social Sciences Index and Abstracts, Psychinfo, Web of Knowledge, Cochrane Database of Systematic Reviews.

All included studies were published in peer-reviewed journals, demonstrating that they met reviewers' expectations in terms of quality and validity (White & Schmidt, 2005).

Question One: The link between childhood abuse or stress and Fibromyalgia.

Flow diagram 1 outlines the process of selecting and excluding studies at each stage (see figure 1 below).

Search terms using keywords were: “Childhood” OR “Child” AND “Adversity” OR “Stress” OR “Abuse” OR “trauma” AND “Fibromyalgia”.

Inclusion criteria: The study included participants with FMS, the study aimed to observe the link between childhood abuse and FMS, studies were in the English language, participants were over 18.

Quantitative studies published after Hauser et al. (2011) systematic review and meta-analysis would be included.

Exclusion criteria: Book reviews, conference papers, studies whereby the experimental group was not exclusive to participants with FMS (for example, combined FMS and arthritis participants), quantitative studies that did not have a control condition.

This search produced one review and two qualitative articles for inclusion.

Question Two: What impact do childhood experiences have on adult functioning? An investigation of affective and perceptual-cognitive capacities.

Flow diagram 2 outlines the process of selecting and excluding studies at each stage (see figure 2 below).

Search terms using key words were: “Alexithymia” OR “Mentalization” OR “Attachment*” AND “Fibromyalgia”.

Inclusion criteria: If the study was interested in the frequency of alexithymia, attachment styles, or mentalization in people with FMS, the study included participants with FMS, studies were in the English language, participants were over 18.

Exclusion criteria: Book reviews, conference papers, studies whereby the experimental group was not exclusive to participants with FMS (for example, combined FMS and arthritis participants).

This search produced seven quantitative articles and one qualitative article for inclusion.

Question Three: What does the literature tell us about the role of social support and how people with FMS relate to others and how do these factors interact with stress?

Flow diagram 3 outlines the process of selecting and excluding studies at each stage (see figure 3 below).

Search terms using key words were: “social” OR “support” OR “interpersonal” OR “relationships” AND “Fibromyalgia”.

Inclusion criteria: The study included participants with FMS, studies were in the English language, participants were over 18. In order to capture the most relevant research, the search included studies from 1995.

Exclusion criteria: Book reviews, conference papers, studies whereby the experimental group was not exclusive to participants with FMS (for example, combined FMS and arthritis participants).

This search produced seven quantitative articles and three qualitative articles for inclusion.

Figure 1. A flow chart that demonstrates how studies were selected for question 1 (PRISMA, 2009). This chart outlines how studies were identified and eliminated at each point of the search process.

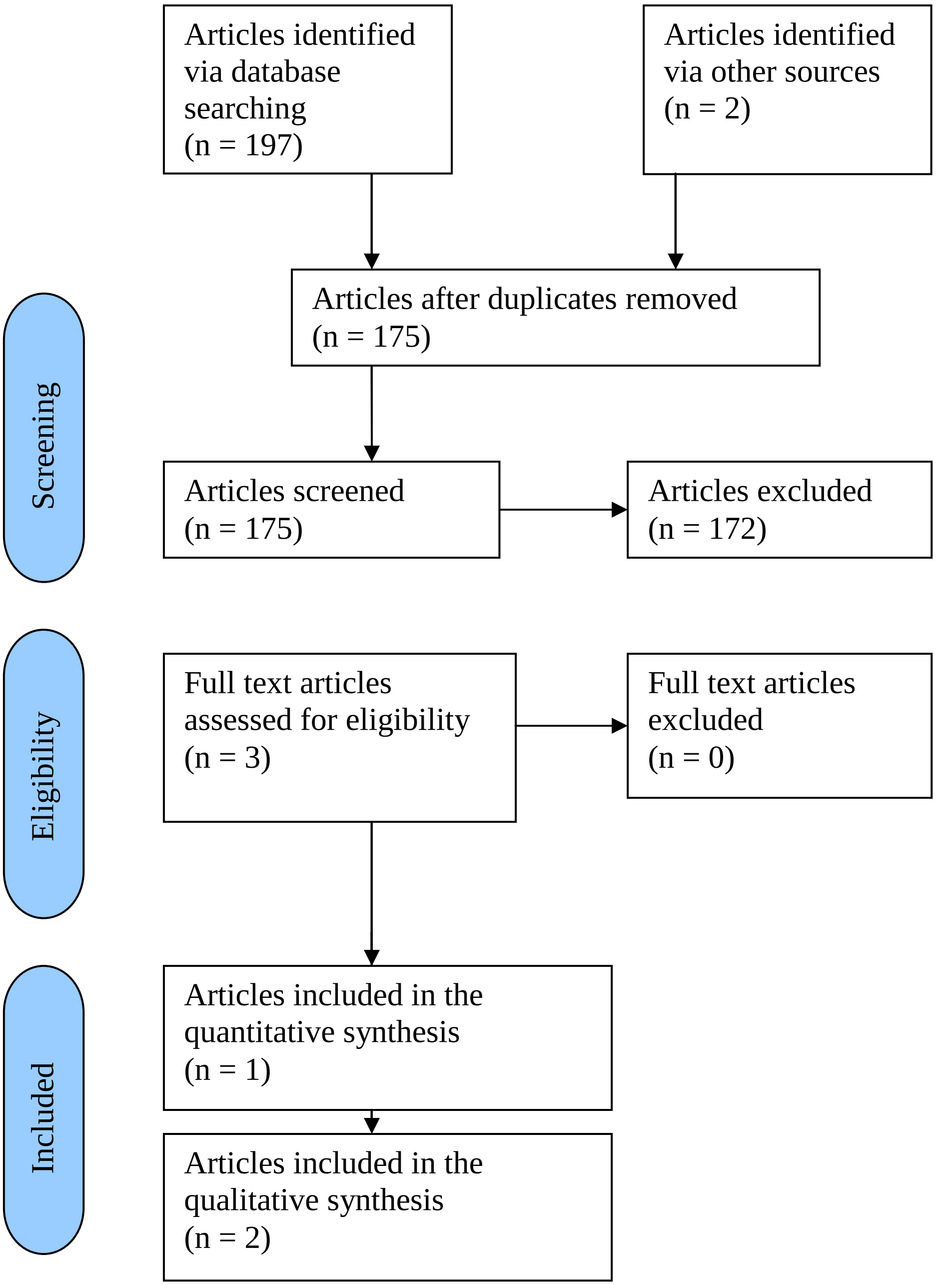


Figure 2. A flow chart that demonstrates how studies were selected for question 2 (PRISMA, 2009). This chart outlines how studies were identified and eliminated at each point of the search process.

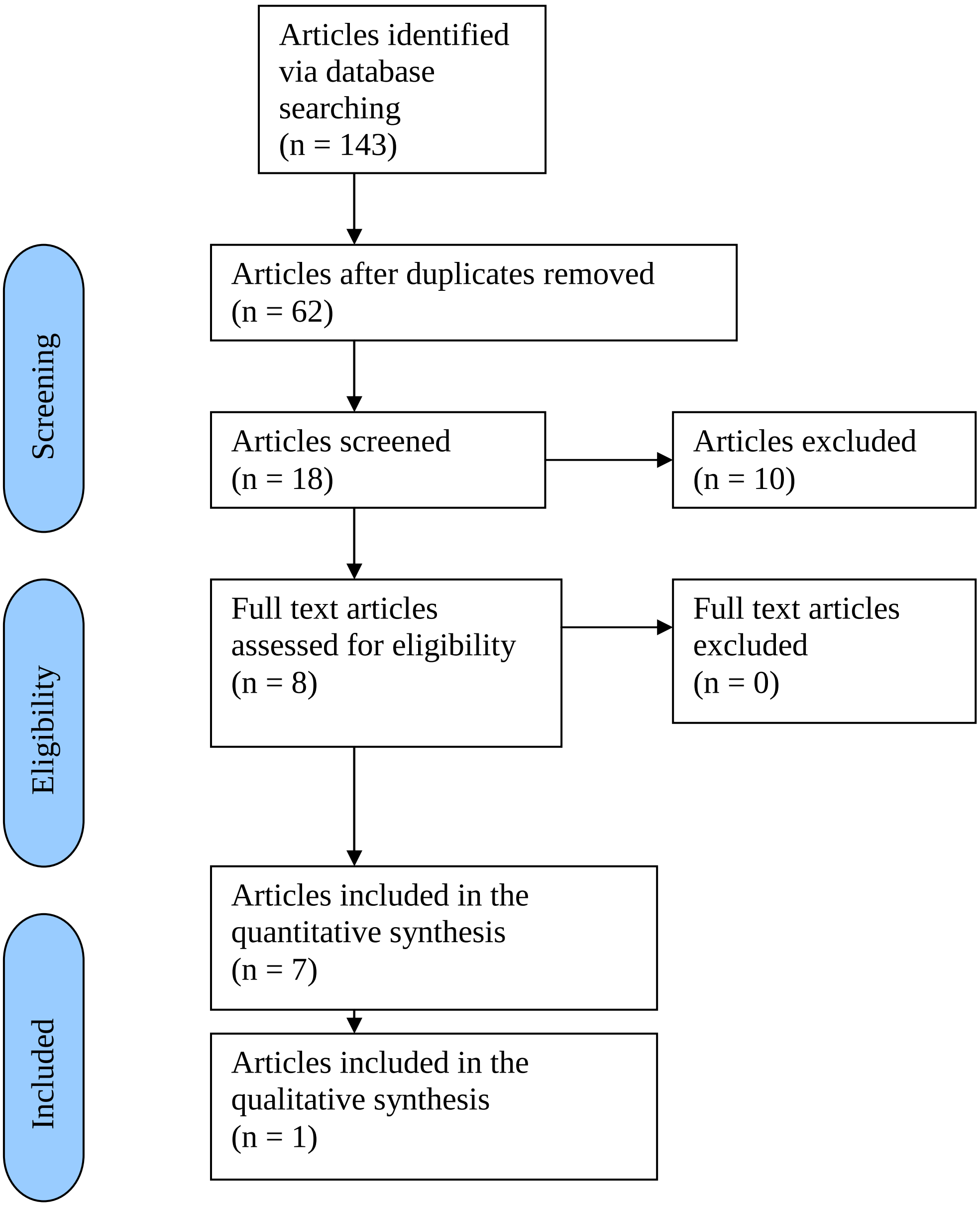
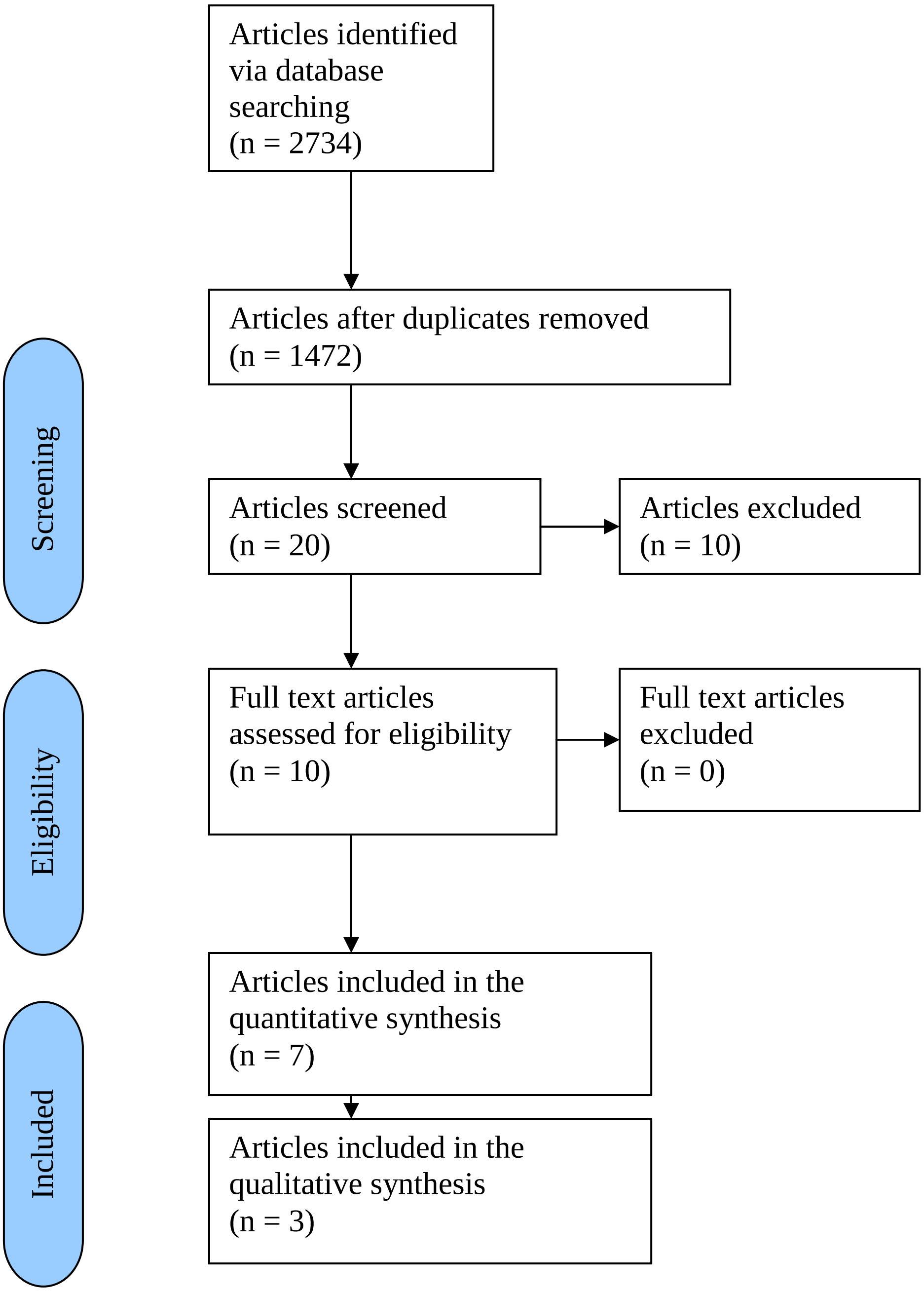


Figure 3. A flow chart that demonstrates how studies were selected for question 3 (PRISMA, 2009). This chart outlines how studies were identified and eliminated at each point of the search process.



SECTION B: EMPIRICAL PAPER

What are people's experiences of relating with the self and others amidst living with Fibromyalgia[1]?

Accurate Word Count: 7999 (plus 472 words)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

SEPTEMBER 2013

DEPARTMENT OF APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Please note: In order to preserve confidentiality, all identifying information has been made anonymous.

---

[1] It is the author's aim to submit this manuscript to Qualitative Health Research.

Abstract

There is a paucity of research that explores how people with Fibromyalgia (FMS) relate to themselves and others, with a particular focus on childhood experiences, mentalization and attachment theory. Ten people with FMS participated in semi-structured interviews, which explored the following areas: Important current relationships, experiences with others and childhood experiences of relationships. Stress and coping were also explored. Interview transcriptions were investigated using Interpretative Phenomenological Analysis (Smith & Osborn, 2003). The following three superordinate themes were identified: “The power of painful childhood experiences”, “the connection between stress and relating to others” and “interpersonal stress is wedded to illness”. Among the participants, childhood was characterised by abuse, illness, bereavement or parental discord. These early events related to various adult consequences in terms of how others and the self were related to. Mirroring childhood experiences, adult relations were often described as destructive. Interpersonal stress was wedded to illness in that others were perceived as invalidating or as ignorant of the suffering experienced. Illness tended to be described as leading to isolation and increased vulnerability to abuse. Literature pertaining to FMS, attachment and mentalization theory was useful in informing the interpretation. Limitations, clinical implications and directions for future research are discussed.

1. Introduction

Fibromyalgia (FMS) is a condition marked by musculoskeletal pain and fatigue, and is estimated to affect 2-4% of the global population (Wolfe, Ross, Anderson, Russell & Hebert, 1995). In a clinical context, FMS is mainly considered to affect women (Gran, 2003). In addition to a physical impact, it has been argued that FMS can lead to psychological impairment – increased rates of depression and anxiety have been observed (Epstein et al., 1999).

1.1. Overview of the Literature

FMS has been cited as a mysterious condition insofar as its aetiological underpinnings are unknown (Wallace & Clauw, 2005). Yet, it has been well documented in the literature that people with FMS have commonly experienced adverse childhoods. In their systematic review and meta-analysis, Häuser, Kosseva, Üceyler, Klose and Sommer (2011) found a significant correlation between sexual and physical abuse in childhood and FMS. Hence, it has been argued that the extreme stress associated with noxious childhood experiences may play a key role in the genesis of FMS. The “trauma hypothesis” postulates that early experiences of abuse are linked to disturbances in the hypothalamic-pituitary-adrenal (HPA) axis system (Weissbecker, Floyd, Dedert, Salmon, & Sephton, 2006). As stress is also considered to perpetuate and maintain FMS, the condition has been named a “stress related pain syndrome” (Luyten & Van Houdenhove, 2013).

In their grounded theory study, Hallberg and Carlsson (1998) touched upon how people with FMS experienced childhood. The authors documented that early loss, inflated responsibility in childhood and familial social problems were frequently experienced. The authors went on to postulate that these early experiences may have contributed to the development of FMS with insecure attachment potentially playing a causal role (Bowlby, 1988). Bowlby argued that there are three key attachment styles; “secure”, “anxious-resistant” and “anxious-avoidant”. Experiences within the first 24 months of an infant’s life greatly influence one’s attachment style.

Wentz, Lindberg and Hallberg (2004) built upon the above research, as their study also referred to the role of childhood stress in FMS. Their qualitative analysis led to a theory, which stated that feeling unprotected as a child led to common compensatory strategies in adulthood (for example, inflated responsibility, over-activity).

The main aim of the above two studies was to generate theory. Although these studies went some way to explore childhood using qualitative methodology, further research is needed to give richer insights into how people with FMS experienced their childhoods. Specifically, evidence is yet to detail how relationships with others were experienced in childhood. As attachment theory has been linked to FMS, it is important that further qualitative research takes into account interpersonal factors.

Research has shown how adverse experiences in childhood can lead to relational consequences in adulthood (Hill, Young, & Nord, 1994) and has gone some way to demonstrate how people with FMS may relate to others in adulthood. Bergman (2005) observed that participants with FMS were more likely to have reduced social networks compared to participants with lower back pain and no pain. People with FMS have also been found to have reduced familial support (Shuster, McCormack, Pillai Riddell, & Toplack, 2009). Kool and Geenen (2012) built on the above research; the authors found that people with FMS have an increased sense of loneliness and invalidation compared to people with other pain conditions. However, the authors did not establish whether a sense of loneliness pre-dated the onset of FMS.

Research has also aimed to create a wider understanding of the interpersonal impact of FMS. Using descriptive phenemonology, Wuytack and Miller (2011) found that participants highly valued family support. However, it was recounted that frequent experiences of lack of support underscored its importance. The husband was often named as the most assisting and intimate figure. Support or lack of it had the ability to “strengthen” or “shatter” a relationship.

Studies are yet to explore how people with FMS experience relationships with themselves and others, for example, via attachment or mentalization studies. Mentalization is the ability to hold mental states in mind. That is, it is the ability to attribute mental states to others or oneself (Fonagy, Gergely, Jurist, & Target, 2002). Mentalization deficits have often been associated with insecure attachment and experiences of invalidating or abusive parenting can inhibit the development of mentalization abilities (Fonagy & Bateman, 2006).

Qualitative research has documented various themes that shed light on how people with FMS relate to others. For example, participants have reported feeling like a burden, feeling stigmatised, invalidated and misunderstood (Paulson, Danielson, & Soderberg, 2002; Asbring & Narvanen, 2002; Soderberg, Lundman & Norberg, 1999, Mengshoel & Heggen, 2004). Although these studies contribute to the understanding of how people with FMS relate to others, as of yet qualitative research has not explicitly explored patterns of relating to others or of relating to self, whilst taking into account formative experiences.

1.2. The Present Study

The aim of the present study is to explore and understand how people with FMS relate to others and themselves. Novel research territory would be covered if qualitative methodology was used to investigate childhood experiences, how these events impacted on later life and experiences of current relationships in people with FMS. Hence, the present study aimed to answer the following research questions:

- How do participants with FMS recount experiences of relationships in childhood?
- What are participants' perceptions about how past experiences influenced the present?
- How do participants with FMS experience relationships with the self and others presently?

2. Method

2.1. Ethical Issues

Ethics approval was received from the NHS Health Research Authority, NRES Committee London-Surrey Borders and a local research and development team (Appendix 1). Ethical guidance was received on numerous facets, such as consent, confidentiality, data storage and the interview procedure. The study adhered to the BPS code of conduct (2009).

2.2. Study Design

The research design was an interview-based qualitative study, which employed interpretative phenomenological analysis (IPA). In keeping with the research questions, this analysis was selected because it focuses on participants’ lived experience.

2.3. Participants

A purposive sample of ten participants was recruited from a pain management service. See Appendix 2 for demographic information. Participants were invited to participate in the study via rheumatologists and clinical psychologists during initial assessments, whereby a consent form and an opt-in form were provided (Appendix 3 and Appendix 4). A participant information sheet was also given, which detailed the purpose of the study, practicalities of engaging in research, confidentiality and the right to terminate participation (Appendix 5). The sample size was based on the guidelines provided by Smith, Flowers, and Larkin (2009) and other similar qualitative research (Cunningham & Jillings, 2006; Råheim & Håland, 2006). Participants were included if they had received a diagnosis of FMS.

2.4. Procedure

Once participants had returned an opt-in form, the researcher made telephone contact. An interview was then arranged and the purpose of the study was reiterated. Participants were given the option to have the interview at an NHS site or at home. All participants chose to be interviewed at home.

Before the interview took place, the participatant information sheet was readdressed. Particular attention was paid to ethics information. Interviews were digitally recorded (between 48 and 103 minutes). Participants were then invited to reflect on the interview experience and a debrief then took place. Information was provided about support services. Participants were informed that they could contact the researcher for the following three days if they wanted to discuss any issues raised by the interview. No participants made use of this.

2.5. Interview Schedule

A semi-structured interview schedule was developed in light of the research questions (Appendix 6). The interview was piloted with an individual who had a physical health condition. The pilot interview was helpful in developing the interview schedule and to aid reflection on the delivery of the interview. Adaptations were also made after receiving guidance from research supervisors, a FMS support group and the ethics panel.

Questions were open-ended, as Smith and Osborn (2003) recommend that the participant is given a "strong role in how the interview proceeds" (p. 63). The following areas were addressed: Important current relationships, stressful experiences with others, other people's understanding of FMS, childhood experiences of relationships and how these early experiences of relationships influenced the participant in adulthood.

2.6. Analysis

Interviews were transcribed and analysed via the IPA procedures recommended by Smith et al. (2009). See Appendix seven for an example transcript. The first major theoretical axis of IPA is that the researcher is required to go “back to the things themselves” (Husserl, 1975, p. 252). That is, experience needs to be explored in its own terms. Interpretation is the second major concern of IPA; participants’ accounts are an attempt to make sense of experience. Hence, the researcher is engaged with a “double hermeneutic” (Smith et al., 2009), as the researcher aims to make sense of the participants’ interpretations. This approach is idiographic in that diversity within individual experiences is sought out. It is inductive, as the researcher aims to allow unanticipated themes to develop from the data (Smith & Osborn, 2003).

Each transcript was rigorously examined; initially, the transcript was read whilst listening to the audio-recording. Each transcript was re-read and initial notes were made on the transcripts. Guided by Smith et al. (2009), linguistic, descriptive and conceptual comments were noted (Appendix 8). The transcripts and notes were then individually re-read and emergent themes were described. Clustering of themes and connections between themes were observed with the use of spider diagrams (Appendix 9).

2.7. Quality Assurance Checks

In order to improve the validity of the research, Yardley’s core principles (2008) were adhered to (Appendix 10). For instance, in order maintain reflexivity, a reflective diary was kept (Appendix 11). This journal was important for maintaining reflective awareness of pre-existing assumptions and experiences. In turn, it is hoped that they exerted less influence on the analysis (Finlay, 2009).

In order to ensure “coherence and transparency” and to verify that the themes were grounded in the data (Yardley, 2008), the codes were checked by a colleague who was unconnected to the research. Interpretations and themes were also shared with supervisors. In order to maintain "commitment and rigour" the guidelines for employing IPA were followed (Smith et al., 2009).

3. Results

The analysis produced three superordinate themes: "The power of painful childhood experiences", "the connection between stress and relating to others" and "interpersonal stress is wedded to illness" (table 1). Nine themes were subsumed under these headings. Each superordinate theme and sub-theme will be discussed and presented with verbatim quotations. Further quotations are available in Appendix 12. It is important to note that the sub-themes correspond to the overarching superordinate themes.

Table 1.

Summary of superordinate themes and sub-themes

Superordinate theme 1: The power of painful childhood experiences

Sub-themes: 1.1: Connecting to others in adulthood, 1.2: Influence on coping, 1.3: Shaping personal values.

Notes from initial coding: Negative childhood experiences, shattered trust, jealousy, intuition, mind-reading, putting others first, protection, lack of self, resilience, independence, managing emotions, family scripts, parenting, others transgressing values, right and wrong, changing values, passing on values.

Superordinate theme 2: The connection between stress and relating to others

Sub-themes: 2.1: Toxic relationships, 2.2: Stress as a vortex, 2.3: Easing the struggle.

Notes from initial coding: familial tensions, exploitation, subjugation, being controlled, invisibility, vicious cycle, fuelling stress, reactive response, unempathic, support, understanding, relieving stress.

Superordinate theme 3: Interpersonal stress is wedded to illness

Sub-themes: 3.1: Illness disrupts relationships, 3.2: Ignorance shown by others of illness and limitations leads to stress, 3.3: Abuse and illness.

Notes from initial coding: Intolerance, burden, lonely condition, needing physical cues, illness inconsistency, over-intellectualising, verbal abuse, financial abuse.

3.1. Superordinate Theme 1: The power of painful childhood experiences

All of the interviewees described difficult experiences in their formative years. Nine participants discussed experiences of emotional, physical and sexual abuse in childhood. Violence and alcoholism were often features of the family lifestyle. Chronic illness, bereavement and family trauma were also reported by five participants. Eight participants spoke of a childhood deprived of love:

> *There was a real resentment. And I was conscious, I am conscious that I'm thinking, 'what can I do to make my mum love me and want me and be proud of me?'* (Ella).

Above, Ella quickly switches from past to present tense. It is arguable that this tense change demonstrates that a desire for love endured from childhood to the present moment. Ella also reported that her mother's disdain left her feeling constantly "worried" and "anxious" as a child. Participants described how these experiences impacted upon them in other ways. For example, themes of powerlessness and exploitation were common. Esther's upbringing had a particularly traumatic effect on her childhood self:

> *I remember when I was four we used to have this song at school, 'how do you spell happy? H-a-p-p-y'. My little internal version was, 'how do I spell happy? D-e-a-t-h'. This was a four-year old! So I knew I was not an ordinary child.*

It seems, therefore, that these experiences had the potential to be psychologically harmful to the child. All participants described how painful childhood experiences affected them in adulthood. Connecting to the self and others in adulthood was a key theme; shattered trust and a strong sense of responsibility were frequently cited. According to some participants, difficult childhood experiences led to relationship vulnerability in adulthood. Early experiences were reported to affect coping. Childhood experiences influenced personal values; values associated with being a parent were particularly prevalent. Each sub-theme pertaining to this superordinate theme will now be outlined.

Sub-theme 1.1: Connecting to the self and others in adulthood

Five participants noted that painful childhood episodes had shattered their trust in others. In some circumstances, this impinged on family relations:

> *Because of my bad experiences in the past, I can't trust nobody else. So, like, my daughter has a new man in her life, I can't trust him* (Jess).

Two participants described how a difficult childhood affected their ability to maintain friendships:

> *It makes me very, very erm reluctant to make new friendships, to make new friends, to be near people. I'm actually quite antisocial* (Martin).

Martin recounted how childhood experiences influenced his reluctance to trust others and to create friendships:

> *If I started to talk about somebody at school and I mentioned what his name was, he would be pooh-poohed instantly and so there would be propaganda launched up against*

> *this poor child's name. So very quickly I learnt that he didn't want to be friends with me at all, he just wanted x, y and z. And rather than having the common sense at the time that I was being manipulated, I fell for it. And your parents are supposed to be the ones who look out for you, protect you and love you.*

It seems that not only was Martin deprived of the opportunity to develop social skills, he was also taught by his parents that others are manipulative and untrustworthy. One participant explained how past experiences had impacted upon how much she could trust her partner:

> *But there's still that barrier there with me over the trust issue because of what's happened with me. I'm always phoning him and checking up on him when he goes out and I know I shouldn't but it's because of what's happened in the past* (Anneka).

Two participants noted that their childhood influenced how they related to others insofar as shattered trust led to an inability to take people at face-value:

> *I have said, 'There is something I don't like. Something's not sitting right'. Or what have you, and it usually turns out that my initial intuition has been very, very correct. It could have been to do with having to judge people from such an early age* (Patricia).

Four participants noted that they had a strong sense of responsibility and this was associated with childhood adversity:

> *Because of all the things that happened in the past, I've just got to make sure that everybody is alright. A stray dog could walk past and I'd go out and give him a biscuit!* (Jess).

At a different point, Jess outlined a childhood experience that provided historical context to her inflated sense of responsibility:

> *My dad hit me round the nose. He hit me all the time. I was stubborn whereas my sister would cower. I got it a lot worse than she did but also she backed off a lot more.*

Jess described a dream that conveyed her childhood wishes:

> *When I was little, I had dreams that my dad was tied up, my mum was attacked in the front room. My dad was being murdered but I saved my brother and sister – they would be in the airing cupboard with me and I'd saved them. When I look back I think, what sort of child dreams that!*

Hence, Jess seems to have observed that a violent and unprotected childhood led to a profound desire to protect and rescue her siblings and this role continued into adulthood.

Linking to how childhood experiences affected one's relationship to the self, two participants explained that a strong sense of responsibility was tied to their identity:

> *When you look in the mirror, what do you see? Yes, I’ve put on loads of weight so who am I? And I don’t know. I don’t know if I have any feelings. I’m just lost in this multi-tasking woman who does all the catering down to the sheets. I don’t exist* (Sally).

During the interview, Sally explained that her extreme dedication and responsibility served to distract her from “what’s going on inside”. However, it seems that putting others first was unhelpful in that this role compounded a nebulous sense of self.

In terms of adult relationships, two participants observed how turbulent childhood relationships had increased their vulnerability. One participant suggested that she had internalised her mother’s open disdain for her. Consequently, she craved concrete demonstrations of love.

> *I knew my mum didn’t like me. I overheard conversations that she had with my dad… For a long time I think I confused having sex with people as people really loving me and wanting me and liking me for what I was* (Ella).

Similarly, another participant described how an abusive childhood lay the foundations of a difficult relationship trajectory:

> *Everything that has happened relationship-wise, I’ve always given everything but I hardly get anything back* (Angela).

Importantly, Angela goes on to demonstrate that her painful childhood experiences are not exclusively damaging:

> *Even though I've had bad relationships and experiences, the more they break you, the stronger you get and it's true.*

To summarise this sub-theme, five interviewees explained that they had difficulty trusting friends or loved ones and this was linked to early adverse experiences. This was usually motivated by a fear that pain would be inflicted on themselves or others. A sense of responsibility was cited by four participants. For three participants, this was born from a desire to protect and rescue, as experiences in childhood endorsed the belief that others were dangerous. Two participants reflected that a strong sense of responsibility and a desire to look after others compromised their sense of identity.

Sub-theme 1.2: Influence on coping

Nine participants described how their childhood affected coping in various ways. Three participants acknowledged that difficult childhood experiences had bolstered a sense of resilience and independence. One participant described how bereavement in childhood had destroyed the family unit:

> *My mum never let me say goodbye to my granddad. How do you cope with something like that at ten? Because it felt like, not only did I lose my granddad, I lost my whole family as well* (Anneka).

She later describes the impact of this experience on her ability to cope:

> *Most things that are thrown at me I can cope with because I suppose it's made me a stronger person.*

There is a distinct sense that a painful childhood influenced how emotions are coped with. This was discussed by five participants. One participant noted the effect that his relationship with his parents had on his current emotional capacity:

> *I quickly learnt that most things they were going to say were hurtful or unhelpful…I just learnt to turn the emotions off. So I don't feel stressed, I don't feel angry, I don't feel happy. I don't know what happiness is or anything like that* (Martin).

Four participants explained that their ability to cope had been marred by earlier experiences. An inability to self-soothe was a recurring comment:

> *Pretty much what I do every day is nothing. I don't think I do really cope. Like when I was 12 with the whole stomach thing… I'd blame mum, I'd go, 'It's all your fault, you're making me go through this'* (Janice).

In this instance, the participant seems to connect her current struggle to cope with her early fractured relationship with her mother.

To summarise this sub-theme, three participants acknowledged that their resilience had been bolstered by early adversity, whereas four participants felt that their ability to cope was marred by painful childhood experiences. Five participants reflected on their ability to cope with emotions.

Sub-theme 1.3: Shaping personal values

Six participants noted how difficult past relationships and experiences had shaped their personal values. The six participants voiced that these experiences seemed to have a particularly strong effect on values in relation to parenting:

> *It made me determined that I would be a really good parent. It made me determined that I would never ever, ever make Toby feel that he was unloved, that he wasn't wanted* (Ella).

It is important to note that personal values were not always a product of fractured relationships. One participant noted that a positive familial background had influenced her values:

> *My dad said, 'Mum, if you can't treat all the girls the same, don't treat any of them'. Which is really lovely that my mum and dad knew what was right and wrong. I think the Church and the foundations of what they taught us was a really good upbringing* (Sally).

Usefully, the above comment illustrates that the participants' experiences of childhood are not uniform. Linking to this, Esther offered an important reflection:

> *I think in terms of your research, it would be dangerous to think that everyone has the same relationship with their past. That's individual. And even the relationship you have with the past - that can change.*

Esther elaborated on this notion by explaining that personal values are also subject to change:

> *Since I became a Buddhist and practiced, I've forgiven my parents and that took a lot of time - that took years. Even the intention to forgive, that was enough. But I realised that any spiritual progress I was going to make, that would stop immediately unless I actually forgave.*

Overall, in terms of personal values, six participants expressed a desire to provide their own children with better experiences. One participant recognised that values and one's relationship to the past are fluid processes in that they are subject to change.

3.2. Superordinate Theme 2: The connection between stress and relating to others.

All participants reported that interactions with others can cause them stress in various ways and that they found these relationships highly damaging. A "vortex of stress" was a metaphor coined by Esther to sum up the experience of becoming trapped in a cycle of stress with others. However, four participants also noted that others sometimes eased difficulties, either by relieving stress or by building a sense of self-worth.

Sub-theme 2.1: Toxic relationships

All participants stated that people in their lives caused acute stress. The phrase "toxic" is employed to underscore how these relationships are perceived as predominantly damaging. Familial tensions were observed as a current source of stress by five participants. In these incidents, the family members are often described as possessing destructive qualities:

> *Oh, I get an absolute feeling of dread when I see my mum’s name on the phone. Oh when I see her on caller ID, knowing I have to see her or hear her voice, knowing she’ll make some stupid, unreasonable demand* (Martin).

Feeling chronically exploited or subjugated by loved ones was a theme that wove into the dialogues of five participants. In some circumstances, exploitation was described as a devastating experience:

> *I was really, really honest and good with somebody – she was staying at my house. She destroyed my relationship with Doug’s father. She took my house, she took my business, she took everything* (Anneka).

Jess explained that she was subjugated and felt that her family dismissed her needs:

> *They were standing in the kitchen the other day, my daughter-in-law, my son and my husband, and they were talking about selling my car; ‘She doesn’t use it anymore, might as well sell it’…‘You do realise I’m sitting here you know!’ ‘You don’t use your car!’ I said, ‘What’s that got to do with it, it’s my effing car! If I have my car rot out there I bloody well will!’*

Jess explained that feeling ignored by her family left her feeling exhausted and helpless. Similarly, Ella explained that feeling dismissed by others made her feel like a “nothing person”. Five participants that other people have the potential to make interviewees feel invisible or secondary.

To summarise this sub-theme, all the participants reported that relations with others could be destructive in numerous ways. Five participants explained that they were acutely associated with stress. Exploitation and subjugation were experienced in adulthood by five participants. Connected with this, these interviewees felt controlled, ignored or invisible.

Sub-theme 2.2: Stress as a vortex

A “whirling vortex” was a metaphor used by Esther to explain the process of getting sucked into and stuck in a stressful process with others. Participants commonly identified how others maintained or exacerbated stress. Connected to this sub-theme is the idea that significant others can fuel existing stress. This was described by four participants. The following example outlines a scenario whereby Anneka and her mother became trapped in a vicious cycle:

> *The DLA and the other new employment forms, they are an absolute nightmare and so stressful to fill out. And my mum and I clash over that. Yeah boy did we clash then, and I actually ended up in hospital because of them. My head and my blood pressure went through the roof and I felt my head was going to explode.*

Five participants described having a reactive response to stress, which in turn maintained the stressful situation. Janice discussed an experience whereby she received verbal abuse from a friend via the internet:

> *I went straight into anger mode. I just typed back a really quick like ‘eff off’ sort of reply. I got very annoyed with her and then told my boyfriend and all my friends and that and they got really annoyed about it* (Janice).

To summarise this sub-theme, the above examples illustrate that for nine participants, interactions with others did not resolve stress but intensified it. It appeared that a perceived lack of empathy from others and a reactive response were key factors that sustained a stress-vortex.

Sub-theme 2.3: Easing the struggle

In contrast to the above, some family members and friends were on hand to alleviate stress. Four participants recounted this experience:

> *My son is fantastic! He's been brought up with it. And he just sits there and says, 'Mmm. Yeah. I think there's a slight case of over-reacting here!' So then I just start laughing, he's very good and just diffuses it* (Ella).

In this example, humour is used to gain perspective. Relief is found in other ways; Esther described how she and her partner helped each other to climb out of a vortex of stress:

> *Acknowledging that it's nobody's fault, you're just in it. So there's no fault that's getting in the way, there's none of that stuff. And then just actually having the breathing space to get out* (Esther).

Four participants cited examples of support from others that brought relief from struggle:

> *I've always felt worthless. Always. I never had a good opinion of myself. I always thought that I was a freak. But my friends tell me I'm not a freak. I'm one of the nicest people they've ever met* (Angela).

To summarise, four participants noted that the presence of others eased difficulties, either by relieving stress or by building a sense of self-worth.

3.3. Superordinate theme 3: Interpersonal stress is wedded to illness.

All the participants considered how stress with others is connected to illness. Interviewees acknowledged and gave examples of the ability of FMS to disrupt relationships in various ways. For example, seven participants noted familial intolerance of illness could increase distress. Three participants mentioned that they felt like a burden to loved ones. In turn, a profound sense of loneliness sometimes emerged. Others' ignorance of one's limitations or illness also heightened a sense of alienation, loneliness and frustration in three participants. Five participants observed that the vulnerability associated with illness made them susceptible to abuse. The sub-themes are outline below.

Sub-theme 3.1: Illness disrupts relationships

The following reflection from Nathan encapsulates this theme:

> *I think it can wreck, I heard it can wreck relationships. For me that’s the cruelty of the disease. It can take without giving back.*

Seven participants described how many people in their lives were intolerant of the illness. This would manifest in various ways, for example, by trying to “solve” or over-intellectualise the condition:

> *I was going through these emotions and this weepiness and I don’t think my daughter [pause] ‘why don’t you get some antidepressants?’ She used to try and tell me what fibromyalgia was and you can get pissed off with that* (Nathan).

An intolerance of illness arose in other ways, for instance, loved ones were quoted as telling participants that their illness was “all in the mind”. Participants described conversations about the illness sometimes being avoided by loved ones, as if it did not exist.

Three participants described feeling like a burden to loved ones. Feeling burdensome led to a number of consequences, including self-inflicted isolation. It also generated fears by sufferers that they would be abandoned. One participant described how feeling this way encouraged her to seek reassurance from friends, however, upon receiving it she doubted the sincerity of their remarks:

> *I don’t know if they get annoyed because I can’t do things. I say, ‘Am I a burden on you?’. They go, ‘No, no, no’, out of politeness. If someone asked them in private, you know, about being a burden, I reckon they’d say, ‘Yeah’* (Janice).

Seven participants described fibromyalgia as a lonely condition. Angela explained that a fear of inflicting her suffering on others leads to isolation:

> *The pain makes me really stressful. It makes me really impatient, really anxious and that's why I like to spend a lot of time on my own because I'm miserable.*

Janice observed that an inability to receive help from others fuelled her isolation:

> *What can they do about it? Nothing. So it's better just to go off and cry by yourself really.*

Various other participants echoed this preference for isolation. In one severe circumstance, illness led to the collapse of a relationship:

> *I mean his dad left us because of my illness. He met somebody else. He said that he wanted a better quality of life that he couldn't get from me. What a bastard* (Ella).

In summary, this sub-theme demonstrates that illness can disrupt relationships in various ways; seven participants remarked that a loved one can find it intolerable, it engendered a fear of being a burden in three participants and it can forced seven participants into an isolated position.

Sub- theme 3.2: Ignorance of illness and limitations leads to stress

Three participants felt that others' ignorance was intensified by the invisibility and inconsistency of the condition:

> *One time I was in ASDA, I'd forgotten my crutches, the sweat was pouring down me and I was going dizzy. And because of the fact I didn't have a crutch or anything with me, I didn't get any help with packing or anything* (Anneka).

Such descriptions were often coupled with a sense of deep frustration and a craving for understanding. Janice explained that ignorance manifested in other ways:

> *It was horrible. I was in the wheelchair and I remember this girl. She must have been about 12. She went to her friend and said, 'Oh just look at her in the wheelchair! Don't you just want to take her home!'*

In this example, Janice's illness was exaggerated, leading to a patronising, inappropriate reaction. Hence, some participants became stressed by others' minimisation or inflation of their illness severity.

Sub-theme 3.3: Abuse and illness

Five participants observed that their illness had left them open to abuse from loved ones. Jess explained how the mental confusion associated with FMS rendered her vulnerable:

> *I feel like my kids are abusing me because they can. There is nothing I can do. Strength-wise, I can't do nothing about it. I get confused. If I get upset, I get really confused so they can say, 'Oh no, we did give mum a tenner'.*

In this instance, Jess explained that distress and confusion can interact, leaving her particularly open to exploitation.

To summarise this superordinate theme, it appears that interpersonal stress is wedded to illness in various ways. Seven interviewees explained that the illness itself can disrupt or ruin relationships. Three participants remarked that others' limitations in outlook, especially their ignorance of the participants' illness, can exacerbate stress. Similar to the impact of painful childhood experiences, five participants illustrated that FMS can increase vulnerability in adult relationships.

Taken together, the superordinate themes illustrate the complex connections between childhood adversity, how others are connected to in adulthood and interpersonal stress and illness. Although relations with the self and others were investigated, how participants related to others was more frequently discussed. Relating to the self was touched upon in subtler ways. For example, childhood experiences caused one participant to crave obliteration of the self. Childhood experiences could also affect how one related to their own emotions, according to five participants. Furthermore, it was noted by three participants that feeling dismissed or controlled by others had the power to extinguish a sense of self.

4. Discussion

The three superordinate themes, "the power of painful childhood experiences", "the connection between stress and relating to others" and "interpersonal stress is wedded to illness" are interlinked. These categories represent the experiences of relating to the self and others amidst living with FMS. The results will be considered in light of the original research questions and in the context of existing theory and research.

Drawing upon attachment and mentalization theory can aid understanding of the psychosocial and intrapsychic experiences outlined by the participants in this study (Bowlby, 1969; Fonagy, 2000). Literature pertaining to fibromyalgia, attachment and mentalization will therefore be explored in this section.

4.1. How do participants with FMS recount experiences of relationships in childhood?

In keeping with the literature, participants described adverse early experiences in childhood. According to Häuser et al. (2011), there is a significant correlation between childhood physical and sexual abuse and FMS. Nine interviewees noted that their childhoods were characterised by abuse. Five accounts were described whereby parental violence and alcoholism were witnessed. Three participants disclosed sexual abuse in childhood. Other adverse experiences were cited by four participants, including extreme illness or family bereavement. Eight participants found their childhoods to be a deeply troubling time, which installed a sense of being worthless or unlovable. One participant recounted that her disturbing childhood experiences led her to crave death. These results corroborate Hallsberg and Carlsson’s (1998) findings; in their grounded theory study, women also described complicated and chaotic childhoods.

Childhood experiences of emotional abuse were commonly described (eight participants). Six interviewees spoke of being directly insulted or ignored by key attachment figures. Experiences of being controlled, exploited or manipulated were also cited. There was a sense that emotional abuse was highly destructive and that participants could feel “destroyed” with words. These experiences contrasted with the findings of Häuser et al.'s (2011) meta-analysis, whereby childhood emotional abuse was not found to be associated with FMS. However, studies included in the meta-analysis did not operationalise emotional abuse and therefore this construct may not have been accurately captured in previous studies. Moreover, study quality was largely poor.

4.2. What are participants' perceptions about how past experiences influenced the present?

Interviewees indicated that childhood experiences affected how others were connected to in adulthood. A recurring theme related to the inability to trust others in the present. Early experiences of abuse seemed to contribute to distrust. This finding corresponds with existing research in that insecure attachment has been associated with difficulties in trusting others (Mikulincer, 1998).

One participant explained that her abusive experiences taught her to be hypersensitive and to "weigh people up". Asen and Fonagy (2012) argued that an uncontaining familial environment can cause some individuals to compensate for their parents' lack of mentalization. This can culminate as excessive efforts to know the mental states of others (pseudo-mentalization), however, such "mentalizing" is prone to inaccuracies. It is possible that early uncontaining experiences affected how participants perceived others in adulthood.

Four participants described having a strong sense of responsibility and spoke of a desire to protect or put others first in adulthood. One participant outlined how this trait developed from feeling vulnerable as a child, from a desire to protect others and from growing up in a perfectionist environment. This result links to findings described by Wentz et al. (1998); these authors theorised that feeling unprotected during childhood led to a high sense of responsibility in adulthood.

A common theme was that childhood experiences increased relationship vulnerability in adulthood. Linking to this finding, turbulent childhood attachments have been found to predict higher rates of physical and psychological violence in adult relationships (Henderson, Bartholomew, Trinke, & Kwong, 2005). As noted in the results section, one participant explained she was unconvinced that she was loveable in adulthood and consequently she considered sex as evidence of affection. She reflected that a lack of love in childhood fuelled this perspective. Fonagy (2000) has elaborated on this thinking style, arguing that it represents a particular mentalization deficit known as a “teleological stance”; some individuals seek physical cues in order to understand the intentions of others.

Nine participants described how their childhood experiences affected their ability to cope. During early development, if comfort and soothing are limited from a caregiver, then the child is not given the opportunity to internalise these skills. In turn, one’s ability to self-soothe and mentalize can be limited (Fonagy & Luyten, 2009). In keeping with mentalization research, it was acknowledged by some participants that a lack of support in childhood led to a limited ability to cope with stress in adulthood.

As noted in the results section, participants described a variety of experiences in relation to the impact of childhood on current stress. A theme that arose from the data was that adverse experiences had the potential to enhance one’s ability to cope, as expressed by three participants. Similarly, the results demonstrate that adversity can motivate individuals to relate meaningfully to others, for example, by being a loving, supportive parent. This was described by six participants. The understanding of coping in relation to FMS has been explored both qualitatively and quantitatively (for example, Hallberg & Carlsson, 2000; Nielson & Jensen, 2004). However, as of yet the literature has not explored how adversity can have a positive influence on one's values or ability to cope in those with FMS.

4.3. How do participants with FMS experience relationships with the self and others presently?

Seven participants reported that others were sometimes intolerant of their illness, distress or uncertainty. For instance, others might instruct the sufferer to get medication or participants were told that their illness is "in the mind". This would lead to a feeling of invalidation. Soderberg, Lundman and Norberg (1999) noted similar experiences in their phenomenological study; the authors interpreted that not being given the opportunity to express oneself was experienced as a violation of human dignity.

Three participants explained that their illness made them feel burdensome to friends and partners. This led to fears of rejection, isolation and an inability to feel reassured. This is in agreement with Paulson, Danielson and Soderberg (2002), who found that a fear of appearing like a burden created a gulf between the sufferers and others.

Loneliness was an experience described by seven participants. Examples of what caused isolation and loneliness included the following: A desire to protect others from one's own suffering, knowing that others are powerless to help and feeling rejected by former friends. This finding supports Kool and Geenan's (2012) study, whereby participants with FMS reported significantly higher rates of loneliness compared to controls. This appears supportive of Wentz et al.'s (2004) qualitative study, which found that emotional support was withdrawn at the emergence of symptoms. Asbring and Narvanen (2002) also found that sufferers withdrew from social circles as a means of avoiding the demands of others.

Discussions regarding emotions illuminated how five participants related to the self. Interviewees repeatedly described “turning off” emotions; an absence of emotions has been described as alexithymia (Sifneos, 1973). Alexithymia has often been associated with growing up in an unresponsive or unempathic environment (Kooiman, Spinhoven, Trijsberg, & Rooijmans, 1998). This result is in line with other findings – research has shown that alexithymia is associated with FMS (Evren, Evren, & Guler, 2006). It has been theorised that alexithymia functions to regulate emotions. However, as this strategy relies on avoidance, this can lead to an exacerbation of pain and distress (Van Middendorp et al., 2008).

As noted, the aetiology of FMS is mysterious and a definite causal pathway has not been established. The present results suggest a hypothesis for the aetiology of FMS, although as no control group was established, these observations are tentative. All participants described formative experiences that may have fostered an insecure attachment style (Hallberg & Carlsson, 1998). In turn, the ability to mentalize and to self-soothe may have been disrupted.

In contrast to other chronic pain conditions, it is possible that a hampered ability to mentalize or to self-soothe may maintain or provide a unique causal pathway to FMS. For instance, one participant wondered whether an inability to understand her emotions may have forced her to physically express the pain that had been inflicted upon her in her childhood.

An alternative aetiological consideration is possible, which links into existing theory about the causal role of the HPA system. It has been posited that that FMS may develop when the HPA axis system rapidly switches from “under-drive” to “over-drive” after exposure to intense stress (Van Houdenhove & Luyten, 2007); if the ability to understand one’s own emotions and self-soothing skills are disrupted, then stressful events will be experienced more intensely, for a longer duration and will be harder to recover from (Kring & Sloan, 2009). It is possible that a reduced ability to manage stress leads to a gradual erosion of the HPA axis system.

In discussing current relationships, all participants discussed how some relations were destructive; interviewees spoke of being exploited, subjugated and controlled and these narratives often seemed to echo childhood experiences. This result links to attachment theory; a person’s early experiences can develop an interpersonal prototype that endures throughout one’s lifetime (Ainsworth & Bowlby, 1991).

From the experiences described, it is possible that people with FMS have an internalised sense that others are untrustworthy, controlling or dangerous. Hence, rather than buffering stress, others may be more likely to exacerbate stress. This increase in stress may contribute to the condition (again by overwhelming the HPA axis system) or may maintain the condition. It is possible that this relational style is unique to people with FMS, however, further research is needed to explore this hypothesis.

It is important to highlight that relationships could be deeply constructive as well as destructive. Family members, partners and friendships were viewed as important in easing struggle by four participants. The value of support has also been recognised in Wuytack and Miller’s (2011) study.

4.4. Overall Summary

This research adds to the understanding of how people experience relating to the self and others amidst living with FMS. All participants' childhoods were often characterised by parental discord, abuse, illness, family trauma or bereavement. Early experiences of fear and powerlessness potentially led to consequences in adulthood. For example, five participants stated that their ability to trust others was shattered and a strong sense of responsibility could be fostered in four participants**.**

Experiences of relating to the self were affected by childhood events. For example, it is possible that an invalidating childhood environment led to an impaired ability to cope with stress and to comprehend and manage one's own emotions. This is in agreement with existing mentalization research.

In the present, five participants remarked that relations with others could be fraught and sometimes involved exploitation and abuse. Seven participants claimed that interpersonal stress was wedded to illness in that others' were intolerant or invalidated distress or had limited insight of the suffering experienced. Illness led to isolation and increased vulnerability to abuse for five participants. In analysing the data, it was helpful to draw on literature pertaining to attachment theory, mentalization and fibromyalgia.

5. Limitations

IPA has limitations in that it relies on small participant groups. However, the aim of phenomenological studies is not to decipher generalisable results but to explore and understand human experience (Husserl, 1975). If results were to be generalised, the study would requires a significantly larger sample and a control group.

All participants were recruited within a pain management service. Hence, support from services was being sought and the participants were aware that they would be asked to talk about feelings and experiences. The participant group is biased in that interviewees may have greater needs than other people with FMS. It would be useful if future studies explored the experiences of those not engaged in pain management services.

In keeping with IPA guidelines, the study was relatively homogenous, as all participants had a diagnosis of FMS (Smith et al., 2009). However, there was a large amount of divergence. For example, there was a broad age range (between 20 and 63) and participants were from different socio-economic backgrounds. It may have been useful to employ an all female sample, as FMS predominantly affects females (White, Speechley, Harth, & Ostbye, 1999). Hence, a possible criticism of this study is that there was significant variance in the sample.

IPA relies on conscious reports of interviewees. Hence, unconscious narratives cannot be commented on (Clark & Hoggett, 2009). Therefore, this project only represents one angle of experience. It may have been useful to analyse body language, facial expressions and voice tone in order to provide a richer data set.

6. Future research

The results of the present study suggest several directions for research. It is possible that some of the interviewees may have demonstrated an insecure attachment style (for example, through their inability to trust others). Reflective function (RF) lies behind one's ability to mentalize; it is the skill of interpreting others' mental states (Fonagy & Luyten, 2009). Arguably, participants sometimes displayed deficits in RF. For instance, a reduced ability to self-soothe may be indicative of reduced RF. Currently, RF and attachment have not been fully investigated via quantitative methodology in people with FMS. Hence, one important research question may be, do people with FMS have different attachment styles or RF compared to the normal population?

In the present study, participants' childhoods were often characterised by criticism, control, neglect and a lack of love from caregivers. Prior studies that have explored emotional abuse and FMS have largely been poor in quality (Häuser et al., 2011). Hence, it is important that future studies more stringently observe the correlation between emotional abuse and FMS.

7. Clinical Implications

The analysis points towards several possibilities for clinical improvements. At present, no guidelines are endorsed by NICE (National Institute for Health and Clinical Excellence) as to how FMS should be treated psychologically. The current research tentatively hypothesises a link between mentalization deficits and FMS. It is therefore possible that mentalization-based treatment may be useful for some individuals with FMS. The research also highlighted that significant others could aid coping and could relieve stress. For some service-users with FMS it may be suitable to employ a systemic focus, which aims to strengthen or to underscore the importance of positive relationships. It would be useful if clinical research explored the effectiveness of these therapeutic options.

It would be potentially beneficial if alexithymia were given greater attention in a clinical context. Interventions that aimed to bolster emotional processing or expression could lead to improved health in those with FMS. Studies have demonstrated that focussing on alexithymia in other physical and mental health conditions can lead to clinical improvements (Beresnevaite, 2000; Graugaard, Holgerson, & Finset, 2004; Lumley, 2004).

The results suggest that other people can often find illness and suffering intolerable and in turn participants’ distress was invalidated. Therefore, it is crucial that clinicians aim to validate peoples’ experience in the face of societal stigma. Interviewees noted that their experiences affected their ability to trust others. When treating people with FMS, it would be helpful if clinicians remained mindful of service-user’s interpersonal needs, for example, by paying particular attention to providing a containing environment.

8. Conclusion

The aim of the present study was to understand how people with FMS experienced relating to the self and others. The study demonstrated that the participants experienced troubled relationships in their childhood, which sometimes created difficulties in later life. On the other hand, adversity also led to the strengthening of character. Relationships in the present were sometimes described as “toxic”. However, interviewees sometimes noted that loved ones could be an invaluable source of support.

The ability to cope was a key theme that revealed how participants related to the self. Many participants explained that they had trouble self-soothing when facing stress. That is, they often felt overwhelmed by stress and some felt that they had an inability to cope. This finding supports the argument that FMS is a "stress related pain syndrome" in that stress may play a causal or maintaining role (Luyten & Van Houdenhove, 2013). Interviewees' experiences of emotions also link to the question of how the self was related to; participants often described feeling cut-off from an emotional self. Other people were described as having the ability to distort the participants' sense of self in that a sense of responsibility and feeling dismissed could make one feel invisible.

This study is limited by potential biases in sampling and by the data collected. Future research should investigate RF and attachment styles in those with FMS compared to a control group. The effect of emotional abuse in childhood also requires further exploration. In order to support people with FMS fully, it is important that clinicians validate the experience of pain and remain mindful of peoples' unique interpersonal needs.

9. References

Ainsworth, M. D. S., & Bowlby, J. (1991). An ethological approach to personality development. *American Psychologist, 46,* 331-341.

Asbring P., *&* Narvanen A.L. *(*2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research, 12,* 148–160.

Asen, E., & Fonagy, P. (2012). Mentalization-based therapeutic interventions for families. *Journal of Family Therapy, 34*, 347-370.

Bartels, A., & Zeki, S. (2000). The neural basis of romantic love. *Neuroreport, 11*, 3829-3834.

Beresnevaite, M. (2000). Exploring the benefits of group psychotherapy in reducing alexithymia in coronary heart disease patients: A preliminary study. *Psychotherapy and Psychosomatics*, *69*, 117-122.

Bergman, S. (2005). Psychosocial aspects of chronic widespread pain and fibromyalgia. *Disability and Rehabilitation, 27,* 675–683.

Bowlby, J. (1969). *Attachment and loss.* New York: Basic Books.

Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development.* London: Routledge.

The British Psychological Society. (2009). Code of ethics and conduct. Retrieved from http://www.bps.org.uk/document---download...64&ext=pdf.

Clark, S., & Hoggett, P. (2009). Researching beneath the surface: A psycho-social approach to research practice and method. In S. Clark & P. Hoggett (Eds.) *Researching beneath the surface: Psycho-social research methods in practice*. London: Karnac.

Clauw, D., & Chrousos, G. (1997). Chronic pain and fatigue syndromes: overlapping clinical and neuroendocrine features and potential pathogenic mechanisms. *Neuroimmunomodulation, 4,* 134-153.

Cunningham, M. M., & Gillings, C. (2006). Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research, 15,* 258–273.

Dailey, P., Bishop, G., Russell. A., & Fletcher, E. (1990). Psychological stress and the fibrositis/ fibromyalgia syndrome. *Journal of Rheumatology, 17,* 1380-1385.

Davis, M. C., Zautra, A. J., & Reich, J. W. (2001). Vulnerability to stress among women in chronic pain from fibromyalgia and osteoarthritis. *Annals of Behavioral Medicine, 23,* 215–226.

Epstein, S., Clauw, D., Klein, D., Kuck, J., Masur, D., & Waid, R. (1999). Psychiatric disorders in patients with fibromyalgia. *Psychosomatics, 40,* 57-63.

Evren, B., Evren, C., & Guler, M. (2006). Clinical correlates of alexithymia in patients with fibromyalgia. *The Pain Clinic, 18,* 167–173.

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology and Practice, 3,* 6-25.

Fonagy, P. (2000). Attachment and borderline personality disorder. *Journal of the American Psychoanalytic Association*, *48*, 1129-1146.

Fonagy, P., & Bateman, A. (2006). Mechanisms of change in mentalization based treatment on patients with a borderline personality disorder: Mentalization based treatment of BPD. *Journal of Clinical Psychology, 62,* 411-430.

Fonagy, P., Gergely, G., Junst, E., & Target, M. (2002). *Affect regulation, mentalization, and the development of the self.* New York: Other Press.

Fonagy, P., & Luyten, P. (2009). A developmental, mentalization-based approach to the understanding and treatment of borderline personality disorder. *Development and Psychopathology, 21,* 1355-1381.

Gran, J. T. (2003). The epidemiology of chronic generalized musculoskeletal pain. *Best Practice and Research: Clinical Rheumatology, 17,* 547-561.

Graugaard, P., Holgerson, K., & Finset, A. (2004). Communicating with alexithymic and non-alexithymic patients: an experimental study of the effect of psychosocial communication and empathy on patient satisfaction. *Psychotherapy and Psychosomatics, 73*, 92-100.

Hallberg L. R. M., & Carlsson S. G. (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Sciences, 12*, 95–103.

Hallberg. L. R. M., & Carlsson, S. G. (2000). Coping with fibromyalgia: A qualitative study. *Scandinavian Journal of Caring Sciences, 14,* 29-36.

Häuser, W., Kosseva, M., Üceyler, N., Klose, P., & Sommer, C. (2011). Emotional, physical, and sexual abuse in fibromyalgia syndrome: A systematic review with meta-analysis. *Arthritis Care & Research, 63,* 808–820.

Henderson, A., Bartholemew, K., Trinke, S., & Kwong, M. (2005). When love means hurting: An exploration of attachment and intimate abuse in a community sample. *Journal of Family Violence, 20,* 219-230.

Hill, E., Young, J., & Nord, J. (1994). Childhood adversity, attachment security and adult relationships: A preliminary study. *Ethology and Sociobiology, 15,* 323-338.

Husserl, E. (1975). *Introduction to the logical investigations*. The Hague: Nijhoff.

Kooiman, C., Spinhoven, P., Trijsburg, W., & Rooijmans, H. (1998). Perceived parental attitude, alexithymia, and defence style in psychiatric outpatients. *Psychotherapy and Psychosomatics, 67,* 81-87.

Kool, M., & Geenen, R. (2012). Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *Journal of Psychology, 146*, 229-241.

Kring, A., & Sloan, D. (2009). *Emotional regulation and psychopathology: A transdiagnostic approach to etiology and treatment*. New York: Guilford Press.

Lumley, M. (2004). Alexithymia, emotional disclosure, and health: a program of research. *Journal of Personality, 72,* 1271-1300.

Luyten, P., & Van Houdenhove, B. (2013). Common and specific factors in the psychotherapeutic treatments of patients suffering from chronic fatigue and pain. *Journal of Psychotherapy Integration, 23*, 14-27.

Mengshoel, A. M., & Heggen, K. (2004). Recovery from fibromyalgia - previous patients' own experiences. *Disability and Rehabilitation, 26*, 46-53.

Mikulincer, M. (1998). Attachment working models and the sense of trust: An exploration of interaction goals and affect regulation. *Journal of Personality and Social Psychology, 74,* 1209-1224.

Nielson, W., & Jensen, M. (2004). Relationship between changes in coping and treatment outcome in patients with fibromyalgia syndrome. *Pain, 109*, 233-241.

Paras, M., Hassan, M., Chen, L., Goranson, B., Sattler, A., Colbenson, K., Elamin, M. B., Seime, R. J., Prokop, L. J., & Zirakzadh, A. (2009). Sexual abuse and lifetime diagnosis of somatic disorders: A systematic review and meta-analysis. *The Journal of the American Medical Association, 302*, 550-561.

Paulson, M., Danielson, E., & Soderberg, S. (2002). Struggling for a tolerable existence: The meaning of men’s lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research, 12*, 238-251.

Råheim M., & Håland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research, 16*, 741–761.

Shuster, J., McCormack, J., Pillai Riddell, R., & Toplak, M.E. (2009). Understanding the psychosocial profile of women with fibromyalgia. *Pain Research and Management, 14,* 239-245.

Sifneos, P. (1973). The prevalence of “alexithymic” characteristics in psychosomatic patients. *Psychotherapy and Psychosomatics, 22*, 255-262.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: Sage Publications.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods.* London: Sage.

Söderberg, S., Lundman, B., *&* Norberg, A. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia*. Qualitative Health Research*, *9,* 575–587.

Van Houdenhove, B., Luyten, P., & Egle, U. (2009). Stress as a key concept in chronic widespread pain and fatigue disorders. *Journal of Musculoskeletal Pain, 17,* 390-399.

Van Middendorp, H., Lumley, M., Jacobs, J., Van Doornen, L., Bijlsma, J., & Geenen, R. (2008). Emotions, emotional approach and avoidance strategies in fibromyalgia. *Journal of Psychosomatic Research*, *64*, 159-167.

Wallace, D., & Clauw, D. (2005). *Fibromyalgia and other central pain syndromes*. Philadelphia: Lippincott Williams & Wilkins.

Weissbecker, I., Floyd, A., Dedert, E., Salmon, P., & Sephton, S. (2006). Childhood trauma and diurnal disruption in fibromyalgia syndrome. *Psychoneuroendocrinology, 31*, 312-324.

Wentz, K., Lindberg, C., & Hallberg, L. (2004). Psychological functioning in women with fibromyalgia: A grounded theory study. *Health Care for Women International, 25,* 702-729.

White, K.P., Speechley, M., Harth, M., & Ostbye, T. (1999). The London fibromyalgia epidemiology study: The prevalence of fibromyalgia syndrome in London, Ontario. *Journal of Rheumatology, 26*, 1570-1576.

Wolfe, F., Ross, K., Anderson, J., Russell, I., & Hebert, L. (1995). The prevalence and characteristics of fibromyalgia in the general population. *Arthritis and Rheumatism, 38,* 19-28.

Wuytack, F., & Miller, P. (2011). The lived experience of fibromyalgia in female patients: A phenomenological study, *Chiropractic and Manual Therapies, 19,* 1-9.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.) *Qualitative Methodology: A practical guide to research methods. Second edition.* London: Sage.

SECTION C: CRITICAL APPRAISAL

Word Count: 2000 (plus 43 words)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

SEPTEMBER 2013

DEPARTMENT OF APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Overview

This critical appraisal will be organised around four key questions.

Question 1: What research skills have you learned and what research abilities have you developed from undertaking this project, and what do you think you need to learn further?

In previous research, I have tended to work quantitatively, as I enjoyed the certainty that this methodology afforded. Knowing this, I actively selected a qualitative approach, as I hoped it would challenge me to develop new research skills and to better understand different epistemological positions.

I am particularly pleased with the skills I have gained from designing and developing a research project. Prior to this project, I had not had the opportunity to liaise with service-users for research purposes. Due to my lack of experience, I felt unconfident about contacting and working with service-users in a non-therapeutic manner. I found the service-user group to be reassuringly friendly, informative and keen to be involved. This experience bolstered my confidence and my ability to effectively liaise with others. I will endeavour to include service-user input from the earliest stages of future research.

Working through the NHS ethical approval process was also a new experience; I learnt some key skills from this process. For example, I felt that explaining my research to a committee enhanced my confidence, presentation and communication skills.

I believe that my reflexive abilities have been built upon from conducting this research project. I realised that it was essential to carefully document my experiences in a reflective journal. A close relative of mine suffers from constant fatigue and chronic pain and I am aware that she has had some difficult life and familial experiences. At one point during transcription, I became tearful and by writing my thoughts down, I was able to reflect on how the interviewee's words mirrored my relative's experience.

As well as helping me view parallels with my own life, a diary enabled me to maintain distance. That is, by bringing my own experiences into consciousness I was able to separate my own experiences from those of the interviewees (Halling, Leifer, & Rowe, 2006).

Conducting research interviews was a new skill for me. During my first interview, I connected well with the participant. However, I realised that I had some difficulty maintaining a "researcher" stance and sometimes drifted into a "therapeutic" stance (Finlay, 2009); the interviewee became distressed at a number of times throughout the interview and I found it challenging to establish clear boundaries about my role. On reflecting on and listening to the interview, it became apparent that it may have been useful if I limited my use of therapeutic language and techniques.

Throughout the process of conducting interviews, I became increasingly confident at taking a "researcher" position and establishing the parameters of this role. I also realised that I needed to keep more appropriate time boundaries, as the first interview was particularly long. Furthermore, I became more confident and skilled at allowing the participant to guide the direction of the interview (Larkin, Watts, & Clifton, 2006) and at providing a competent debrief (Hopf, 2004).

When analysing the data, I found this to be one of the most challenging and uncertain phases of the research. I found the coding stage particularly overwhelming and I was surprised by how time-consuming this task was. I realised, however, that devoting time and rigour to the coding was crucial. Afterwards, I was highly immersed in the data and observing emerging themes felt intuitive. I will attempt to maintain this commitment to rigour when conducting future qualitative research (Yardley, 2008).

Although I have learnt a great deal about IPA, I would very much like to consolidate my research skills in the future. From conducting this research project, I have greatly enhanced my understanding of phenomenological epistemology. However, I would like to continue to learn about the philosophical underpinnings of IPA (Husserl, 1975). I would like to bolster my abilities by branching out into different qualitative domains, for example, by using grounded theory.

Question 2: If you were able to do this project again, what would you do differently?

The sample was somewhat homogenous in that participants all had received a diagnosis of fibromyalgia (FMS). However, it is arguable that divergence within the sample was significant, in that the age and economic range was broad, and the study involved participants of both sexes. It may have been useful to only have employed female participants, as this would have been more in keeping with Smith et al.'s (2009) recommendation to maintain homogeneity in the sample.

I would have considered the incorporation of participant validation into the analysis (Reid & Gough, 2000). A potential benefit of participant validation is that it may have opened up discussion about how well balanced my interpretation was (Smith, Flowers, & Larkin, 2009).

However, I acknowledge that the analysis reflects my own interpretation of the transcripts and therefore the usefulness of participant validation is debatable (Horsburgh, 2003).

I met all participants on one occasion. I was consistently surprised and humbled by how much participants opened up during the interview, as extremely difficult experiences were often shared. Given that these interviews were often an emotional experience and they tapped into difficult memories, I am pleased that I chose to offer participants the opportunity to get in touch with me for three days after the interview. However, if I could repeat the process, I would have liked to have offered two interviews on different occasions. This may have felt like a more containing experience for the participant and a deeper discussion may have ensued (Smith et al., 2009).

It may have been useful to have incorporated a systemic element into to the research. If I could repeat the project and if I was less confined by time restraints, I would also have collected data from family members or partners. This may have provided a richer interpretation or led to the emergence of additional themes. If a larger amount of time was available, this form of triangulation may have produced interesting results (Burns & Grove, 2001).

At times, I found the amount of data collected to be overwhelming. At one point, I felt troubled that I could not adequately represent all participants and all perspectives. The transcripts were saturated with psychological concepts and themes that more attention could have been given to (for example, existentialism, recovery). However, due to the brevity of my dissertation, I did not have the opportunity to elaborate further.

Excellent research supervision helped me to focus my analysis and to accept the limited scope I had to represent all potential themes. Perhaps it would have been useful if I limited how much data I collected in order to reduce a sense of being overwhelmed. In order to hone analytic skills, Smith et al. (2009) recommend that researchers should begin with small participant groups; I would consider this recommendation for future research.

Remaining reflective was highly important and it felt crucial to “bracket off” my experiences and assumptions (Yardley, 2008). However, in hindsight it is possible that I could have reflected upon my experiences to a greater extent. I felt incredibly emotionally moved by the tragic experiences that were shared with me. Hence, it is possible that my strong emotional reaction influenced my interpretations, in that these painful experiences stood out to me as highly significant. Perhaps if I allowed greater emotional distance, more positive themes may have arisen to the surface. In the future, I will aim to be more mindful of my emotional reactions, by having further conversations with my supervisors about this potential bias.

Question 3: Clinically, as a consequence of doing this study, would you do anything differently and why?

I intend to work in a chronic pain setting in the future and I feel that conducting this research has illuminated how I may adjust my clinical practice in various ways.

I conducted all research interviews in the participants’ home. This felt like a privileged experience and I often felt like a welcomed guest. I believe that this setting, along with the disrupted therapist-client binary, adjusted the power dynamics between the participants and me. I felt that they conversed with me openly and critically, and because of this, participants were able to offer comments about how they related to psychology. As noted in the results, Esther remarked,

> *I think in terms of your research, it would be dangerous to think that everyone has the same relationship with their past. That's individual. And even the relationship you have with the past - that can change.*

This sentence had a profound effect on me. When working in a clinical setting, Esther's advice taught me to not make assumptions about people's historical context and to value people's unique experiences, rather than falling back on generalisations.

Many participants spoke of feeling invalidated and disrespected by health professionals. Barriers encountered were discussed during the interviews, for example, having to walk a long distance from a car park to the hospital, uncontaining therapeutic environments and insensitive appointment letters. These comments have taught me to be particularly mindful of the needs of those with chronic pain and I will endeavour to encourage sensitivity when working in pain management teams in the future.

From extensively listening to and analysing the transcripts, I began to notice subtle aspects of my communication style that I had previously overlooked. For example, I noticed that I could be overly talkative when I was introducing myself to participants and I occasionally seemed uncomfortable with silences. Since conducting the research, I have paid greater attention to my communication style. Within sessions, I have reflected upon whether speaking at certain times is therapeutically useful. Since the research project, I have also made the decision to audio-record all my sessions. I have noted that listening to audio-recordings permits a far more detailed understanding of the session.

Along with the audio-recordings, the use of a reflective journal has taught me to pay greater attention to the role of transference and counter-transference in a clinical context. I experienced a dramatic range of emotional responses throughout the interviews. For example, at different points in the interviews I observed that I felt warmth, confusion, rejection and irritation.

In one difficult incident, I left feeling as if I had been positioned in an abusing role, as the participant had seemed uncomfortable with both the interview questions and my presence. Subsequently, she finished the interview early and a full debrief was not possible – this left me feeling extremely guilty.

A reflective diary allowed me to consider that I may have been unconsciously empathising with the participant who explained that she felt intensely burdensome to her friends and family; consequently, she experienced an overwhelming sense of guilt (Gabbard & Wilkinson, 2000). Because of these experiences, I now spend more time in supervision reflecting on the therapeutic process and the potential sources of strong feelings.

Question 4: If you were to undertake further research in this area, what would that research project seek to answer and how could you go about doing it?

From conducting the project, several future research avenues appear possible. I believe that a quantitative investigation into the attachment styles of people with FMS would be a crucial study. The Adult Attachment Interview could be used to measure attachment styles (George, Kaplan, & Main, 1985). It would be useful if the outcomes from the experimental group were compared to a control group.

The ability to keep in mind the mental states of others (reflective function) is considered to be related to attachment styles (Fonagy & Target, 1997). Hence, it may also be important to compare the reflective function of people with FMS to a control group. If different attachment styles or reflective function abilities were evident, then this result would have valuable clinical implications; treatment may be adapted to adjust to one’s mentalization abilities and attachment needs.

The results of the study fit with the current research, which suggests that people with FMS have decreased abilities to understand and articulate emotions (Evren, Evren, & Guler, 2006). Hence, a pertinent future research question may ask, “How do people with FMS respond to treatment that aims to enhance emotional understanding?” It would be important that participants were compared to a control group and that pre- and post- measures were administered.

References

Burns, N., & Grove, S. K. (2001). *The practice of nursing research: Conduct, critique and utilisation.* Philadelphia: WB Saunders.

Evren, B., Evren, C., & Guler, M. (2006). Clinical correlates of alexithymia in patients with fibromyalgia. *The Pain Clinic, 18,* 167–173.

Finlay, L. (2009). Debating Phenomenological Research Methods. *Phenomenology & Practice, 3,* 6-25.

Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in self-organisation. *Development and Psychopathology, 9,* 670-700.

Gabbard, G. & Wilkinson, S. (2000). *Management of countertransference with borderline patients.* Maryland: The Rowman & Littlefield Publishing Group.

George, C, Kaplan, N, & Main, M. (1985). *Adult Attachment Interview*. Berkeley: Unpublished manuscript.

Halling, S., Leifer, M., & Rowe, J.O. (2006). Emergence of the dialogical approach: Forgiving another. In C. T. Fischer (Ed.), *Qualitative Research Methods for Psychology: Introduction through Empirical Studies* (pp.247-278). New York: Academic Press.

Hopf, C., (2004). Qualitative Interviews: An Overview. In U. Flick, E. von Kardofs, & I. Steinke (Eds.), *A Companion to Qualitative Research.* London: Sage Publications.

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing, 12,* 307-312.

Husserl, E. (1975). *Introduction to the logical investigations*. The Hague: Nijhoff.

Reid, A., & Gough, S. (2000). Guidelines for reporting and evaluating qualitative research: What are the alternatives? *Environmental Education Research, 6,* 59-91.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: Sage Publications.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Methodology: A practical guide to research methods. Second edition.* London: Sage.

SECTION D: APPENDICES OF SUPPORTING MATERIAL

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

SEPTEMBER 2013

DEPARTMENT OF APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix 1: Ethics approval letter.

This has been removed from the electronic copy.

Appendix 2: Demographic information.

	Participant	Age	Ethnicity	With Partner
1	Ella	53	White British	No
2	Martin	42	White British	Yes
3	Anneka	39	White British	Yes
4	Esther	55	White British	Yes
5	Janice	20	White British	Yes
6	Jess	41	White British	Yes
7	Angela	43	White British	No
8	Patricia	50	White British	No
9	Sally	45	White British	Yes
10	Nathan	63	White British	No

Appendix 3: Consent form.

Version 3 14/04/2012

(Form to be on headed paper)

Centre Number: Study Number:

Participant Identification Number for this study:

CONSENT FORM

Title of Project: What are people's experiences of relating with the self and others amidst living with fibromyalgia?

Name of Researcher: Caroline Haig

Please initial box

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

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my data collected during the study may be looked at by individuals from the sponsor organisation, my lead supervisor, regulatory authorities, and from the NHS Trust where it is relevant to my taking part in the study. I give permission for these individuals to have access to my data. ☐

4. I agree to be interviewed with XXXXXX and I understand that this interview will be recorded, transcribed and analysed. ☐

5. I agree that anonymous quotes from my interview may be used in published reports of the study findings. ☐

6. I agree to take part in the above study. ☐

Name of Participant____________________ Date________________

Signature ___________________

Name of Person taking consent ______________ Date_____________

Signature ____________________

Appendix 4: Opt-in slip.

Version 1 **08/02/2012**

Fibromyalgia Research Study
Opt-in slip

If you agree to take part in the study described in the information sheet then please complete the following details. The researcher will contact you shortly. Many thanks for your cooperation.

Name:

Signature:

Contact details (telephone and/or email address):

Preferred time to be contacted: Morning Afternoon Evening Any
(please circle)

Any further comments (optional):

Appendix 5: Participant information sheet.

Version 3 14/04/2012

Participant Information Sheet

Interviews about Fibromyalgia: Experiences of stressful events and relationships whilst living with Fibromyalgia.

We would like to invite you to take part in our research study. One of our team will go through the information sheet with you. This should take about ten minutes. Talk to others about the study if you wish.

PART 1: PURPOSE OF STUDY

What is the purpose of the study?

In 2012, a research study will take place that aims to recruit those with a diagnosis of fibromyalgia. Little is known about the effects of stress on relationships in those who live with Fibromyalgia. This study aims to investigate and increase understanding of how stress impacts on relationships and social interactions in patients with a diagnosis of fibromyalgia.

Why have I been invited?

You have been invited because you have experience of living with fibromyalgia. Approximately 6 to 10 people will be interviewed for this study.

Do I have to take part?

It is up to you to decide to join the study. You can take this information sheet away with you and think about joining the study. If you decide to join, you can fill in the opt-in sheet and send it in the provided stamped addressed envelope. You will be asked to sign a consent form at a later date.

What will happen to me if I take part?

The study would involve one audio-recorded interview with the lead researcher that would last approximately 1 hour. The interview can take place at the participant’s home or at an NHS site. A short discussion will take place at the end of the interview for the participant to offer any comments or feedback.

In order to make the participant as comfortable as possible, the participant is welcome to pause the interview and move around the room.

Expenses

Up to ten pounds can be reimbursed for travel expenses.

What are the possible disadvantages of taking part?

This study is interested in exploring current experiences and those that have occurred in the past, including childhood experiences. Discussing some of these experiences may be distressing. The participant is welcome to end the interview at any time.

Possible support after the interview

If participants feel they could benefit from support or information about living with Fibromyalgia, it is possible for them to access the psychology and pain management service at XXXXX after the interview. Referral to the Pain Clinic can take place via the participant's GP.

Telephone support from the pain management team will also be available for several days after the interview. If you wish to receive telephone support please contact the pain management team on XXXXXX.

What are the possible benefits of taking part?

We cannot promise that the study will help you. However, being interviewed may offer some insights into your experiences. Moreover, understanding people's experiences of stress in regard to social interaction could have important implications in the NHS – for example, it may influence how psychological services can be offered to best meet individual's needs and outlook on life.

What happens when the research study stops?

If you wish the results of the study can be sent to you.

PART 2: ADDITIONAL INFORMATION

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will destroy any identifying information. Information can be destroyed and omitted from the study if you wish.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to XXXXX on XXXXXX. If you remain unhappy and wish to complain formally via the NHS complaints procedure, details can be given from XXXXX via email (XXXX). Alternatively, you can phone the pain management team on XXXXX.

Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. However, if it is disclosed that harm may be caused to yourself or others, then this information may be shared with other professionals.

Data will be stored securely at all times and will be analysed on password-protected NHS computers. Only the lead researcher (XXXXXX) will have access to personal data. Analysis of the interview may be looked at by authorised people to check that the study is being carried out correctly. The interviews will be kept for ten years on a password protected CD in a locked cabinet. After ten years, this will be destroyed.

Identifying information will be anonymised. Direct quotations from the interviews may be included in the write-up of the research.

What will happen to the results of the research study?

It is intended that the results will be published in a scientific journal. Participants will not be identified in any report or publication.

Who is organising and funding the research

This study is funded solely by Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group, called a Research Ethics Committee. This study has been reviewed and given favourable opinion by the XXXXXX. This information sheet is yours to keep. At a later point, a consent form will be signed, which you can also keep.

Further information and contact details

If you are interested in taking parting the study or would like some more information please email XXXXX at XXXXX or telephone the pain management team on XXXXXXX.

You can also contact this person if you have any concerns during the study.

Appendix 6: Interview schedule.

Relations with self and others amidst living with FMS

(The questions may vary according to the individual interviewee).

- Thank individual for their participation.
- Readdress consent and information sheet – explain that the interview will involve exploring different areas relating to stress, including childhood experiences and other past events as well as the participant's current situation.
- Highlight confidentiality and its limits.
- Outline that the interview can be stopped at any time.
- Interview will last approximately 1 hour and will be recorded on a digital recorder.

Current Situation

1. I will begin the interview by asking about your current relationships. In your every day life, who are your most important relationships (this can be family, friendship, partner etc)?

Probes:

- Can you describe this relationship?
- Can you tell me what sort of things you do together?
- Can you tell me what sort of things you talk about?
- What do you think X thinks about you?
- What sort of things does X say about you?

2. Can you think of a situation in the last week or month that felt difficult, tense or stressful that involved someone else? Can you describe it to me?

Probe:

- What were your thoughts at that time?
- What's it like hearing yourself say that?

3. Do you think other people understand your condition (FMS)?

Probe:

- Can you point to any experiences that link to the thought that "no one understands me"? (Use individual's own words, e.g. "no one understands me")

Childhood experiences

Okay, let's talk about your experience when you were young, such as when you were in primary school. (In order to attune thinking to this time, ask: what was your primary school called? Where did you live at this point?)

1. Can you tell me what your family and relationships were like at this time?

2. Can you tell me who were the most important family members and relationships at this time?

Probes:

- How did X influence you at the time?
- What sort of things did X say to you during your childhood?
- Can you tell me what sort of things you did together?
- If you were upset or experiencing something difficult, what did X say?

3. How have your childhood experiences influenced who you are today?

Probes:

- How do you think (use individual's own language, e.g. "mum ignored me when I cried") influenced a) your thoughts b) how you see yourself now?
- How do you think (e.g. your mum ignoring you when you cried) influenced how you cope with difficult circumstances?
- (in order to be more containing, end on a positive note) What relationships were helpful in your childhood? How do they continue to help you presently? Do other relationships help you presently?

End of the interview:

Debrief

Q: Can you tell me what it was like to participate in this interview?
Q: How did it feel to discuss the issues that came up?
Q: Has this interview raised any concerns?
Q: Is there anything you would like to say that hasn't already been discussed?

- Provide information on care pathways/ avenues of support.

At the end:
Thank you very much for taking part in this research project. If you have anything you would like to ask at a later point I can be contacted via XXXXXX.

Thank you for your time.

Appendix 7: Example transcript.

This has been removed from the electronic copy.

Appendix 8: Example of initial codings.

This has been removed from the electronic copy.

Appendix 9: Example of spider diagram used for data analysis.

This has been removed from the electronic copy.

Appendix 10: Yardley’s (2008) Core Principles.

Core principles for evaluating the validity of qualitative studies (Yardley, 2008):

1) Sensitivity to context:
- Relevant theoretical and empirical literature
- Socio-cultural setting
- Participants’ perspectives
- Ethical Issues
- Empirical data

2) Commitment and rigour:
- Thorough data collection
- Depth/breadth of analysis
- Methodological competence/skill
- In-depth engagement with topic

3) Coherence and transparency:
- Clarity and power of your argument
- Fit between theory and method
- Transparent methods and data presentation
- Reflexivity

4) Impact and importance:
- Practical/applied
- Theoretical
- Socio-cultural. (p. 243-244)

Appendix 11: Reflective diary examples.

11th July 2011

I had my initial meeting with my external supervisor today. I am very excited about the prospect of carrying out research in FMS. My current placement in pain management has hugely built my interest in this area and I have started to notice some further opportunities for research. My external supervisor has expressed particularly interest in social cognition and mentalization. She has given me a few papers to start my thinking; I think I'll start with Subic-Wrana et al's (2010) paper regarding theory of mind – seems like a good starting point.

09th August 2011

I just had supervision. We have noted that a few researchers have observed facets of mentalization and FMS in a quantitative context (in press). Hence, it makes sense to conduct a qualitative study. I'm interested in the idea if using this approach; I really would like to directly work with peoples' rich experiences and for my research to involve some in depth, meaningful interaction. We thought about service user involvement – we know of several support groups both nationally and locally and I'll contact them soon. I feel nervous about doing this. I guess I'm concerned that my research won't be taken seriously or that approaching them will seem interfering.

30th August 2011

I am feeling really overwhelmed at this point. There are so many possibilities for investigating mentalization, social cognition – in many ways it feels like new territory in the context of FMS. Given how much is known about disrupted attachment and FMS I am amazed at how little research there is regarding adult attachment and how people with FMS relate to others. I have emailed various research leads about my thoughts - their ideas are broad and varied. It feels like all these different perspectives and further adding to my confusion.

29th May 2012

Feeling relieved that I have got ethics approval and recruitment can now start! My external supervisor has allayed some anxieties regarding recruitment; she predicts it may not be too difficult process with this client group. In her experience, people with FMS frequently express a frustration with the lack of knowledge and therefore people may feel motivated to be involved. I'm feeling so motivated at this juncture of my research; I'm excited to start hearing about people's experiences yet also very nervous. I'm nervous about engaging with people at a rich level in a short amount of time.

31st August 2012

I just had my first interview. Beforehand, I felt very nervous, unsure whether I'd get the balance right for a semi-structured interviewed or whether I'd be able to glean a meaningful interview. The lady was in her mid-forties, lived on the top of a council block and was supported by her son. She seemed really distressed about this living situation and told me about upsetting difficulties with neighbours. There was a real sense of loneliness about this lady. She told me of her extreme isolation and she seemed reluctant to let me leave. I felt that she was trying to "entertain" me, telling me jokes and stories at the end. This felt touched with sadness, as throughout the interview she vacillated between coping and despair. I felt guilty that I couldn't offer her more but also relieved that she seemed to enjoy the interview process.

22nd November 2012

I conducted two interviews today. The first was very distressing. She appeared very anxious when she opened the door and the flat felt airless and claustrophobic. She began by saying that she "had been dreading this interview all day". I felt like an abuser during the interview in that she seemed uncomfortable with me. She told me about horrific childhood experiences – this left me feeling incredibly sad and angry that children can be so unprotected and unloved.

20th April 2013

I am finding the process of data analysis a touching experience. I have been surprised by how I am continually relating to the data in ne ways. I am becoming attuned to subtle nuances within the transcripts that I previously may have brushed over. For example, when recently attending to the ninth transcript, I felt incredibly emotional when reading her words about "not existing" and being "lost" in a multi-tasking" woman. It made me feel saddened that women are continually subjugated via traditional gender roles. It reminded me of my own family context and the expectations that loved ones have been subjected to.

Appendix 12: Further examples of quotations.

Superordinate theme one: The power of painful childhood relationships

Sub-theme 1.1: Connecting to others in adulthood

I find it very hard to trust people. I mean I'm at peace here with my animal and my son who I trust and I enjoy my garden. I like doing creative things. So I actually find I've become a bit of a recluse really (Patricia).

There was definitely a stage where I wouldn't go to anyone, even with the breakdown of my marriage and all that. I just wouldn't go to anyone (Ella).

But I'll tell you honestly that when my dad died, I made my mind up that I would do everything for my mum because I didn't want her to be on her own (Ella).

Erm, I'm always there for other people even though I'm going through so much myself. It makes me want to look after people, because they are my friends! (Angela).

My husband lives up North so it is a case of seeing each other when we can. He suffers from depression. He attempted suicide last Christmas, as you do. So I carry, carry, carry him (Sally).

I think it has made me desperate to be love. It made me feel like I made the wrong choices for the wrong reasons (Ella).

I now can't have a relationship. I can't ever be with anyone. I don't trust anyone enough – who would want someone now who was riddled with pain and is bitter? (Angela).

Sub-theme 1.2: Influence on coping

It's taught me to stand on my own two feet because when I was a kid theer was no-one there to back me up (Martin).

Everything's stressful. Everything's stressful (Angela).

A few weeks ago my friend Ed died. We thought he killed himself but he had an aneurism on the brain and he died outright. I can't feel nothing. I feel nothing. I think I've had too much hurt (Angela).

I cannot be angry, I cannot be cross because of the fear that I will just destroy someone like I was destroyed with words (Esther).

On an emotional level now I feel very aware of myself and that's because I've been able to talk to my counsellor. Going back to childhood, I always felt that I was watching things rather than in it (Patricia).

Sub-theme 1.3: Shaping personal values

I'm always giving them cuddles, kisses – what I wanted. I suppose that's why I did it, that's what I wanted my parents to be like (Anneka).

The last thing I ever wanted to do was to raise my hand to my kid. Or to ever make my kid feel the way that I felt over the years (Martin).

Because of my history I am so in tune with what my son does that I am aware of what's going on, if there are any problems, if he's being bullied, and fortunately he has turned out to be very level-headed, he is a lovely lad (Patricia).

Superordinate theme two: The connection between stress and relating to others

Sub-theme 2.1: Toxic relationships

The friends who make cutting remarks, I don't know if that is jealousy or something else. I suppose I don't really get the friendship thing because some friends behave appallingly badly (Nathan).

My friends have been quite unpleasant about my sister that I can't enter into that circle of animosity (Ella).

But no she doesn't understand sometimes. She doesn't listen a lot. She always thinks she knows best and jumps in before you've finished something and she's always been like that though, my mother (Anneka).

My sister's a thief. She kept stealing and stealing from me. She was just using me (Janice).

Sub-theme 2.2: Stress as a vortex

When I get stressed I tend to take it out on my mum because nine times out of ten she's the one causing me to get stressed out and erm that's where we clash big time (Anneka).

I'm my dad's world so he gets upset about it, like when I'm having a bad day and stuff. He's very like that. When I'm upset about it, he'll be upset about it as well (Janice).

I'm constantly stressed. It heightens – it's mainly by the people you love who heighten it the most (Jess).

There's this image in Buddhism where they say that the anger is like a hot coal and you can throw it but it is your hand that gets burnt, which I think is quite a good image really (Esther).

Sub-theme 2.3: Easing the struggle

I've got my youngest daughter, she's at home. Sometimes she does my housework. She does a lot sometimes. If I get anxious about things she calms me down (Jess).

I'm hypersensitive to language and so in a ay I felt that I couldn't answer so I was like 'eek!' I got all defensive and then actually it was ok because she responded really well and actually we were able to work back actually so it was really good (Esther).

Emily won’t wake me up in the morning. She’ll leave me to sleep until about 11 o’ clock and that will be kind of a decent recharge of the batteries. So it’s not been a bundle of laughs for her. But she’s stood by me (Martin).

The most important person in my life is my son. A lot of tough things have happened in the past, he has been experienced a lot of things that I have as well, so we do have a close relationship (Patricia).

Superordinate theme three: Interpersonal stress is wedded to illness

Sub-theme 3.1: Illness disrupts relationships

I’ve been off work since February and I don’t think they can cope with how much I sleep. I just don’t think they can comprehend (Sally).

My daughter was turned against me and all through her teens I couldn’t manage her. She was a handful, I couldn’t deal with it. I was so ill I just could not deal with her. She just used to make me so miserable. I just wish she would hold me and say ‘Mum, I love you’, and that made it very hard to love her (Angela).

I felt like I was very much a burden to my friends. Like when I moved in here, they did all of that and I feel like a right burden to them (Anneka).

I can’t do social things and I think that’s why a lot of my friends have suddenly thought ‘Oh God’ (Ella).

Lesser women, I shouldn’t say that. But other women have left me because of how tired I am and I get grumpy (Martin).

Sub-theme 3.2: Ignorance of illness and limitations lead to stress

And they said, ‘Oh we’ve invited all these people round for dinner’ and I said ‘No. I can’t deal with all these people’. And I said ‘I have to go to bed in the afternoon for sleep and I can’t’. And they said, ‘oh you do what you want and you know, we understand’. But they didn’t understand! (Ella).

The only time people have acknowledged that there’s something wrong is when my hands have actually locked and they’ve seen the blackness and the colour change and they’ve seen how swollen that goes and they’re like, ‘Well that’s not right’ (Anneka).

I think one of the hardest thing for people to get was the good days and bad days. And also the idea of me trying to pace myself. I can do one thing and it looks like I’ve got a lot of energy and then suddenly I’m on the floor (Esther).

People have always said ‘you’ve got tennis elbow, oh it’s an old sprain that is playing up’. I’ve got ‘housemaid’s knee’, I’ve got ‘whiplash in my neck’ [laughs]. Back pain. There’s always an explanation as to why I’ve got these pains all over me. So it was never actually diagnosed as fibromyalgia (Patricia).

Sub-theme 3.3: Abuse and illness

A relative of the people next door, they were shouting quite loudly in the back garden, well I "do nothing anyway", "I don't even work" and all the rest of it. So he felt right that he had taken money from me because I don't work (Patricia).

You fall out with someone and they use it against you. Like, I fell out with a girl the other day and she said, 'You spastic, you C-U-N-T, get back in your wheel chair!' Oh, we used to be friends, thanks for that (Janice).

My sister is just being a cow, she's actually taken the ME into [pause] she's actually taking the mickey out of myself, which has been so frustrating and no matter how much I try and say, 'You know what, you are actually rude', she's like, 'oh I forgot ME is just me, me, me'" (Sally).

Appendix 13: End of study declaration and letter for R&D team and ethics committee.

This has been removed from the electronic copy.