Dissimilarity in couples' beliefs in long-term illness,

and its relation to coping strategies and health outcomes

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Executive summary

The diagnosis of a health condition can present an individual and their significant others with complex and ongoing challenges. The role of psychological factors in adjusting to illness has been increasingly recognised, including that of the person's subjective beliefs about the illness. Much of the research thus far regarding these personal beliefs has utilised Leventhal and colleagues' (e.g. Leventhal, Meyer & Nerenz, 1980) self-regulatory, or "Common Sense Model" (CSM), of illness. The CSM posits that individuals utilise parallel cognitive and emotional processing to produce these lay beliefs, termed "illness representations". It is theorised that these representations then lead to the use of particular coping strategies, which are subsequently evaluated and revised if needed.

Research originally showed that these illness representations could be coherently ordered into five cognitive dimensions (Leventhal & Cameron, 1987); Identity, Cause, Consequences, Timeline, and Curability/controllability. Timeline and Curability/controllability were later subdivided into Timeline Acute/chronic and Timeline Cyclical, and Personal and Treatment Control respectively (Moss-Morris et al., 2002). Two additional illness representation dimensions, Illness coherence and Emotional representations, were also added (Moss-Morris et al., 2002).

The CSM has been applied to a range of health conditions with demonstrated discriminant validity, including cancer, coronary heart disease, chronic kidney disease, chronic obstructive pulmonary disease, psoriasis, and rheumatoid arthritis, amongst others (Hagger & Orbell, 2003). The predictive validity of illness representations for health outcomes has been demonstrated across conditions, for both psychological and physical health outcomes (Hagger & Orbell, 2003). Illness

representation dimensions have also been associated with particular coping strategies, which can act as a mediator between representations and health outcomes (Hagger, Koch, Chatzisarantis & Orbell, 2017).

However, models of health beliefs, including the CSM, have been accused of neglecting the wider social context of adjusting to a long-term health condition. These models have traditionally focused on the unwell individual, with the role of the partner predominantly as provider of information and/or practical or emotional support. Yet, there is now a substantial body of research showing that illness can also impact detrimentally upon the relationship and on their partner, including on their quality of life, physical health, mood, and social isolation. This includes the condition of Fibromyalgia (FM), of which the detrimental impact upon the partner relationship has been well-chronicled (e.g. Arnold et al., 2008).

This shift in thinking has been echoed in the evolution of models of dyadic coping in illness, which propose reciprocal interaction throughout adjustment to the health condition. These models include the Developmental-Contextual Model (DCM) (Berg & Upchurch, 2007), the Systemic Transactional Model (STM) (Bodenmann, 1995, 2005), and the Cognitive-Transactional Model (CTM) (Badr & Acitelli, 2017). The DCM (Berg & Upchurch, 2007) and the CTM (Badr & Acitelli, 2017) both utilise the illness representation dimensions from the CSM in their construct of illness appraisals, which are proposed to then influence coping and outcomes. However, to understand dyadic coping, research is first needed to identify the processes by which couples develop shared appraisals of the illness.

Most research using the CSM in couples has focused upon the extent of similarity, or "congruence", in the couple's illness representations. However, there

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appear to be conflicting findings. Some have found that dissimilarities on illness representation dimensions were related to poorer health outcomes, whilst others have related dissimilarity to improved health outcomes for the participant or their partner. Furthermore, this can seem dependent on whether one member of the dyad holds more "positive" illness representations. Some have suggested that partners' representations in fact act as a mediator or a moderator. In FM, studies have found varying agreement within the couple about its symptoms. However, no study as yet had used the CSM to examine dissimilarity in couples' beliefs in FM.

Therefore, the aims of this thesis were: i) to synthesise and analyse the existing evidence regarding dissimilarity of illness representations, coping strategies, and health outcomes from studies using the CSM in the systematic review, and ii) to examine these associations in a FM population in the empirical study. Communication was additionally included as a variable in the empirical study, due to its established impact upon health outcomes and inclusion in a recent model of dyadic coping (CTM; Badr & Acitelli, 2017).

Systematic review

The systematic review followed PRISMA guidelines (Moher, Liberati, Tetzlaff & Altman, 2009). Inclusion criteria for studies included: examination of illness representations as intended by the CSM, the use of a version of the Illness Perception Questionnaire to measure illness beliefs, illness outcomes as categorised by a previous meta-analysis (Hagger & Orbell, 2003), a cross-sectional/cohort/longitudinal design, and with participants who had a diagnosis of a physical health condition and whose named partner was their intimate partner/spouse.

The primary search strategy involved searching five online databases; PsycINFO, Cochrane Library, PubMed, ProQuest Dissertation & Theses, and Google Scholar. The first stage of data collection incorporated searches for identification of studies using pre-determined keywords. Following removal of duplicates, titles and abstracts were screened for eligibility. Articles considered potentially appropriate were retrieved in full text. Exclusion of studies based on eligibility criteria resulted in 10 studies for quantitative analysis.

Following data extraction, a narrative synthesis of the data and appraisal of quality was undertaken for the 10 studies. The synthesis examined characteristics regarding the study, its participants and partners, their relationship, and the health condition of interest. Measurement of illness beliefs, measurement of health outcomes, and statistical analysis were also explored across the studies.

It was found that there may be illness-specific differences regarding dissimilarity in illness representations, at least in relation to physical health outcomes. With respect to psychological outcomes, the significant associations with illness representations for both participant and partner were mostly weak to moderate. The strongest, and highest number of, associations seemed to occur on the Emotional representations and Consequences dimensions. It was almost unanimously found that holding dissimilar beliefs predicted poorer physical and psychological health outcomes, and less adaptive coping strategies, for the participant. This was in contrast to the majority of the results for psychological outcomes for partners, whereby dissimilar beliefs were associated with improved outcomes. For the most part, it was discovered that when couples held similar beliefs, this led to particular outcomes that were similar to those found in the CSM literature on individuals. When couples did

have conflicting views, one study (Sterba et al., 2008) found that, as long as the participant held more "positive" views, their psychological adjustment was unaffected by their partner's "negative" beliefs.

Empirical study

The empirical study aimed to explore dissimilarity in FM couples, specifically whether they would be associated with more ineffective coping strategies and poorer health outcomes as hypothesised. It was posited that dissimilarity would contribute to health outcomes, over and above the contribution of participants' beliefs. The types of beliefs held by the couple were also examined regarding their impact on FM, as well as the influence of illness-related communication upon health outcomes.

A cross-sectional design recruiting couples from four sources was used to examine these aims. 92 participants were recruited from: face-to-face FM support groups, an NHS community pain service, and online through the website of a FM charity and FM support groups on Facebook. Participants were eligible for the study if they were aged 18 or over, had a clinical diagnosis of FM, were able to read and understand English, and had been with their partner for at least 6 months.

Participants and partners both completed measures of illness representations (Illness Perception Questionnaire-Revised; Moss-Morris et al., 2002) and of illness-related communication (Couples' Illness Communication Scale; Arden-Close, Moss-Morris, Dennison, Bayne & Gidron, 2010), whilst participants also undertook measures of physical health (Revised Fibromyalgia Impact Questionnaire; Bennett et al., 2009), psychological health (Hospital Anxiety and Depression Scale; Zigmond &

Snaith, 1983), and coping strategies (Behavioural Responses to Illness Questionnaire; Spence, Moss-Morris & Chalder, 2005).

In the empirical study, there were fewer significant associations found than anticipated, with only two significant relationships discovered. Firstly, there was a weak positive relationship discovered between dissimilarity on the Timeline Cyclical dimension with psychological distress. There was also a weak negative relationship found between dissimilarity regarding Consequences with FM impact. The participant's beliefs were found to contribute significantly to health outcomes on the Consequences and Personal Control dimensions, whilst dissimilarity in the couple did not add significantly to these outcomes apart from on the Timeline Cyclical dimension.

There were no significant differences in couples' belief types across the illness representation dimensions, apart from the Consequences dimension. On this dimension, it was discovered that couples with similarly "negative" views scored significantly higher on FM impact than when couples held similarly "positive" views, or if the participant was "positive" but the partner held "negative" views.

The role of illness-related communication in FM remained unclear after analysis, with the only significant finding being a weak negative relationship between level of communication and psychological distress.

Conclusions

Regarding the CSM, the findings from the review and the empirical study seemed consistent with contemporary thinking that the role of the partner is more influential than an information- or support-providing role as previously conceived

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(e.g. Leventhal et al., 1980). The empirical study also may support the idea that shared appraisals occur in a transactional manner, as per the STM (Bodenmann, 1995, 2005) and CTM (Badr & Acitelli, 2017). Additionally, the empirical study added to the literature of specific processes that may be occurring for an FM population.

The review and empirical study found similar limitations. For instance, the dominant use of cross-sectional designs in application of the CSM has made conclusions as to both individual and dyadic processes more challenging. The review also found substantial heterogeneity across the included studies, which limited generalisability. In the empirical study, the final sample was predominantly female, White British, and recruited online, which may have introduced particular confounding variables due to their characteristics. There were also several areas where validity was compromised in the systematic review, including the lack of data on non-responders, the use of convenience sampling, and the use of postal surveys. Thus, the suggested foci of further research recommended in the review and empirical study was similar in its nature; namely, the use of longitudinal design, using consistent and objective outcome measures, measuring illness and relationship variables, and measuring the partner alongside the participant.

Despite their limitations, both the systematic review and empirical study had relevant implications both clinically and theoretically. Both drew attention to potential areas for interventions in couples' therapy, particularly condition-specific interventions for different illnesses (Fischer, Baucom & Cohen, 2016). In the review, the finding of dissimilarities on certain dimensions, particularly couples' beliefs regarding Emotional representations and Consequences, illustrated that certain beliefs may be helpful to prioritise in assessment and intervention to increase shared

understanding. In couples where one member has FM, beliefs around the cyclical

nature of the FM seemed particularly pertinent to consider, such as planning for flare-

ups.

Though it was difficult to draw firm conclusions aligning with dyadic models

of coping, the systematic review highlighted the impact of dissimilarity on poorer

individual outcomes, whilst the empirical study indicated the importance of the

individual's beliefs in FM. These findings were discussed in terms of their relevance

to the existing models, which seemed particularly applicable to transactional models

such as the CTM (Badr & Acitelli, 2017). Future research, particularly longitudinally,

may help to consider how to support couples in different health conditions going

through their illness journey, and contribute further to evidence regarding these

dynamic dyadic processes.

Systematic Review

Abstract

The importance of the individual's illness beliefs in adjustment to long-term illness has long been recognised in models in health psychology, including Leventhal and colleagues' "Common Sense Model" (CSM) (e.g. Leventhal, Meyer & Nerenz, 1980). However, the CSM has been criticised for its minimisation of the role of the individual's partner, of which there is a burgeoning body of research demonstrating their influence, as well as a recent growth of models exploring couples' coping. Most research using the CSM in couples has focused upon the extent of similarity/dissimilarity in the couple's beliefs ("illness representations"); however, there has not yet been a comprehensive review of these findings. The main aim of the review therefore was to investigate the extent to which dissimilarity of illness representations was associated with health outcomes for both participant and partner.

Using pre-determined keywords, the search of five electronic databases (PsycINFO, Cochrane Library, PubMed, ProQuest Dissertation & Theses, and Google Scholar) initially yielded 553 studies. Studies were assessed using specified eligibility criteria, including: examination of illness representations as intended by the CSM, use of a version of the Illness Perception Questionnaire, illness outcomes as categorised by a previous meta-analysis, a cross-sectional/cohort/longitudinal design, and with participants with a diagnosed physical health condition and whose named partner was their intimate partner/spouse.

This resulted in 10 studies deemed eligible for quantitative analysis. A narrative synthesis of the studies was undertaken, as well as a critical appraisal of

their quality using the Appraisal tool for Cross-Sectional Studies (Downes, Brennan, Williams & Dean, 2016).

Findings suggested that holding dissimilar beliefs seemed to predict poorer health outcomes for the participant, but could have the opposite result for their partner. There seemed to be illness-specific differences in dissimilarity of illness representations, at least in relation to physical health outcomes. The associations between dissimilarity and psychological outcomes were mostly weak to moderate, with particular importance highlighted on the Emotional representations and Consequences dimensions. It was also discovered that the direction of these views may be important for improved outcomes, namely when at least the participant held "positive" views of the illness' consequences.

However, there were several limitations to this review, including the heterogeneity across studies, low sample sizes of the studies with significant findings, and threats to validity, such as use of convenience sampling. This led to suggestions for further research, particularly taking place within illnesses, using longitudinal designs, using consistent and objective measures, and recruiting from multiple settings.

Introduction

The diagnosis of a long-term health condition can present an individual and their significant others with complex and longstanding challenges (Badr & Acitelli, 2017). The role of psychological factors in adjusting to the diagnosis and management of illness has been increasingly recognised (Kaptein et al., 2003). One psychological aspect which has received considerable attention is the person's subjective beliefs about the illness, which constitute a key component in several models in health psychology (Shaw, 1999).

Much of the research thus far regarding these personal beliefs has utilised Leventhal and colleagues' (Leventhal et al., 1980; Leventhal & Nerenz, 1985) self-regulatory, or "Common Sense Model" (CSM), of illness (Benyamini, Gozlan & Kokia, 2009). The CSM posits that individuals undertake parallel cognitive and emotional processing to produce these subjective beliefs, termed "illness representations". It is theorised that these representations then lead to the use of particular coping strategies, in an attempt to minimise fear and avoid danger from the perceived health threat (Leventhal & Cameron, 1987). In the final stage of the model, the individual reviews the effectiveness of their coping, and may subsequently revise their representations and coping strategies (Leventhal, Brissette & Leventhal, 2003).

Research has shown that these illness representations can be coherently ordered into five cognitive dimensions (Leventhal & Cameron, 1987). These are: Identity (the label of the illness and its symptoms), Cause (of the illness), Consequences (the potential impact upon the individual's functioning and way of life), Timeline (the timeframe of illness duration and recovery), and

Curability/controllability (the extent to which the individual believes that their illness can be controlled or cured by themselves or others). In later revision by Moss-Morris and colleagues (Moss-Morris et al., 2002), two additional dimensions were added; Illness coherence (how comprehensively the individual understands their illness) and Emotional representations (the individual's affective response to their illness). The Timeline scale was also divided into Timeline-cyclical and Timeline-chronic (referring to the recurrence and course of the illness, respectively), and Curability/controllability was separated into Personal Control and Treatment Control (regarding their views over the extent that they personally, or their treatment regime, can control their symptoms) (Moss-Morris et al., 2002).

The CSM has been applied to a range of health conditions with demonstrated discriminant validity (Petrie, Jago & Devcich, 2007). This has included cancer (e.g. Richardson, Schüz, Sanderson, Scott & Schüz, 2016), coronary heart disease (e.g. Aalton, Heijmans, Weinman & Aro, 2005), chronic kidney disease (e.g. Jansen et al., 2013), psoriasis (e.g. Fortune, Richards, Main & Griffiths, 2000), and rheumatoid arthritis (e.g. Graves, Scott, Lempp & Weinman, 2009), amongst others. This has also included neurological diseases (Whitehead, Stone, Norman, Sharpe & Reuber, 2015) and mental health difficulties (Lobban, Barrowclough & Jones, 2005; Vollmann et al., 2010; Watson et al., 2006).

The predictive validity of illness representations for health outcomes has been demonstrated in meta-analyses for both psychological (Dempster, Howell & McCorry, 2015; Hagger, Koch, Chatzisarantis & Orbell, 2017) and physical health outcomes (Hagger & Orbell, 2003; Hagger et al., 2017). For instance, perceiving a strong illness identity, more serious consequences, chronic timeline, lower

controllability over the illness, cause by psychological factors, and having a higher

emotional response to their illness have all been associated with poorer illness

outcomes (e.g. Jopson & Moss-Morris, 2003; Wittkowski, Richards, Griffiths &

Main, 2007), including the development of later illness (e.g. Chronic Fatigue

Syndrome; Moss-Morris, Spence & Hou, 2011). Conversely, having a weaker illness

identity, lower emotional response to the illness, and higher controllability over the

illness have been associated with better illness outcomes (e.g. Gray & Rutter, 2007;

Scharloo et al., 2000). Systematic reviews examining particular conditions have

shown varying correlation sizes in these associations (e.g. Coronary Heart Disease;

Foxwell et al., 2013; Type II Diabetes; Hudson et al., 2014; cancer; Richardson et al.,

2017). Indeed, some studies have found that illness representations can outweigh

illness severity and mood in explaining illness outcomes (Fortune et al., 2000;

Groarke, Curtis, Coughlan & Gsel, 2005; Steed, Newman & Hardman, 1999).

However, it is important to note that others have not found the expected strength of

association between illness representations and outcomes (e.g. in adherence

behaviours; Aujla, Walker, Sprigg, Abrams, Massey & Vedhara, 2016; Brandes &

Mullan, 2014), and reviews have suggested that coping strategies may in fact be

stronger predictors (Hagger & Orbell, 2013; Hagger et al., 2017).

Illness representation dimensions have also been associated with particular

coping strategies, which can influence health outcomes both directly and indirectly

(Hagger et al., 2017). Identity, Consequences, Timeline, and Emotional

representations have all been linked with emotion-venting and avoidance coping

strategies, which can then lead to poorer health outcomes (Hagger & Orbell, 2003).

Conversely, Curability/controllability and Illness coherence have been related to

cognitive reappraisal, problem-focused, and social support-seeking coping strategies (Hagger et al., 2017).

There have been several limitations from the existing literature which have hampered the pursuit of consistent findings. Firstly, as noted in several published reviews (e.g. Dempster et al., 2015; Hagger & Orbell, 2003; Hagger et al., 2017), there has been a lack of clear operationalisation and measurement of coping and outcomes. This has been particularly problematic with the construct of coping, which has often used measures of generalised, rather than disorder-specific, coping strategies (Hagger et al., 2017), and has been interchangeably treated as a covariate, mediator, or moderator (Dempster et al., 2015). This has affected the ability to conclude definitively about its role (Dempster et al., 2015). Study findings have also been vastly affected by the use of cross-sectional designs, which impacts on conclusions regarding causality (Hagger & Orbell, 2003). Additionally, there are numerous variables in illness, such as illness type and severity, which may potentially be acting as moderators, and have not been able to be statistically examined in reviews (Hagger & Orbell, 2003). As such, adding reliable and valid evidence to the CSM literature has at times been hindered by these complexities.

The idea of targeting illness representations to facilitate improvement in health outcomes has been central to a number of Cognitive Behavioural Therapy-based interventions. Several studies have had success in improving outcomes, including psychological wellbeing (Goodman, Morrissey, Graham & Bossingham, 2005), functional outcome (Broadbent et al., 2009; Petrie, Cameron, Ellis, Buick & Weinman, 2002), and social and vocational outcomes (Broadbent et al., 2009). However, a systematic review into Coronary Heart Disease found that the outcomes

were "unclear" in representation-targeted interventions (Goulding, Furze & Birks, 2010). It has also been found that these focused interventions might be more likely to influence proximal outcomes (e.g. satisfaction with information) as opposed to distal outcomes (e.g. health status) (Glattacker, Heyduck & Meffert, 2012). With a number of the existing interventions focusing on populations with coronary conditions, there is a clear need for further research in different conditions before drawing conclusions about their efficacy.

However, models of health beliefs, including the CSM, have been accused of neglecting the wider social context of adjusting to a long-term health condition (Jackson, McKenzie & Hobfoll, 2000). These models have traditionally focused on the unwell individual (Revenson & DeLongis, 2011), with the role of the partner predominantly as provider of information and/or practical or emotional support (Berg & Upchurch, 2007). Yet, the reciprocal influence of the wider system, and particularly that of the partner, has been increasingly recognised over the last two decades (Badr & Acitelli, 2017). There is now a substantial body of research showing that illness can also impact detrimentally upon the partner, including on their quality of life (Kornblith, Herr, Ofman, Scher & Holland, 1994), physical health (Ferraz & Quaresma, 2000), mood (Axelsson & Sjödén, 1998), and social isolation (Rolland, 1994). This shift in focus has also been reflected in governmental guidelines. In the U.K., current recommendations exist for couples' therapy in depression with a chronic physical health problem (National Institute for Health and Care Excellence [NICE], 2009) as well as recognition of need for family/carer involvement in epilepsy (NICE, 2012), fertility problems (NICE, 2013), prostate cancer (NICE, 2014), motor neurone disease (NICE, 2016), and stroke rehabilitation (NICE, 2013).

This change has also been echoed in the evolution of theories and models of dyadic coping, which propose reciprocal and interdependent interaction throughout the navigation of a stressor such as illness (DeLongis & Holtzman, 2005; Revenson & DeLongis, 2011). Whilst numerous theories have been proposed, including "congruence of couples' coping" (Revenson, 1994), "relationship-focused dyadic coping" (Coyne & Smith, 1991), "we-talk" (Rohrbaugh, Shoham, Skoyen, Jensen & Mehl, 2012), and "empathic coping" (DeLongis & O'Brien, 1990), three models in particular have attempted to consolidate these processes and their relation to outcomes. These are: the Developmental-Contextual Model (DCM) (Berg & Upchurch, 2007), the Systemic Transactional Model (STM) (Appendix 1; Bodenmann, 1995, 2005), and the Cognitive-Transactional Model (CTM) (Badr & Acitelli, 2017).

Two of these models, the CTM (Figure 1; Badr & Acitelli, 2017) and DCM (Figure 2; Berg & Upchurch, 2007), both utilise the concept of illness representations from the CSM in the formation of each member's beliefs. However, the CTM (Badr & Acitelli, 2017) argues that the sharing of appraisals occurs in a transactional manner, in which dyadic appraisal is only achieved when either the illness is considered a shared problem, or when the individual's coping strategies are ineffective and the partner is responsive to communication efforts. In contrast, the DCM considers the couple as "mutually involved in each other's stressors" (p.933; Berg & Upchurch, 2007) and that appraisal, coping, and adjustment is viewed as a dyadic unit from the outset.
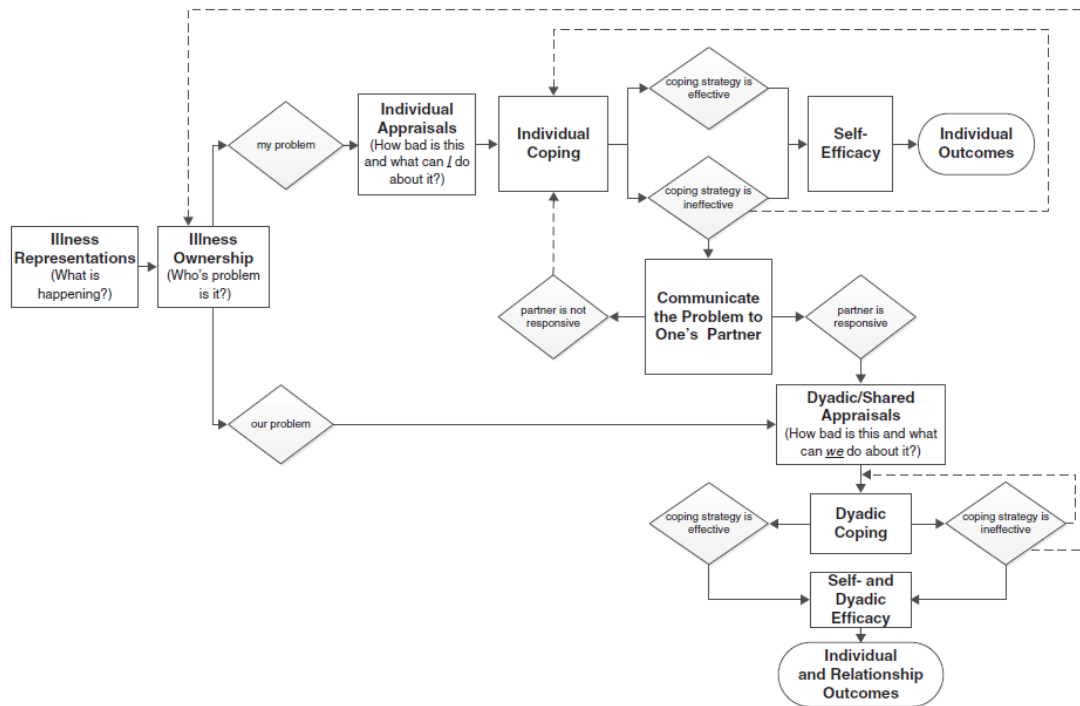
Figure 1: The Cognitive-Transactional Model of couples' adjustment (Badr & Acitelli, 2017)
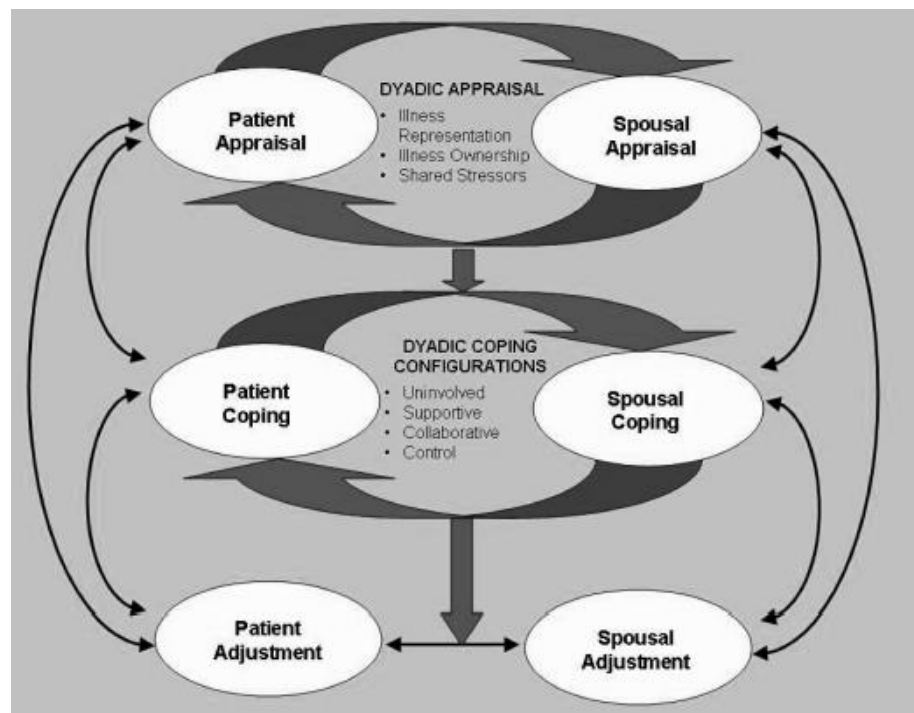

Figure 2: The Developmental-Contextual model of couples' adjustment (Berg & Upchurch, 2007)

These models have all been supported to an extent by research showing the reciprocal interaction and outcomes in illness for both members in their psychological wellbeing (e.g. Kayser, 2005; Manne & Badr, 2008), and physical outcomes (e.g. Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010; Holtzman & DeLongis, 2007). However, studies based on these models have not necessarily used the original illness representation dimensions (Checton, Magsamen-Conrad, Venetis & Greene, 2015; Fagundes, Berg & Wiebe, 2012) or the same variables as included in the models. Thus, at present, further evidence is needed to substantiate the theoretical links of these models. As acknowledged by the authors of the CTM (Badr & Acitelli, 2017), to understand dyadic coping, research is first needed to identify the processes by which couples develop shared appraisals of the illness. Therefore, as a well-established model, a review regarding the application of the CSM and its constructs to the couples' context seems pertinent at this stage. This also may add to the research conducted on the individual in the CSM, to further solidify associations with coping and outcomes.

Most research using the CSM in couples has focused upon the extent of similarity, or "congruence", in the couple's illness representations (e.g. myocardial infarction; Figueiras & Weinman, 2003). This has involved studies examining the difference between scores on each illness representation dimension for both participant and partner, and the subsequent influence of this similarity/dissimilarity on outcomes. However, there have appeared to be conflicting findings. Some have found that dissimilarities on illness representation dimensions were related to higher psychological distress (e.g. psoriasis; Richards et al., 2004) and worse physical functioning (Addison's Disease [AD]; Heijmans, de Ridder & Bensing, 1999).

However, dissimilarities have also been associated with higher psychological adjustment, as long as the participant holds more "positive" beliefs (Sterba et al., 2008). There also seem to be discrepancies between different illnesses (e.g. Chronic Fatigue Syndrome [CFS] versus AD; Heijmans & de Ridder, 1998; Heijmans et al., 1999), and across different illness representation dimensions (Heijmans et al., 1999). Some have suggested that partners' representations act in fact as a mediator (Type II diabetes; Pereira, Pedras, Machado & Ferreira, 2016; cancer; Stanton, Luecken, MacKinnon & Thompson, 2013) or a moderator (e.g. Karademas & Giannousi, 2013). Therefore, aggregating this evidence to clarify these associations is of utmost importance, in order to consider the process of developing shared appraisals and dyadic coping.

To the author's knowledge, there have been no systematic reviews as yet into dissimilarity in couples' illness representations using the CSM. Therefore, the main aim of this review is to synthesise and analyse findings from different health conditions, in order to investigate the extent to which dissimilarity of illness representations is associated with coping strategies and health outcomes for both participant and partner. This review will include longitudinal, cohort, and cross-sectional studies, in order to explore these associations over time. It is hoped that further information regarding couples' dissimilarity and outcomes may guide service provision of appropriate interventions for the couple facing illness.

Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009).

Study inclusion criteria

Studies were included if they:

(a) Examined illness representations as intended by the "Common Sense" (CSM) model of illness representations (e.g. Leventhal et al., 1980). This was intended to ensure homogeneity of concepts used in health beliefs.

(b) Utilised a version of the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) to measure illness representations. This includes the Illness Perception Questionnaire-Revised (Moss-Morris et al., 2002) and the Brief IPQ (Broadbent, Petrie, Main & Weinman, 2006). These are standardised, validated measures, and this criterion was used in order to classify illness representations clearly into the CSM categories.

(c) Illness outcomes, as per the categories identified by Hagger and Orbell (2003) in their meta-analysis of the CSM. Their categories incorporated: disease state, physical functioning, psychological distress, psychological wellbeing, role functioning, social functioning, and vitality (Hagger & Orbell, 2003). Reviews have indicated heterogeneity across studies of the outcomes measured (e.g. Dempster et al., 2015), and thus, the use of these categories was intended to prioritise homogeneity.

(d) Had a cross-sectional, cohort, or longitudinal design. This was due to our aim of synthesising the evidence regarding associations, in order to identify possible mechanisms of change to inform future interventions.

(e) Had participants:

    a. Whose named partner in their study was their intimate partner or spouse.

    b. Who had a diagnosis of a physical health condition.

Studies were excluded if they:

(a) Included illness beliefs as defined by any alternative model other than the CSM, e.g. Health Belief Model (Becker, 1974), Theory of Planned Behaviour (Ajzen, 1991), Protection Motivation Theory; Maddux & Rogers, 1983). This was intended to ensure homogeneity of concepts used in health beliefs.

(b) Did not utilise a version of the IPQ (Weinman et al., 1996), IPQ-R (Moss-Morris et al., 2002), or Brief IPQ (Broadbent et al., 2006). Whilst previous reviews (e.g. Hagger & Orbell, 2003) have used content analysis to map constructs from other measures onto the CSM constructs, it was deemed prudent to include only IPQ-based measures to maximise homogeneity of constructs.

(c) Did not measure outcomes related to health. This meant that studies solely examining relationship outcomes, such as marital adjustment, were excluded.

(d) Had a qualitative, experimental, or case-control studies design. This was to examine associations quantitatively, without the influence of an intervention.

(e) Had participants who were:

    a. Part of another type of dyad other than the participant-partner. This excluded parent-child, healthcare professional-participant, etc. This exclusion was intended to allow relationship variables to be considered in analysis, such as relationship quality or satisfaction, which have shown consistent associations with illness outcomes (Kiecolt-Glaser & Newton, 2001).

    b. Not diagnosed with a physical health condition. This excluded studies investigating mental health conditions, which has been adopted by the existing systematic reviews in the field (Dempster et al., 2015; Hagger & Orbell, 2003; Hagger et al., 2017). The aim of this exclusion was to be able to compare dissimilarity findings to the findings from these reviews based on the individual.

(f) Were unable to be translated into an English version. Authors of studies that were not written in English were contacted and an English version was requested. If they were unable to provide this, an online translation programme was used to establish its eligibility for inclusion. This was undertaken to minimise location bias.

Sources of information

The primary search strategy involved searching five online databases; PsycINFO, Cochrane Library, PubMed, ProQuest Dissertation & Theses, and Google Scholar. The first three databases were selected for peer-reviewed publications, whilst ProQuest and Google Scholar were utilised for grey literature and to minimise location and publication bias. Reference lists of existing systematic reviews were hand-searched for additional references, as well as book chapters from reference lists.

Searches of the leading authors in the field were also undertaken, and several authors were contacted in case of upcoming or unpublished work. Reference lists of studies reaching the data extraction stage were also hand-searched. These steps were taken in order to ensure the maximum number of eligible studies.

The database search was carried out in 8th December 2017, with hand-searching taking place between this date and the end of January 2018. There were no date or location restrictions utilised in the search strategy.

Search strategy

For all databases apart from Google Scholar, keyword search was undertaken for all databases where the terms relating to *couples* were required to be in the Title ("couple OR partner OR spous* OR dyad*"), and terms relating to *illness* ("illness OR condition") and *beliefs* ("representation* OR perception* OR attribution*") were required in the Abstract. The first search term was selected for topic breadth, whilst the remaining search terms were based on key terms commonly used in psychological research into the CSM.

In Google Scholar, the search phrase "couples illness representations" was entered and the first 300 citations screened.

Study selection and data extraction

Figure 3 presents the process of the study search and selection strategy.

In accordance with PRISMA recommendations (Moher et al., 2009), the first stage of data collection involved the first reviewer (CB) undertaking searches using the electronic databases and additional sources (n=704). Duplications were removed

(n=151). The first reviewer (CB) then screened titles and abstracts for eligibility

(n=553), with a subset (10%, n=55) cross-checked by a second reviewer (RC;

Doctorate student). This obtained an inter-reliability rating of κ= 0.85, indicating

"almost perfect" agreement (McHugh, 2012).

Articles considered potentially appropriate were retrieved in full text (n=34).

The first reviewer independently assessed eligibility of the retrieved articles, but

discussed exclusions with the second reviewer (RC). The reasons for exclusion of

studies are included in Figure 3. Any disagreements were resolved through discussion

between the two reviewers (CB and RC). This resulted in the final studies for

quantitative analysis (n=10).

The following data was extracted, and is presented in Table 1: authors, date of

publication, location, study design, sampling, setting, inclusion and/or exclusion

criteria, nature of the sample (number, sex, age, health condition), measurement of

illness beliefs, measurement of outcome variables, and main findings of the study.

Data extraction was cross-checked by a second reviewer (RC).

Quality assessment

Study quality was evaluated using the Appraisal tool for Cross-Sectional

Studies (AXIS) (Downes et al., 2016). A shortened version of the criteria used in the

quality assessment can be found in Appendix 2. No studies were excluded on the

basis of their quality. The first reviewer (CB) undertook the ratings, but these were

cross-checked by a second reviewer (RC). Any disagreements regarding ratings were

resolved by discussion.

Data synthesis

The characteristics of the study, associations, and outcomes were reported

using Cochrane-recommended guidelines for narrative synthesis (Popay et al., 2006).

A meta-analysis was originally planned to synthesise results statistically. However,

following data extraction, this was deemed inappropriate, due to the clinical and

methodological heterogeneity of the extracted studies. This heterogeneity involved

the health conditions studied, the measures utilised, and the outcome variables
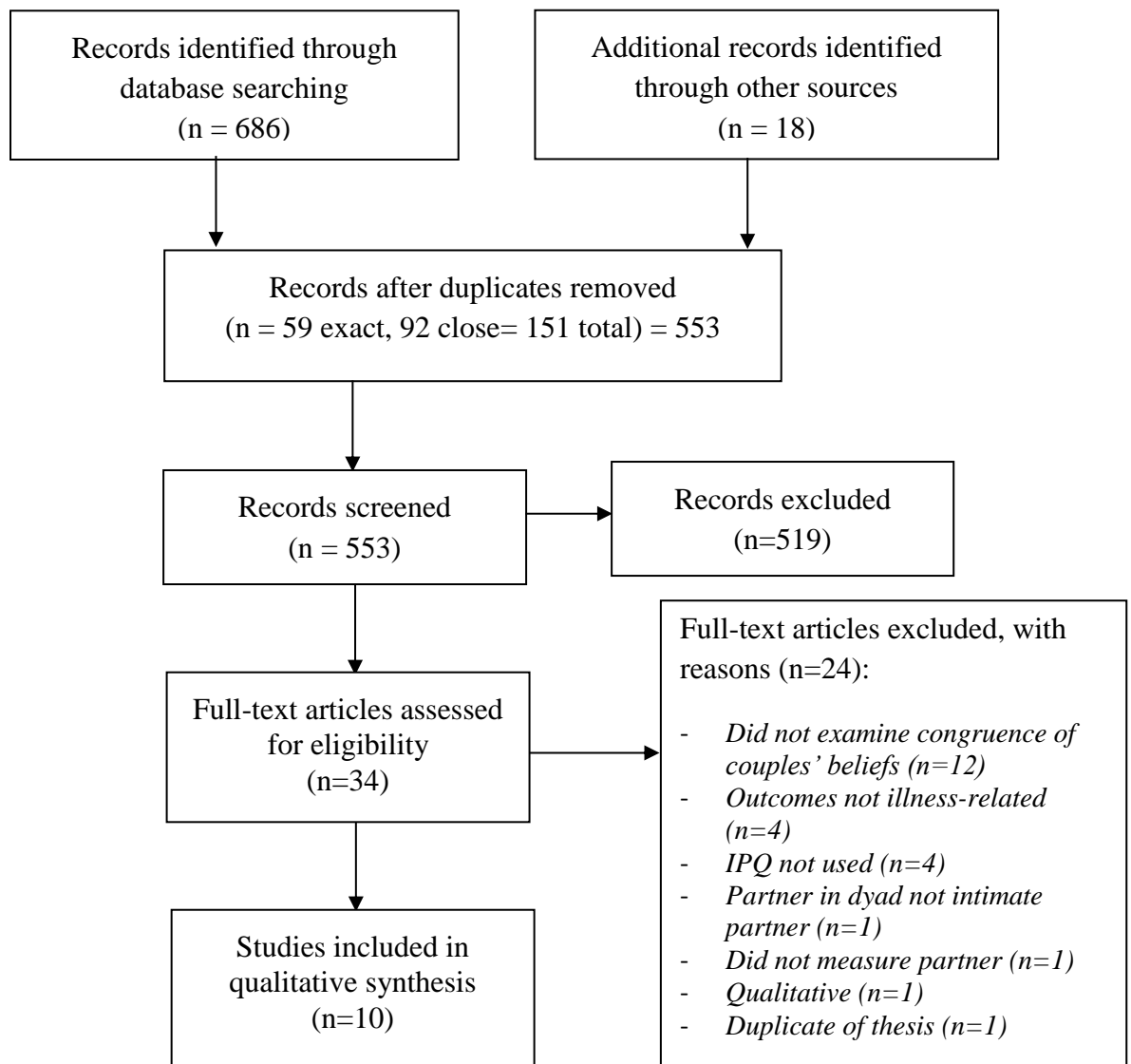
selected for investigation.

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┌─────────────────────────────┐      ┌─────────────────────────────┐
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│  database searching         │      │  identified through other   │
│  (n = 686)                  │      │  sources (n = 18)           │
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          │  Records after duplicates removed         │
          │  (n = 59 exact, 92 close= 151 total) = 553│
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          ┌────────────────────────┐      ┌────────────────────────┐
          │  Records screened      │─────▶│  Records excluded       │
          │  (n = 553)             │      │  (n=519)               │
          └────────────────────────┘      └────────────────────────┘
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          ┌────────────────────────┐      ┌────────────────────────────────────┐
          │  Full-text articles    │      │  Full-text articles excluded, with │
          │  assessed for          │─────▶│  reasons (n=24):                   │
          │  eligibility           │      │  - Did not examine congruence of   │
          │  (n=34)                │      │    couples' beliefs (n=12)         │
          └────────────────────────┘      │  - Outcomes not illness-related    │
                                │         │    (n=4)                           │
                                ▼         │  - IPQ not used (n=4)              │
          ┌────────────────────────┐      │  - Partner in dyad not intimate    │
          │  Studies included in   │      │    partner (n=1)                   │
          │  qualitative synthesis │      │  - Did not measure partner (n=1)   │
          │  (n=10)                │      │  - Qualitative (n=1)               │
          └────────────────────────┘      │  - Duplicate of thesis (n=1)       │
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Figure 3: Diagram of the study search process

Results

Study characteristics

Ten studies involving 879 couples were included (see Table 1). "Participant" refers to the individual with the health condition being researched, whilst "partner" refers to their partner in the couple dyad.

80% of the studies (n=8) were conducted in Europe, including four in the U.K. (Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Richards et al., 2004). Regarding the remaining European studies, two took place in Greece (Giannousi et al., 2016; Karademas et al., 2010), one in Portugal (Figueiras & Weinman, 2003), and one in the Netherlands (10%; Heijmans et al., 1999). The two studies outside Europe were undertaken in the United States (Croom, 2012; Sterba et al., 2008).

The majority of studies (80%, n=8) involved a cross-sectional study design, whereby congruence/dissimilarity of illness representations was associated with outcomes at a singular time point (Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Croom, 2012; Giannousi et al., 2016; Heijmans et al., 1999; Karademas et al., 2010; Richards et al., 2004). Only two studies utilised a cohort study design, with one study examining changes in health behaviour at three time points (Figueiras & Weinman, 2003) and one study exploring psychological adjustment over two time points (Sterba et al., 2008).

Study participants were often (60%) recruited from the outpatient setting being attended for treatment (Ackroyd et al., 2011; Avison & Clarke, 2009; Croom, 2012; Giannousi et al., 2016; Karademas et al., 2010). One study recruited from an

inpatient setting following participants' hospitalisation (Figueiras & Weinman, 2003), whilst another utilised solely patient organisations (Heijmans et al., 1999). Two studies sampled from a range of settings (Richards et al., 2004; Sterba et al., 2008).

Purposive sampling, whereby suitability of participants was assessed beforehand by clinicians or medical records, was used in four studies (Ackroyd et al., 2011; Avison & Clarke, 2009; Croom, 2012; Giannousi et al., 2016). Conversely, four studies (Figueiras & Weinman, 2003; Karademas et al., 2010; Richards et al., 2004; Sterba et al., 2008) used opportunity sampling when participants were attending for treatment. Two studies sent out letters for participants to opt-in (Brannigan, 2006; Heijmans et al., 1999).

The majority of studies (n=7) used questionnaire packs to be returned by post (Ackroyd et al., 2011; Brannigan, 2006; Croom, 2012; Giannousi et al., 2016; Heijmans et al., 1999; Richards et al., 2004; Sterba et al., 2008), with two studies requiring completion of measures face-to-face (Avison & Clarke, 2009; Figueiras & Weinman, 2003; Karademas et al., 2010). Both studies with a cohort design (n=2) used postal questionnaires for follow-up (Figueiras & Weinman, 2003; Sterba et al., 2008).

Table 1: Summary of included studies (n=10)

Authors and year	Location / Study design and sampling / Setting / Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Ackroyd, Fortune, Price, Howell, Sharrack & Isaac (2011)	• U.K. • Cross-sectional • Convenience sampling • Outpatient MS clinic *Inclusion criteria:* • Able to complete questionnaires independently • No additional chronic medical conditions	Participants: - 72 participants (30 male, 42 female) - *Age:* 47.5 years (mean), SD=10.70 - Multiple sclerosis Partners: - 72 partners (44 male, 28 female) - *Age:* 48.6 years (mean), SD=10.90	- IPQ-R, using all 8 original scales. - 5-point Likert scale.	Post-traumatic growth - *Posttraumatic Growth Inventory* (21 items). 6-point Likert scale. Depression- *Chicago Multi-Scale Depression Inventory* (42 items). 5-point Likert scale. Bodily functioning- *Self-report Expanded Disability Status Scale* (8 items). Ordinal scale from 0-10. Cognition- *Multiple Ability Self-Report Questionnaire* (38 items). 5-point Likert scale.	Dissimilarity between participant and partner scores - Analysis not undertaken. Health outcomes *Patient post-traumatic growth-* ns. *Partner post-traumatic growth-* - Consequences (*r*=.332, p<.01) and Emotional representations (*r*=.254, p<.05) positively associated with partner post-traumatic growth Predictors of patient post-traumatic growth - Analysis not undertaken. Predictors of partner post-traumatic growth - Patient mood (β=.359, p=.001), Patient growth (β=.319, p=.003), and Dissimilarity on Consequences (β=.285, p=.007)
Avison & Clarke (2009)	• U.K. • Cross-sectional • Community Stroke Team • Purposive sampling *Inclusion criteria:*	Participants: - 51 participants (33 male, 18 female) - *Age:* 64.9 (mean), SD=9.25 - Stroke	- IPQ-R, using all 8 original scales. - 5-point Likert scale.	Impaired cognition- *Patient Competency Rating Scale* (30 items). 5-point Likert scale.	Dissimilarity between participant and partner scores ns.

Table 1: Summary of included studies (n=10)

Authors and year	Location / Study design and sampling / Setting / Inclusion/exclusion criteria	Sample / Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Avison & Clarke (2009) *(cont.)*	• Diagnosis of stroke. • Able to speak English. • In a relationship with their partner >1 year pre-stroke. • Partner identified in records as main source of support. *Exclusion criteria:* • If they had had a Transient Ischaemic Attack (TIA), or at risk of death. • Those living in a residential setting, or at home but with >28 hours a week support. • Diagnosis of comorbid physical or mental health disorder.	Partners: - 51 partners (18 male, 33female) - *Age:* 63.1 years (mean), SD=9.45		Psychological adjustment- *Hospital Anxiety and Depression Scale (HADS)* (14 items). 4-point Likert scale. Expressed emotion- *Five Minute Speech Sample.* 5 minutes of speech, coded by independent rater into one of four categories.	Health outcomes *Psychological adjustment* **Anxiety** ns. **Depression** ns. *Expressed emotion* - Emotional representations positively associated with expressed emotion (r=.33, p=.04).
Brannigan (2006)	• U.K. • Cross-sectional • 1. Rheumatology outpatient clinic; 2. Postal survey of those who didn't attend clinic; 3. Local osteoporosis support group	Participants: - 27 participants - Demographic variables not reported for couples' analysis - Osteoporosis Partners: - 27 partners (5	- IPQ-R, using all 8 original scales. - 5-point Likert scale.	Psychological distress- *Hospital Anxiety and Depression Scale* (14 items). 4-point Likert scale. Functional ability- *Modified Health Assessment Questionnaire*	Dissimilarity between participant and partner scores - Sig. difference within couple on Illness coherence (t=-3.41, p=0.001), and on Cause: Diet/eating habits (z $score$= -2.56, p=.01), Ageing (z $score$= -2.49, p=.01), Alcohol (z $score$= -2.58, p=.01).

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Brannigan (2006) (cont.)	• Convenience sampling *Exclusion criteria:* • Severe and enduring mental health problems.	female, 22 male) - *Age:* 66.09 years (mean), SD=10.69		(20 items). 4-point Likert scale. Quality and adjustment of a relationship- *Dyadic Adjustment Scale* (32 items). Varying response scales. Severity of osteoporosis- 1) *Ratings of bone mineral density* from medical records. 2) *Self-report VAS* for patients' rating of severity (10-point Likert-scale). 3) *Self-report number of fractures* since diagnosis.	Health outcomes *Functional ability* - Emotional representations positively associated with functional ability (r=.61, p<.01) *Psychological distress* **Anxiety** - Emotional representations positively associated with Patient anxiety (r=.51, p=.001) **Depression** - Emotional representations positively associated with Patient depression (r=.67, p=.001) Predictors of patient anxiety - Patient age (β=-.44, p=.03), and Dissimilarity on Emotional representations (β=.41, p=.03) Predictors of patient depression - Severity rating (β=.48, p=.01), Psychiatric history (β=.49, p=.01), and Dissimilarity on Emotional representations (β=.35, p=.09)
Croom (2012)	• United States • Cross-sectional • Two sites of cancer centre • Purposive sampling	Participants: - 88 participants (88 females) - *Age:* 58.2 years (mean), SD=11.3 - Cancer (40% breast,	- IPQ-R, using all 8 original scales. - 5-point Likert scale.	Relationship quality- *Revised Dyadic Adjustment Scale* (14 items). 6-point Likert scale. Social constraints in	Congruence between participant and partner scores - Analysis not undertaken. Health outcomes *Patient psychological adjustment*

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Croom (2012) *(cont.)*	*Inclusion criteria:* • Female • Diagnosed with stage III or IV cancer >1 month • Living in the same residence as a spouse/unmarried partner >1 year • Able to read and write English. *Exclusion criteria:* • Presence of a pre-existing comorbid medical or psychological condition.	35% gynaecological, 25% lung) <u>Partners:</u> - 88 partners - *Sex:* Unknown - *Age:* 59.8 years (mean), SD=11.3		<u>talking about cancer</u>- *Cancer Rehabilitation Evaluation System* (3 items). 3-point Likert scale. <u>Psychological adjustment</u>- *Hospital Anxiety and Depression Scale* (14 items). 4-point Likert scale.	**Anxiety** ns. **Depression** ns. *Partner psychological adjustment* **Anxiety** - Timeline Cyclical negatively associated with Partner anxiety (r=-.246, p<.05) - Illness coherence negatively associated with Partner depression (r=-.261, p<.05). **Depression** ns. <u>Predictors of Partner anxiety</u> ns. <u>Type of congruence with Patient depression</u> - "Similarly high" on Identity had sig. higher depression than "conflicting" and "similarly low" (F(3,74)=7.989, p<.001) <u>Type of congruence with Partner anxiety</u> - "Similarly low" on Timeline Cyclical had sig. lower anxiety than "conflicting" and "similarly high" (F (3,79)=3.510, p=.019).

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Figueiras & Weinman (2003)	• Portugal • Cohort (3 time points) • Convenience sampling *Inclusion criteria:* • Not reported	Participants*:* - 70 participants (70 male) - *Age:* 53.2 years (mean), SD=8.8 - First-time Myocardial Infarction Partners: - 70 partners (sex unknown) - *Age:* 49.8 years (mean), SD=8.8	- IPQ-R, using 5 original scales. - 5-point Likert scale.	Measures adapted from standardised questionnaires from Medical Outcome Survey, plus several items from Portuguese version of the SF-36. Physical disability- *Medical Outcome Survey* (10 items). 3-point Likert scale. Psychological adjustment- *Mental Health Index* (5 items). 6-point Likert scale. Vitality- *Medical Outcome Survey* energy-fatigue scale (4 items). 6-point Likert scale. Health distress- *Medical Outcome Survey* (6 items). 6-point Likert scale. Sexual functioning- *Medical Outcome Survey* (4 items). 4-point Likert scale.	Dissimilarity between participant and partner scores - Analysis not undertaken. Type of congruence with health outcomes *Physical disability* - "Similarly high" on Consequences had sig. higher physical disability than "conflicting" and "similarly low" (F(2,67)=8.4, p<.001). *Sexual functioning* - "Conflicting" on Identity had sig. poorer sexual functioning than "similarly high" and "similarly low" (F(2,67)=3.3, p<.05). *Recreational activities* - "Similarly high" on Consequences (F(2,67)=15.4, p<.001) and Identity (F(1,67)=5.4, p<.01) had poorer levels of recreational activities than "conflicting" and "similarly low". *Social activities* - "Similarly high" on Consequences (F(2,67)=8.1, p<.001) and Identity (F(2,67)=6.4, p<.01), and "Conflicting" on Curability/controllability (F(2,67)=3.2, p<.05), had poorer

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Figueiras & Weinman (2003) *(cont.)*				Impact on social activities- *Sickness Impact Profile* Social Interaction subscale (16 items). Dichotomous scale (True/False). Impact on recreational activities- *Sickness Impact Profile* Recreation subscale (4 items). Dichotomous scale (True/False). Diet change- Health behaviours scale previously used in Weinman et al. (2000) study (7 items). 5-point Likert scale. Marital functioning- *Medical Outcome Survey* (6 items). 3-point Likert scale.	levels of social activities than other groups. *Vitality* - "Similarly high" on Consequences (F(2,67)=21.1, p<.001) and Identity (F(2,67)=5.4, p<.01) had lowest levels of vitality than "similarly low" and "conflicting". *Psychological adjustment* - "Similarly high" on Consequences (F(2,67)=16.4, p<.001) and Identity (F(2,67)=8.9, p<.001) had lower psychological adjustment than "similarly low" and "conflicting". *Health distress* - "Similarly high" on Consequences (F(2,67)=20.1, p<.001) had higher distress than "similarly low" and "conflicting". *Positive changes in eating behaviour* - "Similarly high" on Curability/controllability (F(2,67)=7.6, p<.001) had higher dietary change than "similarly low" and "conflicting".
Giannousi, Karademas & Dimitraki	• Greece • Cross-sectional • Hospital oncology	Participants: - 149 participants (90 males, 59 females)	- IPQ-R, using 7 subscales. -Scales of	Psychological wellbeing- *Hospital Anxiety and Depression Scale* (14	Health outcomes *Patient psychological wellbeing* - Consequences positively

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
(2016)	department • Purposive sampling *Inclusion criteria:* • Age >18 • First-time cancer diagnosis • Ability to provide informed consent • Being married >1 year • Diagnosis < 1 month ago; Treatment started	- *Age:* 58.93 years (mean), SD=13.76 - Cancer (lung, breast, gastrointestinal) <u>Partners:</u> - 149 partners (59 males, 90 females) - Age: 58.17 years (mean), SD=11.75	Identity and Cause omitted. -5-point Likert scale.	items). 4-point Likert scale.	associated with Patient psychological symptoms (β=.10, p<.05) *Partner psychological symptoms* ns. <u>Interaction</u> -Spouse Illness coherence sig. moderator between Patient Illness coherence and Psychological symptoms (β=.02, p<.05)
Heijmans, de Ridder & Bensing (1999)	• Holland • Cross-sectional • Taken from previous study (Heijmans & de Ridder, 1998) • Purposive sampling *Inclusion criteria:* • Being married • Aged18- 65 • Diagnosis of CFS or AD	<u>Participants:</u> - ***CFS:*** 49 participants (45 females, 4 males) - *Age:* 40.4 years (mean), SD=10.3 - ***AD:*** 52 participants (37 female, 15 male) - *Age:* 45.3 years (mean), SD=12.4 <u>Partners:</u> - *CFS:* 49 partners (sex unknown) - *Age:* 42.7 years (mean), SD=10.5 - *AD:* 52 partners - *Age:* 45.9 years (mean), SD=14.3	- IPQ, using all five original scales. - 5-point Likert scale.	<u>Quality of the marital relationship</u>- *Measure not reported* (5 items). Scale not reported. <u>Coping</u>- Shortened version of *Utrecht Coping Questionnaire* (15 items). 4-point Likert scale. <u>Adaptive outcome</u>- *Short Form Health Survey-36* (number of items not reported). Likert scale with varying number of points.	**Chronic Fatigue Syndrome** <u>Dissimilarity between participant and partner scores</u> - Sig. difference on Timeline (Not reported, p<.001) and Consequences (Not reported, p<.001) <u>Health outcomes</u> *Physical functioning* - Timeline positively associated with physical functioning (*r*=.42, p<.01) *Social functioning* - Biological cause negatively associated with social functioning (*r*=-.30, p>.01) *Psychological adjustment* - Timeline positively associated

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Heijmans, de Ridder & Bensing (1999) *(cont.)*					with psychological adjustment (r=.30, p<.01) *Vitality* - Timeline positively associated (r=.25, p<.05) and Biological cause negatively associated with vitality (r=-.29, p<.01). <u>Predictors of psychological adjustment</u> - Dissimilarity on Identity (β=-.29, p<.05), Controllability (β=.28, p<.05), Cause (psychological) (β=-.34, p<.05) and Cause (environmental) (β=.38, p<.05) **Addison's Disease** <u>Dissimilarity in illness representations</u> - Significant difference on Timeline (Not reported, p<.001), Curability/controllability (Not reported, p<.05), and Consequences (Not reported, p<.001). <u>Health outcomes</u> *Physical functioning* - Identity (r=-.32, p<.01), Timeline (r=-.38, p<.001), and Consequences (r=-.30, p<.01) all negatively associated with physical functioning

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Heijmans, de Ridder & Bensing (1999) *(cont.)*					*Social functioning* - Identity (r=-.39, p<.001, Timeline (r=-.57, p<.001), and Consequences (r=-.48, p<.001) all negatively associated with social functioning *Psychological adjustment* - Timeline (r=-.37, p<.001, and Consequences (r=-.26, p<.05) negatively, and Controllability (r=.24, p<.05) positively, associated with psychological adjustment *Vitality* - Identity (r=-.27, p<.05), Timeline (r=-.39, p<.001). and Consequences (r=-.36, p<.01) all negatively associated with vitality Predictors of physical functioning - Relationship satisfaction (β=.27, p<.05) - Dissimilarity on Timeline (β=-.43, p<.001) and Identity (β=-.24, p<.05) Predictors of social functioning - Spouse burden (β=-.30, p<.01) - Dissimilarity on Timeline (β=-.29, p<.05) and on Identity (β=-.24, p<.05)

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Heijmans, de Ridder & Bensing (1999) *(cont.)*					<u>Predictors of psychological adjustment</u> - Dissimilarity on Timeline (β=-.29, p<.05) and Controllability (β=.26, p<.05) <u>Predictors of vitality</u> - Spouse burden (β=-.20, p<.05) - Dissimilarity on Timeline (β=-.28, p<.01) and Consequences (β=-.27, p<.01)
Karademas, Zarogianno s & Karamvakal is (2010)	• Greece • Cross-sectional • Cardiology outpatient hospital departments • Convenience sampling *Inclusion criteria:* • Past MI, plus history of cardiovascular difficulties since • Age < 70 • Able to complete questionnaires independently	<u>Participants:</u> - 73 participants (8 females, 65 males) - *Age:* 58.82 years (mean), SD=8.79 - Severe Myocardial Infarction <u>Partners:</u> - 73 partners (sex unknown) - *Age:* 55.86 years (mean), SD=9.29	- IPQ-R, using 7 subscales. - Scales of Identity and Cause omitted. - 5-point Likert scale.	<u>Illness-related coping-</u> *Coping with Health Injuries and Problems scale* (21 items). 5-point Likert scale. <u>Self-rated health</u>- Likert scale (1 to 100).	<u>Dissimilarity between participant and partner scores</u> - Sig. difference on Timeline Acute/chronic (t=5.32, p<.01), Personal Control (t=2.06, p<.05), and Emotional representations (t=4.84, p<.01) <u>Health outcomes</u> *Adherence to medical advice* - Treatment Control (r=-.26, p<.05) and Timeline Cyclical (r=-.24, p<.05) negatively associated with adherence to medical advice *Wishful thinking* - Consequences positively (r=-.25, p<.05) and Emotional representations negatively (r=-.33, p<.01) associated with wishful thinking.

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Karademas, Zarogiannos & Karamvakalis (2010) *(cont.)*					<u>Predictors of palliative coping</u> - Dissimilarity on Timeline Acute/chronic (β=.39, p<.05) <u>Predictors of wishful thinking</u> - Dissimilarity on Timeline Acute/chronic (β=.45, p<.01) <u>Type of congruence with self-rated health</u> ns. <u>Type of congruence with instrumental coping</u> - "Similarly high" on Treatment Control (F(2,63)=3.21, p<.05) had higher instrumental coping than "similarly low" and "conflicting" - "Similarly low" on Timeline Cyclical (F(2,63)=4.14, p<.05) had higher instrumental coping than "similarly high" and "conflicting" <u>Type of congruence with palliative coping</u> - "Similarly high" on Personal Control (F(2,63)=3.19, p<.05) had higher palliative coping than "similarly low" and "conflicting" - "Similarly low" on Illness coherence (F(2,63)=3.38, p<.05) had higher palliative coping than

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Karademas, Zarogianno s & Karamvakal is (2010) *(cont.)*					"similarly high" and "conflicting" <u>Type of congruence with wishful thinking</u> - "Similarly high" and "conflicting" on Personal Control (F(2,63)=5.70, p<.01) had higher wishful thinking than "similarly low" - "Similarly low" and "conflicting" on Illness coherence (F(2,63)=5.13, p<.01) had higher wishful thinking than "similarly high" - "Similarly low" on Timeline Cyclical (F(2,63)=3.19, p<.05) had higher wishful thinking than "similarly high"
Richards et al. (2004)	• U.K. • Cross-sectional • Recruited from: 1) Psoriasis specialty clinic, 2) General dermatology outpatient clinics, or 3) Inpatient ward setting. • Convenience sampling *Inclusion criteria:* • Couple co-habiting. • Partner had no	Participants: - 58 participants (28 males, 30 females) - *Age:* 44 years (mean), SD=12 - Chronic plaque psoriasis Partners: - 58 partners (30 males, 28 females) - *Age:* 47 years (mean), SD=13	- IPQ-R, using 7 dimensions. - 5-point Likert scale.	Physical severity of psoriasis- *Self-Assessment Psoriasis Area Severity Index.* Silhouette of body, plus 3 Visual Analogue Scales. Psychological distress-1) *Hospital Anxiety and Depression scale* (14 items). 3-point Likert scale. 2) *Penn State Worry*	<u>Dissimilarity between participant and partner scores</u> ns. <u>Predictors of Patient psychological distress</u> ns. <u>Predictors of Spouse psychological distress</u> **Depression** - Dissimilarity on Emotional representations (β=-.35, p<.01), and Dissimilarity on Timeline

Table 1: Summary of included studies (n=10)

Authors and year	Location / Study design and sampling / Setting / Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
	comorbid medical condition. • Able to speak English.			*Questionnaire* (16 items). 5-point Likert scale.	Acute/chronic (β=-.30, p<.01) **Worry** - Dissimilarity on Consequences (β=-.41, p<.001) and Timeline Cyclical (β=.08, p<.001)
Sterba, DeVellis, Lewis, DeVellis, Jordan & Baucom (2008)	• United States • Cohort (2 time points) • Recruited from: 1) Local patient groups, 2) Rheumatology outpatient clinics, 3) Arthritis resource webpages *Inclusion criteria:* • Married • Diagnosed with RA > 1 year *Exclusion criteria:* • Comorbid fibromyalgia or systemic lupus erythematosus	Participants: - 190 participants (190 female) - *Age:* 49 years (mean), SD=12.9 - Rheumatoid Arthritis Partners: - 190 partners (190 male) - *Age:* 51 years (mean), SD=13.6	- IPQ-R, using 5 dimensions of Personal Control, Emotional Representations, Timeline cyclical, Consequences, and Timeline acute/chronic. -6-point Likert scale.	Psychological adjustment- 1) *Positive And Negative Affect Schedule* (20 items). 5-point Likert scale. 2) *Centre for Epidemiologic Studies Depression Scale* (20 items). 4-point Likert scale. 3) *Satisfaction With Life Scale* (5 items). 7-point Likert scale. 4) *Life Orientation Test-Revised* (10 items). 4-point Likert scale. Arthritis functioning- 7 subscales of *Arthritis Impact Measurement Scale* (number of items not reported). 5-point Likert scale.	Congruence between participant and partner scores - Significant associations on all dimensions (p<.001) Health outcomes *Psychological adjustment* - Personal Control (*r*=.20, p<.05), Illness coherence (*r*=.16, p<.05), Timeline Cyclical (*r*=.17, p<.05), and Consequences (*r*=.19, p<.05) all positively associated with psychological adjustment. Predictors of Patient psychological adjustment - Congruence on Personal Control (β=.16, p<.001), and Timeline Cyclical (β=.10, p<.05) Type of congruence with Patient psychological adjustment - "Similarly high" on Personal Control (F(3,161)=4.61, p<.01) had higher psychological adjustment than "similarly low" or "conflicting".

Table 1: Summary of included studies (n=10)

Authors and year	Location Study design and sampling Setting Inclusion/exclusion criteria	Sample Number, sex, age, health condition	Measurement of illness beliefs	Measurement of outcome variables	Main findings regarding dissimilarity
Sterba, DeVellis, Lewis, DeVellis, Jordan & Baucom (2008) *(cont.)*				<u>Physician ratings of functional status</u>- *Collected from treating rheumatologist* (number of items not reported). Scale not reported. <u>Marital variables</u>- 1) *Kansas Marital Satisfaction Scale* (3 items). 7-point Likert scale. 2) *Quality Marriage Index* (6 items). First five items on 7-point Likert scale, sixth item on 10-point Likert scale. 3) *Perceptions of support* (4 items from previous study). No scale given.	- "Similarly low" on Timeline Cyclical (F(3,161)=5.58, p<.01) had higher psychological adjustment than "similarly high" or "conflicting". - "Similarly high" on Illness coherence (F(3,161)=6.73, p<.01) had higher psychological adjustment than "similarly low" or "conflicting". - "Similarly low" and "patient low, partner high" on Consequences (F(3,161)=5.77, p<.01) had higher psychological adjustment than "similarly high".

Participant characteristics

Sample sizes ranged from 27 (Brannigan, 2006) to 190 couples (Sterba et al., 2008). In general, samples were of a reasonable size, with a mean sample size across the 10 studies of nearly 88 couples (*M=* 87.90) per study. Of the available data (n=9), 39.3% of the participants identified as male and 60.7% as female. Three studies recruited participants of one particular gender; two of these studies stipulated this in their eligibility criteria (Croom, 2012; Sterba et al., 2008), but this remained unclear in the remaining study (Figueiras & Weinman, 2003).

The mean age of participants (n=9) was 52.03 years, with an average standard deviation of 11.02 years. All participants from studies with available demographic data (n=9) were aged between 40-60 years (Ackroyd et al., 2011; Avison & Clarke, 2009; Croom, 2012; Figueiras & Weinman, 2003; Giannousi et al., 2016; Heijmans et al., 1999; Karademas et al., 2010; Richards et al., 2004; Sterba et al., 2008).

Of the 879 partners who took part (n=10), there was a mean age of 53.46 years old. Four studies did not collect information regarding the gender of the partner, but out of the remaining studies (n=6; Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Giannousi et al., 2016; Richards et al., 2004; Sterba et al., 2008), 66.4% partners were male and 33.6% female.

Illness characteristics

The illness types surveyed were heterogeneous in nature, with only four studies surveying the same health condition. This included two studies examining cancer (Croom, 2012; Giannousi et al., 2016), and two looking at myocardial infarction (Figueiras & Weinman, 2003; Karademas et al., 2010). However, there

were also differences within these conditions, with Croom (2012) requiring participants to have a diagnosis of stage III or IV cancer, and Giannousi et al (2016) exploring first-time diagnosis of cancer. Whilst Figueiras and Weinman (2003) required this to be the participant's first occasion of myocardial infarction, Karademas et al (2010) necessitated that participants had experienced significant cardiovascular problems since the myocardial infarction.

Two studies looked at illnesses of neurological origin; Multiple Sclerosis (n=1; Ackroyd et al., 2011) and stroke (n=1; Avison & Clarke, 2009). The remaining studies sampled those with osteoporosis (Brannigan, 2006), Chronic Fatigue Syndrome and Addison's Disease (Heijmans et al., 1999), psoriasis (Richards et al., 2004), and rheumatoid arthritis (Sterba et al, 2008).

From those with available data (n=7), duration of symptoms ranged from 5.82 weeks (Avison & Clarke, 2009) to 18 years (Richards et al., 2004). Two studies focused on first occurrence of the health condition (Figueiras & Weinman, 2003; Giannousi et al., 2016).

Relationship characteristics

Studies with available relationship data (n=5) varied greatly in the relationship variables measured. However, studies indicated that the average couple was in a long-term relationship, with a mean of 22.95 years of either living, or being in a relationship, together (n=3; Croom, 2012; Heijmans et al., 1999; Sterba et al., 2008). Three studies requested couples to have been in a relationship for at least a year prior to their health event (Avison & Clarke, 2009; Croom, 2012; Giannousi et al., 2016),

and four others required couples to be married (Giannousi et al., 2016; Heijmans et al., 1999; Karademas et al., 2010; Sterba et al., 2008).

Measurement of illness beliefs

Just over half of the studies (n=7; Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Croom, 2012; Figueiras & Weinman, 2003; Heijmans et al., 1999; Richards et al., 2004) used the full scales of the IPQ (Weinman, Petrie, Moss-Morris & Horne, 1996) or IPQ-R measure (Moss-Morris et al., 2002). Two studies omitted the scale of Identity (Giannousi et al., 2016; Karademas et al., 2010), and one study (Sterba et al., 2008) selected the five particular subscales of the IPQ-R that were of principal interest. Two studies examined the similarity, or "congruence", of illness beliefs in the couple (Croom, 2012; Sterba et al., 2008), rather than their dissimilarity.

Measurement of health outcomes

The majority of studies (n=6) focused upon outcomes of psychological health (Ackroyd et al., 2011; Avison & Clarke, 2009; Croom, 2012; Giannousi et al., 2016; Richards et al., 2004; Sterba et al.; 2008). One study also measured illness-related coping strategies (Karademas et al., 2010). The remaining studies (n=3) studied both psychological and physical health outcomes (Brannigan, 2006; Figueiras and Weinman, 2003; Heijmans et al., 1999).

Psychological measures across the studies varied notably, though there was some consistency in the use of the Hospital Anxiety and Depression Scale to assess psychological wellbeing (n=5; Avison & Clarke, 2009; Brannigan, 2006; Croom, 2012; Giannousi et al., 2016; Richards et al., 2004). Other psychological measures included measures on expressed emotion (Avison & Clarke, 2009), post-traumatic

growth (Ackroyd et al., 2011), vitality (Heijmans et al., 1999), worry (Richards et al., 2004), satisfaction with life (Sterba et al., 2008), and optimism (Sterba et al., 2008).

Measures on physical health outcomes varied even further, and often adapted general measures for the health condition of interest. Three studies used generic Visual Analogue Scales for participants to evaluate their current functioning (Brannigan, 2006; Karademas et al., 2010; Richards et al., 2004). The two studies investigating neurological conditions also measured cognitive ability (Ackroyd et al., 2011; Avison & Clarke, 2009); one as a covariate (Avison & Clarke, 2009), and one as an independent variable (Ackroyd et al., 2011).

Half of the studies (Brannigan, 2006; Croom, 2012; Figueiras & Weinman, 2003; Heijmans et al., 1999; Sterba et al., 2008) also measured variables regarding the couples' relationship, including its quality (Dyadic Adjustment Scale; Brannigan, 2006; Croom, 2012), communication between the couple (Cancer Rehabilitation Evaluation System; Croom, 2012), and relationship satisfaction (Kansas Marital Scale; Sterba et al., 2008).

All studies (n=10) utilised self-report measures, with two studies obtaining supplementary objective medical information from health records (Brannigan, 2006) or the treating clinician (Sterba et al., 2008).

Partners often were asked to complete the same measures as participants, apart from ratings of physical function (n=6; Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Croom, 2012; Giannousi et al., 2016; Richards et al., 2004). In one study (Avison & Clarke, 2009), partners completed an additional assessment of their expressed emotion. The remaining four studies only asked for partners' ratings of

illness representations (Figueiras & Weinman, 2003; Heijmans et al., 1999; Karademas et al., 2010; Sterba et al., 2008).

Statistical analyses

Most studies examined difference in the couples' illness representations initially by univariate analysis through correlations (Ackroyd et al., 2011; Avison & Clarke, 2009; Brannigan, 2006; Croom, 2012; Giannousi et al., 2016; Heijmans et al., 1999; Karademas et al., 2010; Sterba et al., 2008). The majority of studies (n=7; Ackroyd et al., 2011; Brannigan, 2006; Croom, 2012; Heijmans et al., 1999; Karademas et al., 2010; Richards et al., 2004; Sterba et al., 2008) then undertook regression analyses to explore dissimilarity/congruence as a predictor. Several studies additionally divided couples into groups depending on the direction of their beliefs, and undertook multivariate analysis examining differences across health outcomes (Croom, 2012; Figueiras & Weinman, 2003; Sterba et al., 2008), or coping strategies (Karademas et al., 2010).

Main study findings

Associations between Dissimilarity and health outcomes

<u>Physical health</u>

Two out of the three studies investigating physical health outcomes (Brannigan, 2006; Heijmans et al., 1999) discovered significant associations. However, these appeared contradicting. Brannigan (2006) found that the more dissimilar couples were on how they felt about the illness (Emotional representations), the poorer the physical functioning of the participant. This was

echoed by Heijmans et al. (1999) for AD participants, who found that the higher the dissimilarity between the couple on Identity, Timeline and Consequences of the illness, the higher the physical disability. However, for CFS participants, the opposite was found by Heijmans and colleagues (1999); that is, the more dissimilar the couple was regarding the Timeline of the illness, the lower the level of the participant's physical disability.

<u>Psychological health</u>

Significant associations between illness beliefs and psychological health outcomes were generally weak to moderate for both participant and partner. The strongest associations were found on the Emotional representations dimension. This was associated with both anxiety and depression in participants (Brannigan, 2006), and with post-traumatic growth (Ackroyd et al., 2011) and expressed emotion (Avison & Clarke, 2009) in partners. The Consequences dimension showed the highest number of significant relationships. This included positive associations found between dissimilarity with psychological symptoms (Giannousi et al., 2016), and congruence with psychological adjustment (Sterba et al., 2008). There were negative associations demonstrated with social functioning, psychological adjustment, and vitality in AD couples (Heijmans et al., 1999).

Two studies (Avison & Clarke, 2009; Croom, 2012) found no significant relationships on any dimension for psychological outcomes.

Associations between Dissimilarity and coping strategies

Karademas et al. (2010) found negative associations between dissimilarity on Consequences and on Emotional representations with the coping strategy of wishful

thinking. They also discovered weak negative relationships between dissimilarity on Treatment Control and Timeline Cyclical with adherence to medical advice.

Dissimilarity as predictor of coping strategies and health outcomes

In terms of coping strategies, Karademas et al. (2010) found that dissimilarity on Timeline Acute/chronic predicted higher levels of palliative coping and higher levels of wishful thinking by the participant.

Regarding health outcomes, significant predictive relationships were found across the illness representation dimensions, with no particular illness dimension dominating the findings. For participants, it was generally found (n=4) that holding dissimilar beliefs predicted poorer outcomes. Holding dissimilar beliefs on Identity (CFS and AD; Heijmans et al., 1999), Emotional representations (Brannigan, 2006), Timeline Cyclical (Richards et al., 2004), and Timeline (AD; Heijmans et al., 1999) were all significant predictors of worse psychological and physical outcomes, with more congruent beliefs on Personal Control and Timeline Cyclical also predicting better psychological outcomes (Sterba et al., 2008). However, an opposing finding in Heijmans et al.'s (1999) study suggested that dissimilarity on Controllability in fact predicted better psychological adjustment in participants with AD.

For partners, there was evidence to show that dissimilarity on several dimensions led to better outcomes. Two studies found that dissimilar beliefs regarding Consequences predicted higher post-traumatic growth (Ackroyd et al., 2011) and lower worry (Richards et al., 2004) for the partner. Dissimilarity on Emotional representations and Timeline Acute/chronic also predicted lower levels of depression in the partner (Richards et al., 2004). However, there was also evidence to suggest

that dissimilarity on Timeline Cyclical predicted worry in partners (Richards et al., 2004).

Associations between direction of beliefs with coping strategies and health outcomes

Four studies explored the direction of beliefs in the couple with health outcomes (Croom, 2012; Figueiras & Weinman, 2003; Karademas et al., 2010; Sterba et al., 2008).

Overall, when the couple shared more "negative" beliefs on Identity and Consequences, this was associated with poorer outcomes, namely poorer levels of recreational and social functioning (Figueiras & Weinman, 2003), vitality (Figueiras & Weinman, 2003), and poorer psychological adjustment (Figueiras & Weinman, 2003). Higher beliefs in Identity was also associated with higher levels of depression (Croom, 2012) and higher health distress (Figueiras & Weinman, 2003).

Conversely, when the couple had shared "positive" beliefs about Curability/controllability, this was associated with higher dietary change (Figueiras & Weinman, 2003), higher psychological adjustment (Sterba et al. 2008), higher instrumental coping, palliative coping, and wishful thinking (Karademas et al., 2010). Likewise, similarly "positive" beliefs about Timeline Cyclical and Illness coherence had higher psychological adjustment (Sterba et al., 2008), lower anxiety (Croom, 2012), and higher instrumental coping, palliative coping, and wishful thinking (Karademas et al., 2010).

When couples held conflicting views, Sterba et al. (2008) found that on the Consequences dimension, as long as the participant held more "positive" beliefs, their psychological adjustment was unaffected by their partner's "negative" beliefs.

Quality assessment

The methodological quality of the studies is presented in Tables 2 and 3. A critical appraisal tool specifically developed for cross-sectional studies (Appraisal tool for Cross-Sectional Studies, AXIS; Downes et al., 2016) was deemed most appropriate to evaluate the studies in this review. The critical appraisal of the Introduction and Methods sections is presented in Table 2, with the remaining Results, Discussion, and Other presented in Table 3.

A tick (✓) demonstrates that the criterion has been deemed to have been met. A cross indicates that either the criterion was not met (✗), and a question mark (*?*) demonstrates that this remains unclear.

In terms of issues affecting external validity, convenience sampling was used in five studies (Brannigan, 2006; Figueiras & Weinman, 2003; Karademas et al., 2010; Richards et al., 2004; Sterba et al., 2008), and the majority of studies (n=8) only utilised one setting for their recruitment. Whilst only two studies (Karademas et al., 2010; Richards et al., 2004) did not report response rates, these varied widely from 21% (Brannigan, 2006) to 84% (Figueiras & Weinman, 2003). Only two studies (Croom, 2012; Sterba et al., 2008) took steps to measure and analyse non-responders, or to compare their study population to baseline statistics.

Regarding internal validity, several studies (n=4) did not seem to present all of the data, including descriptive data on dissimilarity scores (Heijmans et al., 1999),

demographic data (Brannigan, 2006), and all of their non-significant results (Ackroyd et al., 2011; Figueiras & Weinman, 2003). One study (Heijmans et al., 1999) reported low internal reliabilities for several of their measures and also omitted information regarding their measures. For one study (Avison & Clarke, 2009), there were significant limitations with two of their measures which they described later in their Discussion.

Table 2: Critical appraisal of study quality for Introduction and Methods

Study (authors and date)	*Introduction* Clear aims/objectives?	*Methods* Appropriate study design?	Justified sample size?	Clearly-defined target population?	Sample frame taken from an appropriate population base?	Appropriate selection process for representative population?	Measures taken to address and categorise non-responders?	Risk factor and outcome variables appropriate to aims of study?	Risk factor and outcome variables measured using valid and reliable measures?	Clear statistical significance/precision estimates?	Methods sufficiently described for repetition?	*Comments*
Ackroyd et al. (2011)	✓	✓	?	?	✓	✓	✗	✓	✓	?	✓	Unclear inclusion criteria; Opportunity sampling; No information about non-responders
Avison & Clarke (2009)	✗	✓	✓	✓	✓	✓	✗	✓	✗	✓	✓	Lack of coherent narrative in Introduction; No analyses on non-responders; Faults with measures
Brannigan (2006)	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	Low response rate; No information about non-responders

Table 2: Critical appraisal of study quality for Introduction and Methods

Study (authors and date)	Clear aims/objectives?	Appropriate study design?	Justified sample size?	Clearly-defined target population?	Sample frame taken from an appropriate population base?	Appropriate selection process for representative population?	Measures taken to address and categorise non-responders?	Risk factor and outcome variables appropriate to aims of study?	Risk factor and outcome variables measured using valid and reliable measures?	Clear statistical significance/precision estimates?	Methods sufficiently described for repetition?	*Comments*
Croom (2012)	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	Missing declaration of statistical level
Figueiras & Weinman (2003)	✓	✓	?	✓	✓	✓	✗	✓	✓	✓	✓	Unclear inclusion criteria; Timeline subscale reduced to one item; No analyses on non-responders
Giannousi et al. (2016)	✓	✓	?	✓	✓	✓	✗	✓	✓	✓	✓	No information about non-responders

Table 2: Critical appraisal of study quality for Introduction and Methods

Study (authors and date)	Clear aims/objectives?	Appropriate study design?	Justified sample size?	Clearly-defined target population?	Sample frame taken from an appropriate population base?	Appropriate selection process for representative population?	Measures taken to address and categorise non-responders?	Risk factor and outcome variables appropriate to aims of study?	Risk factor and outcome variables measured using valid and reliable measures?	Clear statistical significance/precision estimates?	Methods sufficiently described for repetition?	*Comments*
Heijmans et al. (1999)	✗	✓	?	✓	✓	✓	✗	✗	✗	✓	✗	No information about non-responders; No information regarding relationship measure; Low internal reliabilities on measures
Karademas et al. (2010)	✓	✓	✓	✓	✓	✓	✗	✓	?	✓	✓	No information about non-responders; Opportunity sampling
Richards et al. (2004)	✓	✓	?	✓	✓	?	✗	✓	?	✓	✓	No analyses on non-responders; Internal consistencies of measures not reported
Sterba et al. (2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Financial incentive to taking part

Table 3: Critical appraisal of study quality for Results, Discussion and Other

Study (authors and date)	*Results* Adequate description of basic data?	No concerns about non-response rate? (%)	If appropriate, descriptive information of non-responders given?	Results internally consistent?	Results presented for all analyses described in Methods?	*Discussion* Discussions and conclusions justified by results?	Limitations discussed?	*Other* Any funding sources or conflicts of interest?	Ethical approval/ consent of participants obtained?	*Comments*
Ackroyd et al. (2011)	✓	✓ (63%)	✗	✓	✗	✓	✓	?	✓	No justification on statistical procedure; Does not report all non-significant results; Does not analyse gender
Avison & Clarke (2009)	✓	✗ (49%)	✗	✓	✓	✓	✓	✗	✓	
Brannigan (2006)	✓	✗ (21%)	✗	✓	✓	✓	✓	✗	✓	Low response rate
Croom (2012)	✓	✗ (76%)	✓	✓	✓	✓	✓	✓	✓	
Figueiras & Weinman (2003)	✓	✗ (84%)	✗	✓	✗	✓	✓	✓	✓	Does not present all results; Funding supported by government organisation

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Table 3: Critical appraisal of study quality for Results, Discussion and Other

Study (authors and date)	Adequate description of basic data?	No concerns about non-response rate?	If appropriate, descriptive information of non-responders given?	Results internally consistent?	Results presented for all analyses described in Methods?	Discussions and conclusions justified by results?	Limitations discussed?	Any funding sources or conflicts of interest?	Ethical approval/ consent of participants obtained?	*Comments*
Giannousi et al. (2016)	✓	✗ (63%)	✗	✓	✓	✓	✓	✓	✓	
Heijmans et al. (1999)	✓	✗ (25%)	✗	✓	✗	?	✓	?	✓	Low response rate; Does not present all results; Conclusions can seem far-reaching
Karademas et al. (2010)	✓	✗	✗	✓	✓	✓	✓	✓	✓	No analysis of demographic variables; Response rate not reported
Richards et al. (2004)	✓	✗	✗	✓	✓	✓	✓	✓	✓	Response rate not reported; Funding partly supported by Psoriasis charity
Sterba et al. (2008)	✓	✗ (74%)	✓	✓	✓	✓	✓	✓	✓	Funding partly supported by Arthritis Research charities/centre

Discussion

The main research question of this systematic review concerned the extent to which dissimilarity in couples' illness representations was associated with coping strategies and health outcomes. This systematic review found ten studies addressing this question, though they were more heterogeneous than expected. However, the narrative synthesis of data enabled some preliminary judgements to be discerned.

There were few studies looking at physical health outcomes, and the findings in one of these studies (Heijmans et al., 1999) appeared contradicting on the dimension of Timeline. Whilst there was a significant finding such that greater dissimilarity in beliefs about Timeline was associated with poorer physical functioning in an AD population, it seemed that, for those living with CFS, the opposite was true (Heijmans et al., 1999). This is interesting, given that several couples' therapy interventions aimed at increasing shared understanding (developed by Keefe et al., 1996, 1999, 2004) have shown reduced levels of pain reported by participants. With these findings occurring within the same study design, this suggests there may be illness-specific differences. Heijmans et al. (1999) deliberately selected the conditions of CFS and AD for comparison due to their shared cardinal symptom of fatigue, but differences in number of comorbid symptoms, impact, and clarity of treatment. This suggests that characteristics of different illnesses may play a part in the dissimilarity of couples' beliefs.

With respect to psychological outcomes, the significant associations with illness representations for both participant and partner were mostly weak to moderate. The strongest, and highest number of, associations seemed to occur on the Emotional

representations and Consequences dimension. Firstly, higher dissimilarity on Emotional representations was associated with higher levels of participant depression and anxiety (Brannigan, 2006), and higher levels of expressed emotion by the partner (Avison & Clarke, 2009). However, this link was not universal; Ackroyd et al. (2011) found this dissimilarity was associated weakly with post-traumatic growth for the partner. The existing dyadic models of coping do not specifically outline how emotional representations may influence coping. However, these findings indicate that the role of emotions regarding the illness, and their expression, may play an important part in health outcomes.

The illness representation dimension of Consequences had the highest number of significant associations; however, these were primarily for the participant, not the partner. The potential for an illness to have wide-ranging impact upon a couple's daily life and relationship has been discussed in the couples' therapy literature (e.g. Revenson & DeLongis, 2011), and a major component in interventions is the couple's discussion of the illness' consequences upon the individual, couple, and others (Baucom, Whisman & Paprocki, 2012). In this review, there was a consistent finding of higher dissimilarity in this dimension being associated with worse psychological outcomes for the participant (Giannousi et al., 2016; Heijmans et al., 1999; Sterba et al., 2008), but most associations were non-significant for the partner. In fact, the only significant association for the partner was with higher levels of their post-traumatic growth (Ackroyd et al., 2011). This suggests that dissimilarity on the Consequences of the illness can have very different outcomes for participant and partner, which may need to be considered by clinicians facilitating these interventive discussions.

Regression analyses were undertaken in most studies to examine the extent to which dissimilarity in representations predicted health outcomes. Apart from one opposing finding (Heijmans et al., 1999), it was unvaryingly found that holding dissimilar beliefs predicted poorer physical health and psychological outcomes for the participant. Dissimilarity was also related to particular coping strategies, such as palliative coping and wishful thinking, which have been related to lower levels of wellbeing (McCabe, McKern & McDonald, 2004). These findings were in contrast to the majority of the results for psychological outcomes for partners, whereby dissimilar beliefs were associated with post-traumatic growth (Ackroyd et al., 2011), lower worry (Richards et al., 2004), and lower depression (Richards et al., 2004). This was unexpected, given that research into cancer has found that partners can demonstrate similar levels of psychological symptoms to the participants themselves (e.g. Ben-Zur, Gilbar & Lev, 2001; Dorros, Card, Segrin & Badger, 2010; Northouse, 1992). However, it has been suggested that partners may hold a more medically-accurate perspective of the illness (Heijmans et al., 1999), or perhaps that, particularly for illnesses involving daily management and high levels of impact, that spousal "burnout" can occur which stops the continuing input of the partner (Helgeson, Snyder & Seltman, 2004). In relation to the existing models of dyadic coping, this lack of shared appraisals is not concordant with the DCM theory (Berg & Upchurch, 2007), but may reflect a lack of shared illness ownership, responsiveness from the partner, or ineffective individual coping strategies in the CTM (Badr & Acitelli, 2017). Further longitudinal research is clearly warranted to chart the processes in both participant and partner that result in these different outcomes.

Looking at the interaction between the type of couple belief with outcome, when the couple shared more "negative" beliefs on the dimensions of Identity and Consequences, this was associated with poorer outcomes (Croom, 2012; Figueiras & Weinman, 2003). When they shared more "positive" beliefs on Curability/controllability, Timeline Cyclical and Illness coherence, these had more favourable outcomes (Croom, 2012; Figueiras & Weinman, 2003; Karademas et al., 2010; Sterba et al., 2008), and were related to more adaptive coping strategies, such as instrumental coping (Karademas et al., 2010). These associations between the direction of beliefs on these particular illness representations with these outcomes have been consistently found in the literature for individuals (Dempster et al., 2015; Hagger & Orbell, 2003; Hagger et al., 2017). This also supports the underpinning idea in the models of dyadic coping that shared appraisals leads to dyadic coping and particular outcomes (Badr & Acitelli, 2017).

Furthermore, Sterba et al. (2008) found that, for the most part, when couples held more "positive" views, they had significantly higher psychological adjustment than if they held dissimilar views or were similarly "negative" in views. This was suggested by the authors to potentially reflect the importance of optimism (Scheier & Carver, 1985) in a dyad's beliefs. As this study measured at two time points, it could be speculated that the individual might be undertaking effective coping resulting in improved outcomes without the involvement of the partner, as may be suggested in the CTM (Badr & Acitelli, 2017).

This review draws attention to promising areas for clinical interventions in couples' therapy. The finding of dissimilarities within couples, particularly their beliefs regarding Emotional representations and Consequences, illustrates that there

may be fruitful areas for clinicians to assess and intervene to increase shared understanding and improve psychological outcomes especially. This may be through the use of joint psychoeducation, which enables addressing information about the illness at the same time as engaging couples' reactions to the information (Baucom et al., 2012). It also appears to be of potential importance to consider how to support couples to help one another to generate optimism when they hold conflicting or similarly negative beliefs. Given the differences found across health conditions in this review, this suggests that further research may need to investigate the potential for condition-specific couples' interventions (Baucom, Shoham, Mueser, Daiuto & Stickle, 1998; Fischer, Baucom & Cohen, 2016). However, given that research into individuals' interventions targeting illness representations is in need of further substantive evidence of its efficacy, the same conclusion can also be drawn for couples' interventions.

In terms of theoretical implications, the study highlights the differences between participants and partners' beliefs and outcomes, lending support to the contemporary research focus on both members in dyadic models of coping (Revenson & DeLongis, 2011). Indeed, the associations between dissimilarity and outcomes for the participant suggest that the role of the partner is more significant than initially conceptualised in the CSM and other health belief models. However, the processes between shared illness representations, coping, and health outcomes remain somewhat uncertain in terms of dyadic coping models. The finding that the participant could have improved psychological adjustment if they solely held more "positive" views (Sterba et al., 2008) seems to support transactional models such as the CTM (Badr &

Acitelli, 2017). Longitudinal studies examining the same variables from the models of dyadic coping are imperative to align future findings in terms of these models.

There were also several limitations noted with the included studies, which may limit their generalisability and limit the strength of conclusions made in this review. First and foremost, the studies which yielded the highest number of associations (Brannigan, 2006; Heijmans et al., 1999) both had fairly low sample sizes. The quality of Heijmans et al's (1999) study in particular raises concerns. Its weaknesses include several low internal reliabilities on the measures used, one measure not being detailed at all, not all results being presented, and the large number of statistical comparisons made with little discussion of corrections to minimise Type I error.

The heterogeneity of the included studies also limited generalisability in this review. Studies varied greatly in their illness types and characteristics, locations, measures, and their selected variables. For instance, studies across different countries have shown different illness representations of the same illness (Baumann, 2003), whilst couples' coping has also been shown to vary cross-culturally (Zimmermann, Baucom, Kelly & Heinrichs, 2008, as cited in Baucom et al., 2012). The differing norms and expectations of gender and spousal roles could additionally affect the level of interdependence among spouses (Triandis, 2001). Hopefully with future studies in this area, comparison across studies will help to delineate the influence of these variables further.

There were also several areas where bias could have been introduced across studies, introducing threats to both internal and external validity. This includes the lack of data gathered on non-responders (most likely due to their cross-sectional

nature), the frequent use of a single setting for recruitment, the use of convenience sampling, and the use of postal surveys. Many of these factors could have attracted a self-selecting sample, particularly when couples who take part together in research have been shown to be higher in their commitment to the relationship (Hill, Rubin, Peplau & Willard, 1979; Kirby & Davis, 1972).

Overall, the quality of the studies seemed good. Most had clear aims, plus clear links between the theory with the health condition of interest. The majority of studies had a satisfactory sample size, and had considered representativeness. Whilst heterogeneous, most measures had acceptable reliability and validity, and several studies added objective health measures alongside self-report measures. Some studies analysed and controlled for confounding variables where possible. Generally, Methods were clearly-stated, and most followed a similar pattern of analysis. Authors also were generally declarative of the limitations of their studies.

There were also several strengths of the review worth noting. By using a more tailored cross-sectional quality assessment tool, rather than self-selecting scales from a tool developed for intervention studies, this enabled a more in-depth analysis of quality and addressed bias more applicable to cross-sectional studies. As its authors note (Downes et al., 2016), the AXIS also focuses on addressing poor reporting, which many widely-used tools do not tend to do, such as the Cochrane Risk of Bias tool (Higgins et al., 2011). There was a wide range of databases used in the search strategy, in order to try to minimise publication and location bias. This may have introduced its own biases, such as the differences in comparing theses and peer-reviewed journals using the same quality tool. However, it also meant that the

searches undertaken felt thorough, and enabled grey literature to be considered alongside journal articles.

However, there remain several limitations to this review which could be improved upon in future. There were several challenges with pursuing a narrative synthesis of data. As some have highlighted, there is a lack of transparency with the method (Dixon-Woods et al., 2005), and a general lack of clarity and guidance on the process of undertaking a narrative synthesis (Lisy & Porritt, 2016). Additionally, due to its relatively recent development, the AXIS tool has not yet been adapted following feedback from its users; a point which the authors are keen to rectify through encouraging feedback (Downes et al., 2016). It also felt more difficult without a numerical scale to provide a global assessment of their quality for ease of comparison; whilst the authors suggest that the factors are not linear and should not be weighted as such, this made the tool feel more subjective.

This review could be helpful to encourage focus and homogeneity of future research into dissimilarity. It seems vital that these studies prioritise undertaking cohort or longitudinal studies. This would enable researchers to examine the dyadic processes of generating illness representations, developing coping strategies, and health outcomes, and how these change over time, including possible moderators and mediators. It could be particularly beneficial to examine these processes from the point of diagnosis if possible. Revenson declared the temporal process of dyadic coping as "one of the most under-studied in research" (p.534, Revenson, 2003), and with the continued proliferation of cross-sectional studies, this continues to be a viable statement. Additionally, the recognition of the significant role of the partner in illness suggests that adding evidence to dyadic models of coping seems most

promising to pursue in future research, even though evidence on individuals in the CSM has provided us with useful knowledge about the illness experience.

Looking at differences within illness conditions, using consistent and objective measures, recruiting from multiple settings, and longitudinally all seem to be integral priorities to add to the models of dyadic coping and rectify this under-studied process of adjustment.

Empirical study

Abstract

Fibromyalgia (FM) is a long-term health condition whose varying symptoms typically include widespread pain, fatigue, stiffness, and cognitive difficulties. The deleterious impact of FM on the individual has been comprehensively detailed in previous research, including upon the individual's relationship.

The "Common Sense Model" of illness (Leventhal et al., 1980) has found particular beliefs, or "illness representations", occurring in an FM population. However, with the increasing recognition of the role of the partner, no study as yet had investigated the importance of shared illness representations with outcomes in an FM population. Therefore, the aims of this study were to investigate the relationship between dissimilarity, both with coping strategies specific to FM and with health outcomes. Illness-related communication was also included as a potentially relevant variable.

A cross-sectional design across four sources recruited a final sample of 92 couples, from face-to-face and online settings. Participants and partners both completed measures of illness representations and of illness-related communication, whilst participants also undertook measures of physical health, psychological health, and coping strategies of "all-or-nothing" and "limiting" behaviour.

There were fewer significant associations discovered between dissimilarity with coping strategies and outcomes than anticipated, with only two significant relationships discovered. Dissimilarity was found to significantly contribute to FM impact over and above the participant's views solely on the dimension of Timeline

Cyclical. Additionally, there were no significant differences in couples' belief types across the illness representation dimensions, apart from regarding its Consequences. The role of illness-related communication in FM remained unclear after analysis.

The significant findings were discussed in terms of clinical implications, including the potential involvement of partners in planning for cyclical flare-ups of FM. The weak or non-significant associations found between dissimilarity and outcomes, as well as the lack of influence by the partner when the participant held more "positive" beliefs, indicated the importance of the participant's beliefs in their own outcomes.

Limitations of the study were discussed, as well as priorities for future research. These included larger-scale studies, longitudinal design, measurement of variables for both members of the dyad, and the inclusion of illness and relationship variables.

Introduction

Fibromyalgia (FM) is a long-term health condition characterised by the presence of widespread pain, stiffness, fatigue, cognitive difficulties, and sleep disturbance, amongst varying other symptoms (Wolfe et al., 1990, 2010). Prevalence estimates are reported to be around 4-6% in the U.K. population (Fayaz, Croft, Langford, Donaldson & Jones, 2016), with the condition being disproportionately diagnosed in females and those aged 30 to 50 (Lawrence et al., 2008; Wolfe, Ross, Anderson, Russell & Hebert, 1995). Despite increased research attention in recent decades, the aetiology and pathology of FM remains unclear (e.g. Palomino, Nicassio, Greenberg & Medina, 2007; Stahl, 2001), with a lack of objective clinical markers for diagnosis (Wolfe et al., 1990). This can result in a long and convoluted healthcare journey, generally taking at least two years to receive a diagnosis following an average of 3.7 consultations with different medical professionals (Choy et al., 2010). Its very existence as a clinical disorder has been disputed (Cohen & Quintner, 1993; Ehrlich, 2003; Hadler, 1996); indeed, the strength of disagreement from different stakeholders has been termed "fibromyalgia wars" (p.671, Wolfe, 2009). As a result of this, in the process of diagnosis, many have had to struggle with recognition, credibility, and distinction from psychiatric conditions (Hadler & Greenhalgh, 2005; Smith, 2002; Zavestoski et al., 2004). Thus, the field continues to struggle with its theoretical and clinical approaches to FM, which can affect those seeking diagnosis and support.

Furthermore, the available guidance around effective treatments for FM remains inconsistent (Häuser, Thieme & Turk, 2010), with research historically focusing on pharmacological routes to symptom alleviation (Kia & Choy, 2017).

However, there has been a marked shift in recent guidelines towards prioritisation of non-pharmacological treatments, including in Canada (Fitzcharles et al., 2012) and Europe-wide (Macfarlane et al., 2016). Accordingly, there has been evidence to suggest that psychological interventions can have small but robust effects in terms of mood and FM symptoms. A meta-analysis of 23 studies, conducted by Glombiewski and colleagues (Glombiewski, Sawyer, Gutermann, Koenig, Rief & Hofmann, 2010), found significant effects of psychological treatment upon symptom reduction, improvement in mood, and functional status. Additionally, a Cochrane review into FM (Theadom, Cropley, Smith, Feigin & McPherson, 2015) identified favourable effects on physical functioning, pain, and mood in psychological therapies compared to usual-care controls. However, the authors of this review (Theadom et al., 2015) remarked on the low quality of the included studies, the lack of follow-up, and inconsistency in the use of outcome measures. As such, the mechanisms of change in effective psychological treatment remain unclear, and pharmacology remains the "mainstay of therapy" in FM (p.2; Kia & Choy, 2017).

Yet, the detrimental impact of living with the multiple symptoms of FM has been well-documented. Qualitative research has chronicled wide-ranging adverse changes for the individual, including loss of identity (Rodham, Rance & Blake, 2010; Sturge-Jacobs, 2002), ability to undertake activities of daily living (Henrikkson & Burckhardt, 1996), loss of career (Arnold et al., 2008), lower quality of life (Bennett, Jones, Turk, Russell & Matallana, 2007), and feelings of isolation (Rodham et al., 2010). In particular, the disruption of relationships with family and friends has been frequently cited (Arnold et al., 2008; Bigatti & Cronan, 2002; Cunningham & Jillings, 2006; Dennis, Larkin & Derbyshire, 2013; Marcus, Lee Richards, Chambers &

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Bhowmick, 2012; Paulson, Norberg & Söderberg, 2003; Wuytack & Miller, 2011).

This can particularly involve the individual's relationship with their partner. In

Marcus et al.'s (2012) exploratory study, half of the 6,126 participants agreed that the

relationship with their partner had been mildly to moderately *'damaged'* due to FM,

or that FM had contributed to a relationship breakdown. Potential contributory factors

may include guilt and perceptions of being a burden in individuals with FM (Arnold

et al., 2008), disbelief and/or lack of validation by partners (Åsbring & Närvänen,

2002; Lempp, Hatch, Carville & Choy, 2009), the invisibility of the illness (Råheim

& Håland, 2006; Söderberg & Lundman, 2001), the unpredictability of FM

preventing engagement in planned activities (Rodham et al., 2010), stigma (Stahl,

2001), and changes in the "carer" role in the relationship (Rodham et al., 2010). These

findings highlight the potential importance of including the partner in clinical

interventions for those with FM.

Models of couples' coping in illness

Over the last two decades, researchers have increasingly recognised the

influence of the relationship in illness outcomes, as well as the cognisance that both

participant and partner can be affected by illness (Checton et al., 2015). Several

models have been constructed or specifically adapted to encapsulate the process of

couples' coping in illness, including the Developmental-Contextual Model (DCM;

Berg & Upchurch, 2007), the Systemic Transactional Model (STM; Bodenmann,

1995, 2005), and the Cognitive-Transactional Model (CTM; Badr & Acitelli, 2017).

The CTM and DCM are presented in Figures 1 and 2 (p.22) of the systematic review,

whilst the STM can be found in Appendix 1. These dyadic models are a relatively

recent development in the field, as models of health beliefs and of coping have

historically considered adjustment to illness from an individualistic perspective (Carver & Scheier, 1999; Heckhausen & Schulz, 1995). In these previous models, the role of the partner has been solely perceived as providing information and/or support to the participant (Berg & Upchurch, 2007).

Central to these dyadic coping models is the notion that couples appraise, cope and adjust to illness in a dynamic and reciprocal manner (Badr & Acitelli, 2017). These models differ in several ways, including the type of appraisals, the point at which the couple starts to engage in dyadic coping, the types of coping strategies, the importance of variables such as self-efficacy and communication, and the types of outcomes. Nonetheless, these models all concur that appraisals of the illness influence the coping and adjustment process, and consequently any discrepancies in the couple between appraisal and coping strategies may be precarious for adjustment (Berg, 2006, as cited in Berg & Upchurch, 2007). Whilst the STM (Bodenmann, 1995, 2005) adopts Lazarus and Folkman's (1984) theory of primary and secondary appraisals, both the DCM and CTM incorporate the concept of illness representations from Leventhal and colleagues' "Common Sense Model" (CSM) into their construct of appraisals (e.g. Leventhal et al., 1980; Leventhal, Diefenbach & Leventhal, 1992). With researchers struggling to find strong, direct associations between dyadic coping and individual outcomes predicted by these models (Badr & Acitelli, 2017), further research is needed to elucidate the links between dyadic appraisals, coping, and outcomes in illness. In particular, given the validity of the role of illness representations in coping and outcomes on an individual basis in the CSM, it may be helpful to focus on such beliefs in a dyadic model.

The CSM in Fibromyalgia

As described in the systematic review (p.16-17), the CSM proposes that people construct "common sense" cognitive and emotional representations of their illness, based on the various sources of information available to them. These then determine their use of particular coping strategies and influence subsequent outcomes (Leventhal & Cameron, 1987).

For individuals with FM, it has been found that individuals often have predominantly negative perceptions of their FM compared to other health conditions (Glattacker, Opitz & Jäckel, 2010; Stuifbergen, Phillips, Voelmeck & Browder, 2006; van Ittersum, van Wilgen, Hilberdink, Groothoff & van der Schans, 2009; van Wilgen, van Ittersum, Kaptein & Wijhe; 2008). The dimensions of Curability/controllability and Consequences have been found to play a particularly key role in relation to physical and social functioning (Glattacker et al., 2010; Stuifbergen et al., 2006); indeed, in one study, together they explained 41% of FM impact (Stuifbergen et al., 2006). Additionally, there have been particular coping strategies identified in the literature that have been related to outcomes in FM. Firstly, the coping strategy of "limiting" behaviours, whereby the person significantly reduces their activity levels in response to illness, has been associated with greater physical disability and low mood in FM (Turk, Robinson & Burwinkle, 2004). Similarly, the use of "all-or-nothing" behaviours, a pattern characterised by the person pushing oneself to their physical limits followed by exhaustion, have been shown to exacerbate symptoms in FM (Nielson, Jensen & Hill, 2001; Ryan & Campbell, 2010; Vincent, Whipple & Rhudy, 2016).

However, studies into illness representations in FM have at times been hampered by small sample sizes (Stuifbergen et al., 2006; van Wilgen et al., 2008), a wide area of geographical locations, and sole examination of female participants, whether in their recruitment (Stuifbergen et al., 2006) and/or their analysis (Glattacker et al., 2010).

Couples' context and the CSM

Similarly with other health beliefs models, there has been notable criticism levelled at the CSM for overlooking the interpersonal context to managing a health condition (Helgeson & Zajdel, 2017; Jackson et al., 2000). Thus, over the last ten years particularly, there have been a number of studies who have shifted their focus onto looking at both members of the couple using the CSM. One manner of examining couples is to look at the extent of their "congruence", or similarity, and whether this relates to outcomes.

As detailed in the systematic review, dissimilarity in couples' illness representations has been related to poorer physical and psychological outcomes for the participant (Brannigan, 2006; Heijmans et al., 1999; Richards et al., 2004; Sterba et al., 2008), and use of particular coping strategies, such as wishful thinking and palliative coping (Karademas et al., 2010). However, as indicated in the systematic review, findings across conditions have been mixed and at times conflicting (e.g. Heijmans et al., 1999), highlighting the importance of looking at illness-specific representations, coping, and outcomes. Dissimilarity in specific dimensions, particularly Emotional representations and Consequences, has been associated with poorer physical and psychological outcomes (e.g. Giannousi et al., 2016). When both members of the couple hold beliefs in a particular direction, this has been associated

with either improved or worsened health outcomes for the participant dependent on the illness representation dimension (Croom, 2012; Figueiras & Weinman, 2003; Sterba et al., 2008). For these reasons, further exploration into the role of shared beliefs in couples where one has FM is warranted, as there may be findings and implications specific to this population.

Couples' perceptions of the individual's FM symptoms has been investigated in at least four studies thus far, though not using the CSM illness representation dimensions (Bigatti, Cronan, Frederick & Kaplan, 2007; Kool et al., 2010; Kool, van Middendorp, Bijlsma & Geenan, 2011; Lyons, Jones, Bennett, Hiatt & Sayer, 2013). These studies found varying degrees of agreement regarding symptom perception, with variation between poor (Bigatti et al., 2007), fair (Kool et al., 2011) and good (Lyons et al., 2013) agreement in couples. However, these studies have utilised a diverse mix of designs, methodology, and measures, which complicates conclusions. Perhaps most crucially, no study as yet has utilised the CSM to examine dissimilarity/congruence in couples living with FM.

The role of communication

The impact of communication upon physical and psychological outcomes in illness has been well-catalogued (e.g. Goldsmith, 2004; Rosland, Heisler & Piette, 2012; Theiss, 2018), as well as upon more general relationship functioning (e.g. Goldsmith, Miller & Caughlin, 2007; Karney & Bradbury, 1995). It is a key part of the CTM model of dyadic coping (Badr & Acitelli, 2017), affecting whether couples are able to share appraisals and then engage in dyadic coping if the person is struggling to cope by themselves. Without communication, couples may diverge in

their representations as they cope in more disconnected ways (Hampson & Glasgow, 1996).

In FM, studies have chiefly looked at the effect of the partner's responses and its relation to the individual with FM's wellbeing (e.g. Kool, Woertman, Prins & van Middendorp, 2006; Reich, Olmsted & van Puymbroeck, 2006). However, Lyons et al. (2013) found that dissimilarity on beliefs about communication problems were associated with dissimilarity regarding symptoms and physical functioning of the person with FM. The authors (Lyons et al., 2013) suggested that couples' interventions in FM may need to target communication in order to decrease this incongruence. Thus, it seems prudent to include communication in further research investigating the couple with FM, particularly if this may lead to better clinical outcomes.

Aims

As outlined by the authors of the CTM (p.46; Badr & Acitelli, 2017), "more studies are needed to understand the associations between illness representations, appraisals, communication, and coping". This seems particularly pertinent in a health condition such as FM, whereby the impact of symptoms upon the individual and their relationship can be significant. By examining illness representations as conceptualised by the CSM, this could help to clarify the extent of shared illness beliefs in this condition, as well as their relationship to coping and outcomes. The inclusion of the variable of communication about the illness seems paramount, given the relationships found in other illnesses and the compelling findings from Lyons et al. (2013).

Therefore, the hypotheses for this study are as follows:

1) Higher dissimilarity on illness representations within the couple will be associated with more ineffective coping strategies (higher limiting and all-or-nothing behaviours) and poorer health outcomes for the individual with FM.

2) Dissimilarity within the couple will significantly contribute to health outcomes, over and above the illness beliefs of the individual with FM.

3) There will be significant differences between the four possible types of couples' beliefs (similarly high; participant high, partner low; participant low, partner high; similarly low) with the impact of FM.

4) Higher levels of illness-related communication will be associated with fewer ineffective coping strategies (lower all-or-nothing and limiting behaviours) and better health outcomes for the individual with FM.

Methods

A cross-sectional design recruiting couples from four sources was used to examine the research aims. This took place across face-to-face and online settings, resulting in a final sample of 92 couples. Participants and partners completed measures of illness representations and of illness-related communication, whilst participants also undertook measures of their physical health, psychological health, and coping strategies.

Procedure

Ethical approval for the project was granted by Bloomsbury Research Ethics Committee in October 2017 (Appendix 3), following a Provisional opinion requesting changes in August 2017. Due to low rates of recruitment and concerns over unrepresentative sampling, a substantial amendment was requested to the Committee in December 2017, to extend the geographical area of the FMS support groups and to recruit via Facebook FM support groups. This was approved in January 2018 (Appendix 4).

Participants (n=92) were recruited from face-to-face FM support groups across London and South of England (n=9), an NHS community pain service in Berkshire (n=1), and online through the website of a U.K.-based FM charity and U.K.-based FM support groups on Facebook (n=82). A diagrammatic representation of the recruitment process can be accessed in Appendix 5.

For the face-to-face FM support groups, group facilitators (n=15) were contacted by email (Appendix 6). In the groups attended in person (n=5), a first-

person version of the description used for the community pain service (Appendix 7) was verbalised by the researcher, and questionnaire packs distributed to interested participants. The two remaining groups were e-mailed a description and online link for dissemination by facilitators.

In the NHS community pain service, after a meeting with the pain management programme course facilitators, it was agreed that the researcher attend one of the group sessions (of a course of 6 sessions) in person to speak about the research and invite people to take part (Appendix 7).

For online participants, there were two major sources of recruitment. First, a large U.K. FM charity approved the advertisement using a brief description of the study and its online link (Appendix 8). This was posted simultaneously on its website and Facebook page on one occasion in December 2017.

Feedback from service users in FM support groups had suggested accessing participants via Facebook, due to concerns that the research may be omitting those whose symptoms prevented them from regular attendance. Following ethical approval, UK-based Facebook groups were identified using search terms of "UK Fibromyalgia", as well as "Fibromyalgia" and the names of UK towns and cities. The group facilitators (n=75) were sent a private message (Appendix 9) from a specially-created Facebook profile by the researcher, detailing the study and requesting permission to post the description and online link on their support group. Just under half (n=36) of the facilitators gave approval for the post to take place.

For participants recruited in person, questionnaire packs contained the participant's information sheet and consent form (Appendix 10), measures (Appendix

11), debriefing information sheet (Appendix 12), as well as a pre-paid envelope to return the completed questionnaires. Partners' information sheet and consent form (Appendix 13), as well as their measures (Appendix 14), were included in the same pack, and labelled with a number to match with participants' questionnaires.

For those accessing the study online, successful completion of the information sheet and consent form then directed participants to the study questionnaires. Upon completion by participants, an automated e-mail was sent to their partner's e-mail address for them to access. This link contained an embedded 6-digit random number to link their questionnaires with the participant's data set.

Participants

Power analysis for the study was based on a similar study exploring couples' dissimilarity in illness representations and physical wellbeing, looking at CFS and AD participants (Heijmans et al., 1999). This study found significant correlations between particular illness representation dimensions and physical functioning, between r=-0.30 to -0.42. We therefore aimed for a sample size of between 45 and 97 couples for a regression analysis with the five predictor variables of illness representation dimensions, power of 0.8, alpha of 0.05, and a medium-to-large effect size.

Participants were eligible for the study if they were: aged 18 or over, had a diagnosis of FM from a medical practitioner, were able to read and understand English, and had been with their partner for at least 6 months. Partners were eligible if they were aged 18 or over, were able to read and understand English, and were identified by the participant as their partner. Previous studies into couples where one has a health condition have often utilised married couples (e.g. Sterba et al., 2008);

however, we deemed this too restrictive as only 50.9% of the U.K. population identify as being married (Office for National Statistics, 2017). Other studies had also previously used cut-offs of 6 months (e.g. Robins, Caspi & Moffitt, 2000). The stipulation of participants having a diagnosis was deemed necessary, in order that they would have received information from professionals about FM, as per recommended European guidelines (Macfarlane et al., 2016).

The final sample consisted of 92 couples. The demographic details for FM participants are presented in Table 4. The mean age of participants was 45.90 years (range 19-74, SD=12.20), with a predominance of female participants (92.4%). The vast majority of participants were recruited online (89.1%), with only one participant (1.1%) recruited from the community pain service. Most participants had continued education post-high school, with 67.4% (n=62) undertaking a subsequent degree or equivalent. The sample in this study was also largely White British, with only 3.3% (n=3) identifying as a different ethnicity.

Table 4: Demographic details of FM participants (n=92) in this study

Demographic variable	Mean (SD), range
Age	45.90 years (SD= 12.20), range 19-74
Gender *(n, %)*	• 85 female (92.4% of sample) • 6 male (6.5%) • 1 non-binary transgender (1.1%)
Highest educational level attained *(n, %)*	• Apprenticeship (or equivalent): 1 (1%)

Highest educational level attained (cont.) *(n, %)*	• GCSE/O-Level or AS/A-Level (or equivalent): 22 (23.9%) • Vocational degree (or equivalent): 26 (28.3%) • Undergraduate degree (or equivalent): 28 (30.4%) • Postgraduate degree or other (or equivalent): 10 (10.9%) • Missing data: 5
Ethnicity *(n, %)*	• White English/Welsh/Scottish/Northern Irish/British: 85 (92.4%) • White- Any other White background: 1 (1.1%) • Any other ethnic group: 2 (2.2%) • Missing data: 4
Recruitment source *(n, %)*	• *Online*- 82 (89.1%) • *Community*- FM support groups- 9 (9.8%) • *Community*- Pain centre- 1 (1.1%)

Measures

Participants completed five measures regarding; illness representations, impact of FM, coping strategies, psychological distress, and illness-related communication. These were designed to take around 15-20 minutes to complete. Their partners completed two measures regarding their illness representations of the participant's FM and the illness-related communication with their partner. This was intended to take around 5-10 minutes to complete.

Illness representations

To measure participants' illness representations, the Illness Perception Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002) was used (Appendix 11). A slightly re-worded version was used to assess partners' representations of the participant's illness (Appendix 14). This use of re-wording to create the partner's version of the IPQ-R has been undertaken in similar studies (e.g. Figueiras & Weinman, 2003; Heijmans et al., 1999; Richards et al., 2004; Sterba et al., 2008).

Whilst the IPQ-R has nine subscales, several researchers have selected particular subscales according to the primary interests of their study (e.g. Sterba et al., 2008). The authors of the questionnaire (Moss-Morris et al., 2002) have encouraged researchers to adapt the measure to their "particular illness and research setting" (p.14; Moss-Morris et al., 2002). Thus, the scales of Timeline Acute/chronic (6 items), Timeline Cyclical (4 items), Consequences (6 items), Personal Control (6 items), and Illness coherence (5 items) were all included in the study.

The questionnaire records responses on a 5-point Likert-type scale, ranging from *strongly disagree* to *strongly agree.* Whilst there are no particular cut-off scores

for the IPQ-R, it is suggested that higher scores indicate higher levels of each representation (Moss-Morris et al., 2002); for instance, higher scores on the Timeline Acute/chronic dimension indicate that the person views the FM as more chronic in nature. Higher scores on the Timeline Acute/chronic, Timeline Cyclical, and Consequences dimensions represent more "negative" beliefs about the person's condition, whilst higher scores on the Personal Control and Illness coherence dimensions indicate more "positive" beliefs ("The Illness Perception Questionnaire Website", n.d.).

In the original paper (Moss-Morris et al., 2002), all subscales showed acceptable internal consistency, ranging from α=.79 for Timeline Cyclical to α=.89 for Timeline Acute/chronic, as well as sound discriminant, known group and predictive validity. In this study, the internal reliability of all subscales was also acceptable (ranging between α=.71 for Timeline Acute/chronic to α=.90 for Illness coherence for participants, and between α=.74 for Consequences to α=.89 for Timeline Acute/chronic for partners).

Impact of FM

To assess the impact of FM, the Revised Fibromyalgia Impact Questionnaire (FIQ-R) was used (Bennett et al., 2009) (Appendix 11). This is a 21-item self-report questionnaire, subdivided into three domains of Functioning (9 items), Impact (2 items), and Symptoms (10 items). Participants rate items on an 11-point Likert-type scale, ranging from *no difficulty* to *very difficult* (Functioning), *never* to *always* (Impact), and *no* [symptom] to *severe* [symptom] (Symptoms). The three domains are summed to total a composite score indicating overall impact of FM. This total score ranges from 0 to 100, with 100 indicating the highest level of negative impact.

The FIQ-R has shown strong internal reliability (ɑ=.95) for the overall measure, with good convergent and discriminant validity, and strong associations with the original version of the scale. In this study, the internal reliability of all subscales was acceptable, ranging from ɑ=.78 on the Symptoms subscale to ɑ=.90 on the Functioning subscale, with ɑ=.92 for the overall scale.

Coping strategies

To measure coping strategies, the Behavioural Responses to Illness Questionnaire (BRIQ) (Spence, Moss-Morris & Chalder, 2005) (Appendix 11) was used. The BRIQ is a 21-item self-report questionnaire, divided into four scales; all-or-nothing behaviour, limiting behaviour, emotional support-seeking, and practical support-seeking. These are rated on a 5-point Likert-type frequency scale, of how often the person has found themselves responding with these behaviours, from 0 *(not at all)* to 5 *(every day).*

As approved by its authors (Spence et al., 2005), the two scales of all-or-nothing (6 items) and limiting (7 items) subscales were selected for use in this study. These scales were described by the authors as the most relevant for further investigation in the development and course of other health conditions (Spence et al., 2005).

Spence et al. (2005) reported good internal reliability for both all-or-nothing (ɑ=.81) and limiting behaviour (ɑ=.89). The all-or-nothing subscale also showed good predictive validity of subsequent symptoms. Cronbach's alpha in this study was fair to good, with ɑ=.82 for all-or-nothing behaviours and ɑ=.78 for limiting behaviours.

Psychological wellbeing

To assess psychological wellbeing, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used (Appendix 11). The HADS is a 14-item self-report measure, with two subscales of Anxiety (7 items) and Depression (7 items). The HADS was developed specifically to detect mood difficulties in medical settings (Zigmond & Snaith, 1983), and has been utilised in the FM population (e.g. Vallejo, Rivera, Esteve-Vives & Rodríquez-Muñoz, 2014). Participants are asked to select the extent to which they agree with a statement regarding how they have been feeling in the past week, with 4 possible options on a Likert-type scale. The two subscales are able to be analysed separately (Zigmond & Snaith, 1983), but it has been recommended that a composite score may be more appropriate in FM individuals (Luciano, Barrada, Aguado, Osma & García-Campayo, 2014). A higher total indicates higher levels of psychological distress.

A review of the 747 studies using the HADS (Bjelland, Dahl, Haug & Neckelmann, 2002) found good internal consistency of α=.83 for the anxiety subscale and α=.82 for the depression subscale. In this study, the internal consistency for the anxiety subscale was α=.84. However, the fourth question on the depression subscale (Q.8: "I feel as if I am slowed down") showed a concerning item-total correlation of .087, well below the recommended 0.3 threshold for inclusion (Field, 2018). This item has been removed previously in studies of Chronic Obstructive Pulmonary Disease (Phan et al., 2016) and Motor Neurone Disease (Gibbons et al., 2011) participants. Thus, with fatigue being a principal symptom of FM (Wolfe et al., 1990), this item was removed in order to increase specificity and sensitivity to psychological

distress in this population. This resulted in an internal consistency of α=.82 on the depression subscale, and an internal reliability for the overall measure of α=.86.

<u>Illness-related communication</u>

For measuring the couple's level of communication about the participant's illness, the Couples' Illness Communication Scale (Arden-Close, Moss-Morris, Dennison, Bayne & Gidron, 2010) was used (Appendix 11). This is a brief 4-item scale, which is slightly re-worded for the partner's version (Appendix 14). Participants and partners rate the extent to which they agree with each item on a 5-point Likert-type scale, ranging from *disagree strongly* to *agree strongly*. A total score is then summed, with higher scores indicating better illness-related couple communication.

Arden-Close et al. (2010) reported good internal consistencies for participants (α=.84) and partners (α=.80), as well as good convergent validity, construct validity, and acceptable test-retest validity. Cronbach's alphas in this study were fair to good, with α=.82 for participant and α=.77 for partner.

Results

Treatment of Data

All analyses were undertaken using IBM SPSS Statistics version 21. Significance level was set at $p<0.05$.

Prior to exploring any significant associations between variables and health outcomes, the normality of their distribution was checked by using visual inspection of box-plots and histograms, means, medians and standard deviations (SDs), and statistical analysis of skewness and kurtosis. On the main study variables of the illness representation subscales, three significant outlying scores were identified, and Winsorized to the next highest score that was not an outlier (Field, 2018).

Demographic variables

The demographic variables of gender, ethnicity, and recruitment source were unable to be statistically examined, due to insufficient numbers in their categories. The demographic variables of age and educational level were statistically examined to check any significant relationships with health outcomes. A one-way independent ANOVA found no significant differences between age groups in health outcomes (p values between $p=.146$ to $p=.972$). However, a one-way independent ANOVA found a significant effect between educational attainment in measures of psychological distress ($F(3,82)=4.55$, $p=.04$). Post-hoc comparisons using Least Significant Difference tests found that those with an undergraduate degree ($M=16.00$, SD=6.25) scored significantly lower on psychological distress than those educated to GCSE or

A-Level (*M*=21.10, SD=6.42), and those who had achieved a vocational degree (*M*=21.58, SD=6.24).

Study variables

The descriptive statistics for each study variable for participants and their partners are given in Table 5. For measures that do not detail cut-off scores (IPQ-R and BRIQ), the range of possible scores is provided with each subscale.

Regarding illness representations, the authors of the IPQ-R (Moss-Morris et al., 2002) do not suggest clinical cut-off scores to interpret scores from this measure, though guidance regarding the direction of scores is described on page 88. When comparing to the frequency from the measure, the mean score of each item on the Timeline Acute/Chronic (*M* =4.40; SD=.53), Consequences (*M* =4.16; SD=.55), and Timeline Cyclical (*M* =3.90; SD=.75) indicate that, in general, FM participants tend to agree with their FM being more chronic and cyclical in nature, and as having negative consequences. The mean scores from the Personal Control (*M* =2.91, SD=.80) and Illness Coherence (*M* =3.39, SD=.92) are lower, and place the mean score in the "neither agree nor disagree" scale.

The website created by one of the authors from the FIQ-R paper ("Fibromyalgia Information Foundation", n.d.) suggest quartile ranges for interpretation of FIQ-R scores. The original paper developing the FIQ-R found a mean severity score of 58.2 (SD=21.6) of the 308 FM participants (Bennett et al., 2009). The quartile ranges given by the Fibromyalgia Information Foundation places the mean of FM participants in this study (*M*=71.86, SD=14.34) in the upper end of the "severe FM" category (scores of 60-74).

In terms of coping strategies, there are no suggested cut-off scores for categorising the person's "limiting" or "all-or-nothing" behaviours. Instead, mean scores on the limiting subscale of $M =3.54$ and on the all-or-nothing subscale of $M=3.67$ indicate behaviours occurring between "some days" to "most days". There was no comparable data on means from the IBS and RA populations surveyed in the original paper (Spence et al., 2005).

For psychological distress measured by the HADS (Zigmond & Snaith, 1983), the merged total of the two subscales ($M =19.63$, SD=6.60), indicates mild/borderline clinical disorder in the average participant in this study sample. Upon closer examination, there was a mean score of 12.13 (SD=4.27) on the Anxiety subscale, and mean of 7.50 (SD=3.47) on the Depression subscale. This indicates the average participant scores in the "moderate" range for anxiety (scores of 11-14) and "mild" score for depression (scores of 8-10).

In terms of the extent of illness-related communication, the mean scores for both participant ($M =13.58$, SD=3.88) and partner ($M =15.07$, SD=3.36) are similar to the ovarian cancer sample (participant $M =13.84$, SD=3.83; partner $M =15.53$, SD=3.21) and MS sample (participant $M =13.61$, SD=3.91) in the original paper (Arden-Close et al., 2010). They also demonstrate a similar finding of participants reporting poorer illness-related communication than partners.

Table 5: Means, standard deviations and ranges for the summed dimensions on each of the study variables for FM participants and partners

Study variable (measure)	FM participants (n=92)	Partners (n=92)
Illness perception dimensions (IPQ-R)		
Timeline Acute/Chronic *(possible range 6-30)*	26.39 (SD=3.19, range 18-30)	26.17 (SD=3.96, range 12-30)
Consequences *(possible range 6-30)*	25.04 (SD=3.38, range 16-30)	24.97 (SD=3.23, range 17-30)
Personal Control *(possible range 6-30)*	19.58 (SD=4.21, range 6-30)	17.46 (SD=4.83, range 6-30)
Illness Coherence *(possible range 5-25)*	15.87 (SD=4.89, range 5-25)	16.93 (SD=4.62, range 5-25)
Timeline Cyclical *(possible range 4-20)*	15.99 (SD=2.90, range 8-20)	15.63 (SD=2.85, range 8-20)
Impact of FM (FIQ-R)		
Total of Function, Overall Impact and Symptoms subscales (FIQ-R Total)	71.86 (SD=14.34, range 36-99)	
Health behaviours (BRIQ)		
Limiting behaviour *(possible range 7-35)*	24.80 (SD=4.54, range 12-34)	

Study variable (measure)	FM participants (n=92)	Partners (n=92)
All-or-nothing behaviour *(possible range 6-30)*	22.02 (SD=4.20, range 12-30)	
Psychological distress (HADS)		
Total of Anxiety and Depression subscales	19.63 (SD=6.60, range 6-37)	
Level of Illness-Related Communication (CICS)		
Level of communication	13.58 (SD=3.88, range 5-20)	15.07 (SD=3.36, range 8-20)

Dissimilarity in the couple's illness representations

Dissimilarity scores on each illness representation dimension were calculated for each couple by following the procedure outlined by several authors (Heijmans et al., 1999; Richards et al., 2004; Sterba et al., 2008) whereby the partner's raw score was subtracted from the participant's raw score. Negative scores were transformed to be positive, thus creating a continuous variable that described the magnitude of difference from the participant's illness representations.

The descriptive statistics for the dissimilarity scores on each illness representation dimension are presented in Table 6.

Table 6: Means and SDs of dissimilarity scores for each illness representation dimension

Illness representation dimension	Dissimilarity score: mean (SD, range) (n=92)
Timeline Acute/Chronic *(possible range 0-24)*	3.77 (SD=3.08, range 0-17)
Consequences *(possible range 0-24)*	2.58 (SD=2.53, range 0-11)
Personal Control *(possible range 0-24)*	5.12 (SD=3.70, range 0-17)
Illness Coherence *(possible range 0-20)*	4.54 (SD=4.07, range 0-20)
Timeline Cyclical *(possible range 0-16)*	2.45(SD=2.32, range 0-11)

Pearson's *r* correlations were undertaken between participants' and partners' scores for each illness representation dimension, and are detailed in Table 7.

Table 7: Correlations between participants' and partners' scores on each illness representation dimension

Illness representation dimension	Correlation
Timeline Acute/Chronic	.105
	.320
Consequences	.401
	.000*
Personal Control	.132
	.210
Illness Coherence	.202
	.053
Timeline Cyclical	.318
	.002*

*p<.05, ** p<.01

Pearson's *r* correlations were computed for the couples' dissimilarity scores on each illness dimension with health outcomes. Table 8 presents the correlation coefficients between the dissimilarity scores, coping strategies, and health outcomes.

Table 8: Correlations between dissimilarity scores, coping strategies, and health outcomes

Variables	Diss. Timeline Acute/ chronic	Diss. Consequences	Diss. Personal Control	Diss. Illness Coherence	Diss. Timeline Cyclical	Limiting behaviour	All-or- nothing behaviour	Overall FM impact	Psychological distress	Illness- related comm.
Diss. Timeline Acute/Chronic	1.00									
Diss. Consequences	.219 .018*	1.00								
Diss. Personal Control	-.030 .387	-.134 .101	1.00							
Diss. Illness Coherence	-.138 .095	-.105 .160	.200 .028*	1.00						
Diss. Timeline Cyclical	.074 .240	.046 .332	.074 .240	.065 269	1.00					
Limiting behaviour	.168 .055	-.100 .172	-.107 .155	.023 .412	.083 .215	1.00				
All-or-nothing behaviour	.013 .450	.011 .458	.015 .442	.049 .322	.063 .275	-.114 .140	1.00			
Overall FM impact	.130 .109	-.188 .036*	-.097 .180	.120 .127	.086 .208	.552 .000**	.182 .041*	1.00		
Psychological distress	.128 .111	-.126 .115	-.116 .136	.100 .172	.200 .028*	.248 .008**	.117 .134	.551 .000**	1.00	
Illness-related communication	-.202 .027*	-.121 .125	.230 .014*	.180 .043*	.007 .475	.035 .369	-.002 .493	.018 .432	-.201 .028*	1.00

*p<.05, ** p<.01

Hypothesis 1 in this study posited that higher dissimilarity on illness representations within the couple would be associated with poorer health outcomes for the person with FM. There were only two significant associations found; this included a significant weak positive relationship between dissimilarity on Timeline Cyclical and psychological distress ($r(92)=.20$, $p=.03$), and a significant weak negative relationship between dissimilarity on Consequences with FM impact ($r(92)=-.19$, $p=.04$).

In terms of the associations between dissimilarity and coping strategies, there were no significant associations found. Whilst there was a possible positive trend between dissimilarity on Timeline Acute/chronic and limiting behaviour ($r(92)=.17$, $p=.06$), this was not significant at the $p<.05$ level.

Relative contribution of dissimilarity to health outcomes

Hypothesis 2 stated that dissimilarity within the couple would contribute to health outcomes, over and above the illness beliefs of the person with FM. In order to examine this hypothesis, hierarchical multiple regression analyses were undertaken. The predictor variable of the participant's score on the illness representation was included at stage 1, followed by the predictor variable of the couple's dissimilarity score for the illness representation at stage 2.

All assumptions of normality were met. There were a sufficient number of cases for the number of predictor variables (Austin & Steyerberg, 2015; Field, 2018).

Tables 9-18 present the results of the regression analyses for each illness representation dimension with the health outcomes of FM impact and psychological distress.

Table 9: Regression analysis examining the significance of change in explained variance on FM impact for the Timeline Acute/chronic illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Timeline Acute/chronic	.013	.024	2.198	.142	.181
Dissimilarity in couples' beliefs about Timeline Acute/chronic	.027	.025	2.320	.131	.160

Table 10: Regression analysis examining the significance of change in explained variance on FM impact for the Consequences illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Consequences	.305	.313	41.012	.000	.546
Dissimilarity in couples' beliefs about Consequences	.301	.003	.372	.543	-.055

Table 11: Regression analysis examining the significance of change in explained variance on FM impact for the Personal Control illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Personal Control	.067	.077	7.547	.007	-.275
Dissimilarity in couples' beliefs about Personal Control	.064	.008	.748	.389	-.088

Table 12: Regression analysis examining the significance of change in explained variance on FM impact for the Illness coherence illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Illness coherence	-.011	.000	.000	.983	.005
Dissimilarity in couples' beliefs about Illness coherence	-.008	.014	1.307	.256	.120

Table 13: Regression analysis examining the significance of change in explained variance on FM impact for the Timeline Cyclical illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Timeline Cyclical	-.006	.005	.456	.501	.087
Dissimilarity in couples' beliefs about Timeline Cyclical	-.007	.010	.871	.353	.099

Table 14: Regression analysis examining the significance of change in explained variance on psychological distress for the Timeline Acute/chronic illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Timeline Acute/chronic	-.001	.010	.871	.353	.123
Dissimilarity in couples' beliefs about Timeline Acute/chronic	.009	.022	1.978	.163	.149

Table 15: Regression analysis examining the significance of change in explained variance on psychological distress for the Consequences illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Consequences	.129	.139	14.482	.000	.363
Dissimilarity in couples' beliefs about Consequences	.121	.001	.139	.710	-.038

Table 16: Regression analysis examining the significance of change in explained variance on psychological distress for the Personal Control illness representation

Variables	Adjusted R² (%)	R² change (%)	*F* change	p	β
Participant's beliefs about Personal Control	.090	.100	9.961	.002	-.312
Dissimilarity in couples' beliefs about Personal Control	.091	.011	1.116	.294	-.106

Table 17: Regression analysis examining the significance of change in explained variance on psychological distress for the Illness coherence illness representation

Variables	Adjusted R² (%)	R² change (%)	F change	p	β
Participant's beliefs about Illness coherence	-.008	.003	.259	.612	-.048
Dissimilarity in couples' beliefs about Illness coherence	-.010	.009	.847	.360	.097

Table 18: Regression analysis examining the significance of change in explained variance on psychological distress for the Timeline Cyclical illness representation

Variables	Adjusted R² (%)	R² change (%)	F change	p	β
Participant's beliefs about Timeline Cyclical	.000	.011	.985	.324	.139
Dissimilarity in couples' beliefs about Timeline Cyclical	.038	.048	4.560	.035	.222

There were significant contributions to the variance in health outcomes discovered on the Consequences, Personal Control, and Timeline Cyclical dimensions. Regarding Consequences, the participant's beliefs added significantly to the variance for the outcomes of FM impact ($F(1,90)=41.01$, $p<.001$, $R^2=.31$, adjusted $R^2=.31$) and psychological distress ($F(1,90)=14.28$, $p<.001$, $R^2=.13$, adjusted $R^2=.14$), but dissimilarity in the couples' beliefs did not contribute significantly to the variance over and above the participant's beliefs for either FM impact ($F(1,89)=.37$, $p=.54$) or psychological distress ($F(1,89)=.14$, $p=.71$). This was also found to be the case for the dimension of Personal Control, with the participant's beliefs adding significantly to FM impact ($F(1,90)=7.55$, $p=.007$; $R^2=.08$, adjusted $R^2=.07$) and psychological distress ($F(1,90)=9.96$, $p=.002$, $R^2=.10$, adjusted $R^2=.09$), but dissimilarity not adding significantly to FM impact ($F(1,89)=.75$, $p=.39$) or psychological distress ($F(1,89)=1.12$, $p=.294$).

For the Timeline Cyclical dimension, dissimilarity between the couple did significantly add to the variance with psychological distress ($F(1,89)=4.56$, $p=.04$, $R^2=.06$, adjusted $R^2=.04$), whilst the participant's own beliefs did not contribute significantly ($F(1,90)=.99$, $p=.32$). However, dissimilarity in the couple only added 4.8% of the variance, suggesting that there may be other contributing factors either not entered or measured.

Relationships between directions of couples' illness representations with FM impact

Hypothesis 3 stated that there will be significant differences between the types of beliefs within the couple with the outcome of FM impact.

Couples were coded into one of four groups based on a median split for participants and partners for each illness representation variable (1= Participant high, partner high; 2= Participant high, partner low; 3= Participant low, partner high; 4= Participant low, partner low). This process has been undertaken in several previous studies examining couples' congruence of illness representations (e.g. Croom, 2012; Karademas et al., 2010; Sterba et al., 2008).

Table 19 presents the frequency and percentage distribution of couples in each group of type of illness representation.

Table 19: Distributions of couples in each illness representation group type

	Group type: n, % (n=92)			
Illness representation dimension	Participant high, partner high *(similarly high)*	Participant high, partner low *(conflicting)*	Participant low, partner high *(conflicting)*	Participant low, partner low *(similarly low)*
Timeline Acute/Chronic	24 (26.1%)	27 (29.3%)	24 (26.1%)	17 (18.5%)
Consequences	33 (35.9%)	15 (16.3%)	16 (17.4%)	28 (30.4%)
Personal Control	29 (31.5%)	20 (21.7%)	19 (20.7%)	24 (26.1%)
Illness Coherence	28 (30.4%)	19 (20.7%)	18 (19.6%)	27 (29.3%)

	Group type: n, % (n=92)			
Illness representation dimension	Participant high, partner high *(similarly high)*	Participant high, partner low *(conflicting)*	Participant low, partner high *(conflicting)*	Participant low, partner low *(similarly low)*
Timeline Cyclical	40 (43.5%)	23 (25.0%)	12 (13.0%)	17 (18.5%)

One-way independent ANOVAs were then employed to compare the FM impact scores from the four groups of direction of illness representations. There was no significant difference across groups for FM impact on the Timeline Acute/Chronic subscale ($F(3,88)=.95$, $p=.42$), Personal Control ($F(3,88)=1.26$, $p=.29$), Illness Coherence ($F(3,88)=2.04$, $p=.11$), or Timeline Cyclical ($F(3,88)=1.26$, $p=.29$) dimensions. However, there was a significant group effect found on the Consequences subscale ($F(3,88)=7.15$, $p<.001$). Post-hoc comparisons using the Tukey's HSD test indicated that the mean score for the similarly high group ($M=79.44$, SD=12.91) was significantly different from the participant low, partner high (conflicting) ($M=68.67$, SD=11.25), and similarly low ($M=64.31$, SD=14.56) groups. However, it was not significantly different from the participant high, partner low ($M=72.71$, SD=12.21) group. These means are presented in Graph 1.
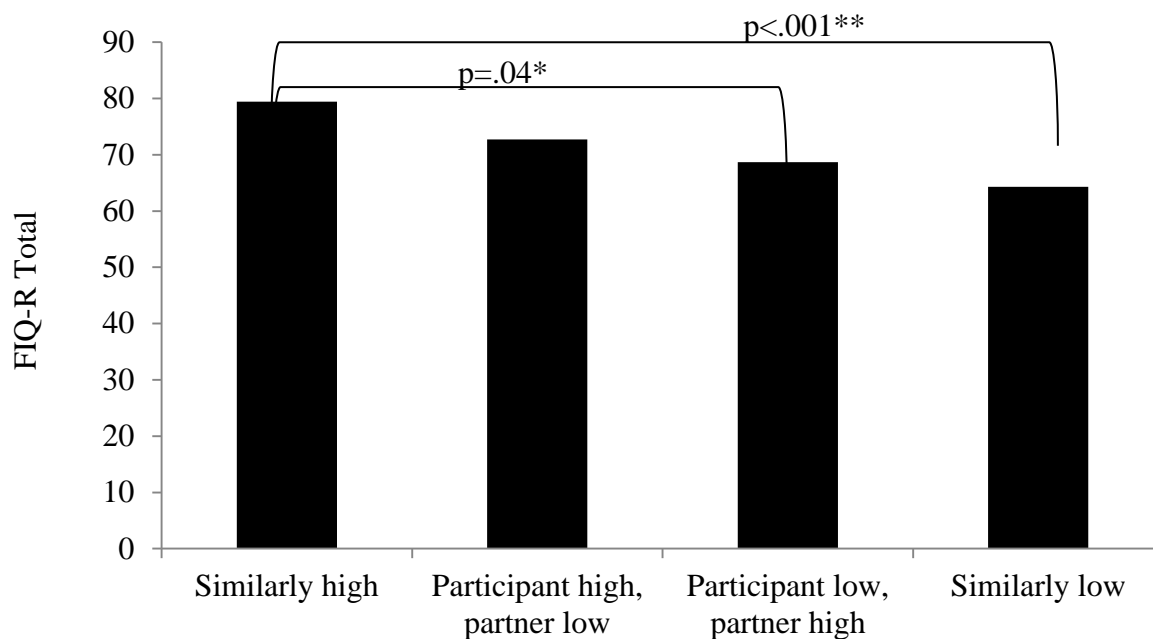
Graph 1: Associations between couples' belief type for Consequences with FM impact

The graph shows FIQ-R Total on the y-axis (0 to 90) with four bars: "Similarly high" (~79), "Participant high, partner low" (~72), "Participant low, partner high" (~68), and "Similarly low" (~64). Significance brackets indicate p=.04* and p<.001**.

*p<.05, ** p<.01

Association between illness-related communication with coping strategies and health outcomes

Hypothesis 4 proposed that higher levels of illness-related communication would be associated with fewer ineffective coping strategies and better health outcomes for the individual with FM. The mean composite score for level of communication between partners was 28.64 (SD=6.29, range 14-40).

Pearson's *r* correlations demonstrated no significant relationships between level of communication with limiting behaviour (r(92)=.04, p=.37), all-or-nothing behaviour (r(92)=-.01, p=.49), or FM impact (r(92)=.02, p=.43). However, there was a weak negative relationship found between level of communication and psychological distress (r(92)=-.20, p=.03).

Discussion

The main objectives of this study were to investigate whether couples'
dissimilarity in their beliefs was associated with coping strategies and health
outcomes for the participant, and if any dissimilarity in the couple contributed to
health outcomes over and above the participant's views. Furthermore, the study aimed
to explore whether the directions of any dissimilar views were associated with
outcomes. Finally, we hoped to further elucidate the role of illness-related
communication in health outcomes in FM.

**Dissimilarity between couples' illness representations, and its relation to coping
strategies and health outcomes**

Hypothesis 1 posited that higher dissimilarity would be associated with more
ineffective coping strategies and poorer health outcomes for the participant, whilst
Hypothesis 2 stated that this dissimilarity would contribute to health outcomes over
and above the participant's illness beliefs.

Regarding Hypothesis 1, there were fewer significant associations found than
anticipated, with only two significant relationships discovered. Firstly, there was a
weak positive relationship discovered between dissimilarity on Timeline Cyclical
with psychological distress; that is, the higher the dissimilarity within the couple
regarding how cyclical the FM is in its nature, the higher the psychological distress
experienced by the participant. This may relate to the cyclical "flare-ups" that many
with FM experience, with over half of participants in a 2-year study experiencing
these episodes (Nöller & Sprott, 2003). These can involve severe and debilitating
pain, fatigue, and flu-like symptoms (Vincent et al., 2016), which participants identify

as being triggered by, and in turn exacerbating, stress (Cunningham & Jillings, 2006; Vincent et al., 2016). Treatment for the individual has suggested pacing and/or relapse prevention strategies for managing flare-ups from a Cognitive-Behavioural therapy perspective (Bennett & Nelson, 2006; Turk & Adams, 2016). However, no recommendations thus far seem to have included the partner or family in this treatment. Yet, findings regarding Hypothesis 2 suggested that dissimilarity contributed a small but significant amount to FM impact, over and above the participant's beliefs. This suggests that a lack of understanding may play a part in the participants' outcomes in these cyclical episodes, and may be helpful to address in psychological support for the couple.

There was also a weak negative relationship found between dissimilarity on Consequences with FM impact, suggesting that the higher the dissimilarity regarding the negative consequences of the FM, the lower the impact of FM for the participant. Across health conditions, beliefs about Consequences have tended to predict poorer outcomes through avoidance behaviours as coping (Dempster et al., 2015), and improved outcomes when problem-focused coping is employed (Hagger et al., 2017). The CTM (Badr & Acitelli, 2017) proposes a transactional process, whereby individuals only engage the partner in generating shared appraisals when the person's coping strategy has been ineffective and if their partner is responsive. It could be possible that participants are in fact employing individual problem-focused coping as an effective coping strategy, meaning that the sharing of appraisals is not required, and the participant is still able to have improved individual outcomes. In concordance with this idea, Revenson (1994) found that incongruence in problem-oriented coping still seemed to result in beneficial outcomes for the participant. This is also supported

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by the finding regarding Hypothesis 2, which found that participants' beliefs about Consequences, but not dissimilarity in the couple, contributed significantly to health outcomes. Additionally, the finding of the participant's beliefs about Personal Control, but not dissimilarity, contributing significantly to outcomes could support this hypothesis. Higher levels of Personal Control have been positively associated with more effective coping strategies (e.g. problem-focused coping strategies, use of social support, and cognitive appraisal) and with better health outcomes (e.g. functioning, vitality, and psychological wellbeing) (Hagger et al., 2017). Whilst unable to infer causality in this study, it could be of benefit to further delineate the processes between beliefs, coping strategies, and outcomes on these particular dimensions.

Direction of dissimilarity

There were no significant differences in belief types across the illness representation dimensions, apart from regarding Consequences. It was discovered that couples with similarly "negative" views of Consequences scored significantly higher on impact of FM than when couples held similarly "positive" views, or if the participant was "positive" but the partner held "negative" views. This finding of similar "negative" views in the couple regarding the illness' consequences relating to poorer outcomes has been found in other conditions, including cancer (Croom, 2012) and myocardial infarction (Figueiras & Weinman, 2003). Furthermore, the finding that participants had significantly lower FM impact if they held a more "positive" view, even if their partner had a more "negative" view, also aligns with a similar finding for psychological adjustment in a rheumatoid arthritis population (Sterba et al., 2008). This may potentially demonstrate effective individual coping regarding this

belief dimension, without sharing appraisals with the partner (Badr & Acitelli, 2017).

In a clinical setting, it has been suggested from the literature on couples' interventions

that targeting worries about the future should be addressed, in order to support

generating optimism and encourage ongoing support in the couple (Martire, Schulz,

Helgeson, Small & Saghafi, 2010). The findings in this study suggest that perhaps this

is only required when the partner, or both members of the couple, may be holding

"negative" beliefs about the consequences of FM.

Role of communication

The role of illness-related communication in FM remained unclear after

analysis, with the only significant finding being a weak negative relationship between

level of communication and psychological distress. This suggests that the higher the

communication in the couple, the lower the distress experienced by the individual

with FM, which accords with existing research. However, the absence of findings

potentially aligns with the CTM (Badr & Acitelli, 2017), which suggests that

communication regarding the illness is only required if the participant's coping

strategies are found to be ineffective.

However, overall, there was a remarkable lack of significant findings for

illness-related communication, given that increased communication has been

consistently linked to improved outcomes in health conditions (e.g. pain, Keefe et al.,

2004; breast cancer, Baucom et al., 2009; Yu & Sherman, 2015). The importance of

the role of communication in couples with FM has been highlighted previously

(Lyons et al., 2013). However, some have suggested that the association between

illness-related communication and psychological distress may be mediated by other

factors, such as relationship intimacy (Manne, Badr, Zaider, Nelson & Kissane,

2010), or partners' responses to self-disclosure (Manne et al., 2004). Thus, this construct may require more comprehensive investigation than this study allowed.

Implications of the study

This study yields several areas of findings that could be of clinical and theoretical utility. Firstly, the association, and contribution, of dissimilarity regarding the cyclical nature of FM with psychological distress suggests that clinical intervention to support couples regarding flare-ups may be potentially beneficial. A study in prostate cancer survivors found that dyadic planning helped to maintain beneficial health behaviours (Keller et al., 2015). Research at present into involving partners in relapse prevention has focused on substance misuse (e.g. Copello, Velleman & Templeton, 2005); thus, further research into the potential involvement of the partner in relapse prevention for flare-ups in FM could be relevant.

Whilst couples' interventions have shown promising efficacy (Shadish & Baldwin, 2003; Fischer et al., 2016), the associations found in this study were weak or non-significant, with a higher similarity of beliefs within the couple in FM than expected. The relatively low dissimilarity mean scores in this study suggest that couples' interventions may not be needed by the vast majority of the couples, even those with "severe FM", yet the range of scores suggests that there may be particular couples in need of intervention. The lengthy duration of symptoms before diagnosis (Choy et al., 2010) may mean that the process of shared appraisals takes place over this protracted period. Before recommendations regarding couples' interventions are made, it needs to be determined as to how and when to help couples who remain holding dissimilar views. Appropriate assessment to identify these couples may also need to be incorporated into future research.

In terms of its theoretical relevance, the applicability of our study to both the CSM and models of dyadic coping is somewhat hindered by its cross-sectional design, which prevents the inference of causality. However, regarding the CSM, the findings are consistent with contemporary thinking that the role of the partner is more influential than previously conceived (e.g. Leventhal et al., 1980). The study also adds to the literature of specific processes that may be occurring for an FM population. In terms of dyadic coping in FM, some of the findings seem potentially concordant with the idea that shared appraisals may occur in a transactional manner, as per the CTM (Badr & Acitelli, 2017). In this process, sharing of appraisals is not necessarily always undertaken, and individuals are able to influence their own outcomes through their individual coping. However, the high similarity in couples may also reflect the established process of shared appraisals, effective dyadic coping configurations, and adjustment by the couple, as per the DCM (Berg & Upchurch, 2007). Certainly, longitudinal research is needed to investigate the sequential interplay of couples' representations, coping, and outcomes in dyads with FM.

Limitations and future research

The dominance of using a cross-sectional design in application of the CSM has been regularly criticised in past reviews (e.g. Hagger & Orbell, 2003; Dempster et al., 2015), and makes it difficult to add to dyadic coping theories, especially transactional models (Badr & Acitelli, 2017; Bodenmann, 1995, 2005). It also could have been beneficial to measure the partner's psychological outcomes to explore the interplay of dyadic processes further. Several studies have discovered the negative impact on the partner's outcomes, rather than the participant's (Ackroyd et al., 2011; Richards et al., 2004), including upon their psychological wellbeing, relationship

satisfaction, and sense of burden (Martire & Schulz, 2012). This may then have ramifications for the partner's own physical health (e.g. Schulz et al., 2009) and ability to support the participant over time (Schmaling & Sher, 2000). Further research should focus on measuring variables for both participant and partner from symptom perception, diagnosis, and to treatment management (Berg & Upchurch, 2007). The use of daily measures from both members and use of multi-level analyses for time-series data is becoming increasingly popular, and may elucidate dyadic processes further (Martire et al., 2012).

Due to the choice not to measure relationship or illness variables, there may also be confounding variables influencing these findings and affecting the internal validity of the study. Lyons et al. (2013) found significant variability across couples with FM in how much incongruence existed, and suggested that spousal strain may be influencing this incongruence. In different health conditions, relationship variables, such as its quality, have been demonstrated to influence psychological adjustment and wellbeing (e.g. Heijmans et al., 1999; Kiecolt-Glaser & Newton, 2001), illness-related communication (Greene et al., 2012), partners' psychological wellbeing (Fang, Manne & Pape, 2001), and improved health markers, such as lower heart rate and improved immunological function (Kiecolt-Glaser & Newton, 2001). There also may be extraneous illness variables in FM, such as baseline health status (Glattacker et al., 2010), that have been shown to influence outcomes. To contribute evidence towards the models of dyadic coping considered in this study, it may also be helpful in future to measure the other constructs included in their models. These include illness ownership, self and dyadic efficacy, and responsiveness of the partner (Badr & Acitelli, 2017; Berg & Upchurch, 2007; Bodenmann, 1995, 2005).

There are also several characteristics of our study sample, which may influence the generalisability of our findings. Our sample were predominantly female (92%), recruited online (89%), and White British (92%). There has been shown to be a clear dominance of females over males in FM (Fayaz et al., 2016). However, there have been shown to be differences between men and women in response to illness; this includes their sharing of experiences (Tamres, Janicki & Helgeson, 2002), the type of support they prefer (Schulz & Schwarzer, 2004), and how comfortable they feel in providing different types of support for each other (Epstein & Baucom, 2002). Indeed, gender is considered an important contextual factor influencing dyadic coping in the DCM (Berg & Upchurch, 2007). There have also been shown to be particular differences in the characteristics of samples recruited online, including younger age (Chou, Hunt, Beckjord, Moser & Hesse, 2009), female (van Uden-Kraan et al., 2008), use of more active coping strategies (Grande, Myers & Sutton, 2006), higher educational level (van Uden-Kraan et al., 2009), and in better health (Cotten & Gupta, 2004). It remains complex to try to deduce the effect that these characteristics could have had; however, a larger-scale study in future may be able to explore the influence of these variables.

Despite its limitations, this study provides a snapshot of the beliefs of couples facing FM, and how these may relate to their outcomes. It has highlighted the importance of the individual at the centre of their care, as well as stimulating ideas as to how to support the couple experiencing dissimilarity in their views on certain dimensions. Future research, particularly from a longitudinal design, could help to consider how to help the couple going through their illness journey, and contribute

further to evidence regarding the dynamic dyadic processes of beliefs, coping, and outcomes.

Integration, Impact and Dissemination

Integration

Aims of the project

The overall aim of this thesis was to examine the role of dissimilarity in couples' illness representations with their coping and health outcomes as per the Common Sense Model of illness (Leventhal et al., 1980; Leventhal & Nerenz, 1985); looking across health conditions in the systematic review, and specifically in a population of people living with Fibromyalgia (FM) in the empirical study. It was hoped that this may also provide evidence towards the processes involved in dyadic coping in illness.

Due to the relatively recent increase in empirical studies, there is a paucity of existing systematic reviews of the CSM, with two reviews incorporating all aspects of the model (Hagger & Orbell, 2003; Hagger et al., 2017), one review examining the role of coping in the model (Dempster et al., 2015), and other reviews focusing on findings within a health condition (e.g. Coronary Heart Disease; Foxwell et al., 2013; Type II Diabetes; Hudson et al., 2014; cancer; Richardson et al., 2017). These reviews have provided findings for the strength and direction of relationships between illness representations, coping, and outcomes from the CSM framework for the unwell individual. However, the influence of the partner in illness has been increasingly recognised, with several models being generated to encapsulate the processes occurring in couples' coping with illness (Badr &Acitelli, 2017). The concept of illness representations is utilised in the appraisal stage of two of these

models (CTM; Badr & Acitelli, 2017; DCM; Berg & Upchurch, 2007), which also look at coping and outcomes for the individual and couple. Thus, it seemed timely and appropriate to investigate the significance of shared illness representations, and its relation to coping and outcomes across health conditions.

In our review, the selected studies were more heterogeneous than expected, across their illness types and characteristics, geographical locations, measures, and variables. This impacted upon the aim to be able to examine them using meta-analysis. However, this also highlighted that there may be illness-specific findings for a FM population, thus underlining the potential value of the empirical study.

Our review yielded findings regarding the existence of dissimilarity in illness representations across health conditions, with the importance of the dimensions of Emotional representations and Consequences particularly demonstrated. Whilst the subscale of Emotional representations was not included in our empirical study, the significance of beliefs about Consequences was also iterated in our FM sample. This suggested some commonalities of particularly pertinent beliefs to be explored in couples.

The systematic review found more significant associations between dissimilarity and outcomes than in our empirical study, particularly regarding psychological outcomes. However, given the moderate-strong nature of correlations between illness representations and outcomes from reviews looking at the individual (Hagger & Orbell, 2003), associations in our review were also weaker than may be expected. The empirical study suggested a higher-than-anticipated level of shared understanding in couples with FM.

This potentially hints at the possible strength of the individual's illness representations in their own health outcomes, rather than dissimilarity in the couple. Both systematic review and empirical study were also concordant in finding that one member of the couple holding "positive" views could benefit outcomes, particularly if this member was the participant. These findings potentially support the transactional models of coping whereby the partner is only involved in sharing appraisals and thus influencing outcomes in certain circumstances (CTM; Badr & Acitelli, 2017; STM; Bodenmann, 2005). However, without further longitudinal research, this remains unanswered in both our review and study.

Notably, the systematic review and empirical study were at times hampered by similar limitations. The critique of the dominance of cross-sectional designs in CSM research, as expressed by other reviews (e.g. Hagger & Orbell, 2003; Hagger et al., 2017) was also noted in the systematic review. However, significant time constraints in the empirical study meant that it would have been exceedingly difficult to conduct a follow-up of participants within the available time period. Furthermore, due to a low number of studies in couples' literature using the CSM and/or the same constructs from models of dyadic coping, both review and study suffered from an absence of consistent measures of coping and health outcomes. This compounded the difficulty in comparing studies, of which there were only a maximum of two in each health condition in the review. In measuring an FM population and using theory from FM individuals to determine the coping strategies and outcome measures in our empirical study, this did not necessarily enhance the ease of comparison across health conditions for future researchers. However,

the review of coping in health conditions using the CSM (Dempster et al., 2015) advocated the use of coping measures tailored to the specific condition, rather than generalised coping measures. Thus, unless studies within conditions become more consistent in their condition-specific measures, coping measures may remain heterogeneous in their selection in future research. The novelty of studies in different conditions also resulted in variability of significance levels, with several studies (e.g. Croom, 2012) in the systematic review adjusting their alpha level to become more conservative. There has also been variation in the illness and relationship variables measured. This was also the case in our empirical study, whereby potential confounding illness and relationship variables were not measured, but could have been affecting outcomes.

Hence, these limitations could have affected the extent to which we achieved our aims. However, in our review, we were able to provide the first known synthesis of the literature regarding dissimilarity and outcomes in couples' beliefs using the CSM in health conditions. This may help to consider the role of illness representations in models of couples' coping, as well as determining which dimensions may be most important to consider in couples' interventions. This also may raise awareness of the differing outcomes for participants and partners when dissimilarity exists. The empirical study gave potential insight into the dyadic interplay specific to FM, as well as the importance of the individual with FM in their own outcomes. Additionally, the sample sizes, in the review and in our empirical study, were mostly satisfactory, thus enabling higher confidence in these findings. Hopefully our review provides ideas for a more consistent direction for future researchers in

this area, including in their designs, measures, and variables. This could ensure that results are comparable and more generalisable.

There seemed to be a natural synergy between the systematic review and empirical study in terms of their theory, rationale, and aims. The stimulus for the systematic review stemmed from the initial development of the empirical study, which was generated by service user feedback from individuals with FM in an Improving Access to Psychological Therapies (IAPT) group. Several clients had expressed that their partner did not understand their FM, and that this lack of understanding was impacting their distress. Upon further investigation, there were no studies found regarding FM couples' illness representations, yet this seemed to be a key component in models of dyadic coping. This guided the evolution of the systematic review, as it was considered that a synthesis of data across health conditions would enable researchers and clinicians to consider the role of dissimilarity of illness representations in couples' coping and outcomes.

The data synthesis of the systematic review was undertaken whilst collecting data for the empirical study. In retrospect, the results of the review meant that there are several modifications that would have been undertaken prior to starting the empirical study. Firstly, whilst there may still have been constraints regarding time, the use of more frequent process measures, ideally daily, could have captured the changes within the couple over time. Additionally, many of the studies in the review utilised measures to examine outcomes in the partner, which could have been a helpful addition in our empirical study. This seemed particularly pertinent given that several findings from the review showed differences between patient and partner outcomes

when dissimilarity existed, including more positive outcomes for the partner. Furthermore, we had selected specific subscales from the IPQ-R measure that were of interest, in order to minimise participant burden. This has been similarly undertaken by several authors (e.g. Sterba et al., 2008), and the IPQ-R authors encourage its adaptation to specific illnesses (Moss-Morris et al., 2002). However, when synthesising the results from the review, this highlighted the impact this could have on comparison of results. This seemed particularly precarious when considering the importance of omitted dimensions such as Emotional representations discovered in our systematic review.

The use of the AXIS tool also highlighted several areas that could have reduced quality in our empirical study, which may have been helpful to anticipate. Its emphasis on data from non-responders could have encouraged us to incorporate a method of follow-up of our participants, to record and categorise the reasons given for decline, or to change some of the methodology. For instance, placing the demographic questions at the beginning of the questionnaires could have been helpful, in order to be analysed even in case of early drop-out. This information regarding non-responders would supplement the data from a previous FM study (Glattacker et al., 2010), which found that drop-outs from the study were more likely to be younger and more psychologically-distressed. The guidelines used in the AXIS tool were also helpful in ensuring quality of the write-up of the study, and to consider what was important in preparation for publication.

Recruitment difficulties and dilemmas

In the FM literature, there has been a dominance of studies recruiting from a singular setting, introducing the bias of potential characteristics specific to these participants. Initially in our empirical study, participants were recruited from 6-week pain management groups in a community setting, FM support groups in Berkshire, and on a UK FM charity website. However, the support groups and the community pain service were experiencing lower attendance than anticipated. This low attendance was attributed by several support group facilitators to the influence of cold weather over the period when we were recruiting, the effect of which has been previously described in a large-scale study in the United States (Bennett, Jones, Turk, Russell & Matallana, 2007). It was suggested by service users that we also may be inadvertently excluding FM individuals whose symptoms prevented them from attending in person. Several service users suggested accessing FM support groups on Facebook. This resulted in an amendment to the original ethics application, asking to recruit using Facebook FM support groups. This was intended to increase the generalisability of the sample and to achieve the desired sample size. The subsequent advertisement, particularly on a large national Facebook FM support group, indeed resulted in the desired sample size for a medium-large effect size being reached, and being able to undertake analyses as planned.

However, the ease of access to a far larger audience of FM individuals also meant that this biased the composition of the sample, with the majority (89%) of the sample then being recruited online. Due to low numbers from the other recruitment methods, any differences were unable to be statistically

examined; however, studies have suggested characteristics of online samples which could have influenced our findings.

Recruiting via a social networking site also presented several dilemmas. Whilst BPS (2012) guidelines recognise the advantage of using social media to facilitate engagement of "hard-to-reach" groups, they also set out guidance for clinicians using this medium, due to the potential for complex ethical predicaments. In advertising the study, there was a range of responses from service users in their comments, and several service users contacted the researcher detailing their FM experiences. This ability to gain prompt and reciprocal feedback from service users was invaluable, and several changes were made as a result of this feedback, such as the discontinuation of the term "syndrome" in describing FM. It also helped to gain insight regarding service users' experiences of NHS services, commercial and pharmaceutical agencies, and perspectives of healthcare professionals. Many reported being grateful for the research, and gave ideas for further research to be undertaken. However, there were also "risks and disadvantages" (American Psychological Association, 2018) for recruiting via these groups. Firstly, the role of being a researcher in groups that were often described as a "safe space" for peer support could feel like a possible encroachment on the purpose of these groups. Additionally, several service users had undergone traumatic experiences, a known risk factor for developing FM (e.g. Weissbecker, Floyd, Dedert, Salmon & Sephton, 2006), and these were sometimes detailed to the researcher. Furthermore, many service users reported perceptions that the role of Psychologist meant that the researcher was implying that their FM and symptoms were psychogenic in nature. The researcher was also asked on

frequent occasions her opinion on the aetiology and state of research of FM, highlighting potential sensitivities regarding the perception of cause and treatment of the condition. Whilst BPS (2012) guidelines were followed, such as having a separate profile for research and obtaining necessary permissions before posting, the guidance from the BPS and British Medical Association (2017) felt inadequate to cover the "unique ethical challenges" (Townsend & Wallace, 2016) that were encountered. This changing and diverse topic could potentially benefit from updated and more comprehensive guidance, as well as providing appropriate training on Clinical Psychology Doctorate courses.

There were also dilemmas in the choice of measures utilised in the study. In order to examine the subscales that were most of interest, the IPQ-R and BRIQ were considered for adaptation by the researchers from their original format. This also gave the advantage of potentially reducing participant burden, which could be relevant in a population whose symptoms include pain, fatigue, and cognitive difficulties (Wolfe et al., 1990). Conversely, this meant that direct comparison to other studies using the full versions of the same measures would be potentially compromised. This disadvantage was also particularly notable during synthesis of the systematic review, with the heterogeneity of studies affecting straightforward comparison. However, the theoretical justification for exclusion of these subscales felt robust enough to vindicate this judgement.

Additionally, the design of our study only involved couples, which introduced an unanticipated dilemma. This meant that those whose relationship status may be related to their FM, such as those who had experienced relationship breakdowns as a result, or who had chosen to remain

single, were excluded. Several service users expressed their frustration at this in both face-to-face and online support groups to the researcher. There was already potential bias introduced by the very nature of couples self-selecting into the study. Research by Marcus et al. (2012) had discovered that just over 10% of their survey respondents felt their FM had contributed to a break-up. Thus, our findings regarding the low dissimilarity of the couple may reflect couples with specific characteristics or processes enabling them to continue their relationship. It could be helpful to either follow couples longitudinally to look at these processes, or use qualitative research to discuss contributory factors with the subset who are no longer in a couple due to their FM.

Service user involvement

The empirical study aimed to incorporate service user involvement throughout its course. As previously stated, the initial idea for the study was developed from service user feedback in groups for FM clients. Upon reflection, it could have been helpful to investigate ideas for research into couples' understanding further with these clients, such as using focus groups. This could have provided interesting differences, as the results from our study showed lower dissimilarity than seemed to be reported anecdotally by these participants. This may have reflected several factors, such as the particular characteristics of the clients attending this service, or biases by the researcher in being interested in this area.

Attending the FM support groups, as well as posting online, gave the opportunity for direct, two-way discussions between researcher and service users. This meant that important feedback about the measures, design,

methodology, and reflections after the study was gained, enabling changes to be made immediately where possible and providing ideas for ways to improve future studies. Several service users gave their details to be involved in the project, and gave feedback on their experience of the study. In future, planning support to prioritise ongoing co-production, such as financial reimbursement (Branfield et al., 2006), would be beneficial to consider.

Impact

Service users

Couples' interventions have tended to fall into three categories (Baucom et al., 1998); couple-based interventions for relationship distress, disorder-specific couples' interventions, or partner-assisted interventions. This has also occurred in couples' treatment in health conditions (Fischer et al., 2016). The dissimilarity shown within the couple across health conditions in the systematic review indicates that perhaps disorder-specific couples' interventions to increase congruence in illness representations may be beneficial to improve outcomes for the service user, particularly on certain dimensions. Effectiveness of this would be evidenced by an increase in shared appraisals, effective coping, and improved outcomes post-intervention, as per the CSM and models of dyadic coping.

For service users with FM, whilst more research is needed regarding the process of shared appraisals, the findings from the empirical study may benefit these couples in the validation of their current coping. The finding regarding dissimilarity in the couple regarding the cyclical nature of the illness also suggests that involving the partner to plan for flare-ups may be of benefit. The findings will be documented in a

lay summary checked beforehand by service users, and disseminated by attendance at face-to-face support groups, and online posting on Facebook support groups. Several FM charities also produce newsletters and magazines, of which an article regarding the research may help to disseminate the findings to service users more widely. Disseminating via these means will also enable feedback with respect to further research directions desired from service users with FM, whose research interests do not appear to have been widely investigated and/or documented.

Researchers

Both the systematic review and the empirical study suggested processes that may be occurring in dyadic coping for particular illnesses. This supports those who had considered the CSM limited in its focus on the individual (Revenson & DeLongis, 2011), as well as its limitations providing further support to researchers who have urged attention to particular designs in future CSM research (e.g. Dempster et al., 2015). This project also provides support towards particular dyadic models of coping; however, as it was not designed according to a specific model, this evidence remains partial.

By disseminating the findings by publication in peer-reviewed journals and attendance of relevant conferences and lectures, this may stimulate research to substantiate the links in particular dyadic coping models, as well as designing studies based on the CSM which address limitations from previous research, such as longitudinal designs.

The empirical study also contributes towards non-pharmacological research into FM, which may increase the dialogue regarding psychological treatments, of which the current evidence is low-quality (Theadom et al., 2015). Future reviews of

psychological treatment for FM, including Cochrane reviews, may indicate if this study has any impact towards an increase in psychological research into this "under-researched and under-recognised" condition (p.109; Carville & Choy, 2008).

Additionally, this review is one of a handful to have utilised the AXIS tool (Downes et al., 2016) to appraise the quality of its studies. Advantages, plus limitations, of the tool will be discussed directly with its developers, who encouraged feedback in personal communication with the researchers prior to the review.

Healthcare professionals

Research into clinicians treating FM have suggested a lack of confidence by healthcare professionals, including in primary care where individuals with FM typically first present and are managed on an ongoing basis (Perrot, Choy, Petersel, Ginovker & Kramer, 2012; Silverwood, Chew-Graham, Raybould, Thomas & Peters, 2017). This also includes professionals still in training who have expressed their anxiety, frustration, and lack of competence in treating "Medically Unexplained Syndromes" (MUS) (Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2015), into which FM is often grouped. In FM, it has been shown that participants have a strong preference for using the internet to source information, yet the quality and readability of these websites are low (Daraz, MacDermid, Wilkins, Gibson & Shaw, 2011). Our findings may suggest that training for clinicians in addressing couples facing illness could be of use, especially in order to improve quality of information conveyed to those with FM. Potential ideas from our findings for this training may include the inclusion of joint psychoeducation by clinicians at diagnosis, and reassurance for clinicians regarding couples' ability to share appraisals and to cope in FM. Evidence

of any changes in confidence and feelings towards MUS will most likely be seen by future research undertaken on similar populations of clinicians.

There is also a wider systemic issue to address in FM, which is the attitude by some healthcare professionals towards the illness. Feedback from service users throughout the empirical study included multiple examples of perceived unhelpful responses from professionals, and research has provided evidence that FM can be considered low "prestige" by medical clinicians in comparison to other health conditions (Album & Westin, 2008).This can influence the teaching and development of medical knowledge, as well as the allocation of resources to conditions, such as provision of services (Album & Westin, 2008). With commissioners being encouraged to support those with MUS (Joint Commissioning Panel for Mental Health, 2017), including IAPT pathways for LTCs (NHS England, 2018), disseminating research about what might be helpful for couples with FM may guide provision of these services, and in turn improve the relationships between patients and providers. This may include using social media to advocate for support for those with FM.

The findings from the review may also be helpful for couple-based organisations, such as Relate, for their work with those experiencing health conditions. Indeed, in their 2015 report *"The Best Medicine? The importance of relationships for health and wellbeing"* (Handley, Joy, Hestbaek & Marjoribanks, 2015), Relate called for the inclusion of couples, families, and social relationships in policy and practice for supporting those with long-term health conditions. This report included briefings to Clinical Commissioning Groups, Health and Wellbeing Boards, and governmental bodies, such as Public Health England and the Department for Work and Pensions. Our findings, particularly from the systematic review, emphasise

the importance of gaining support for those experiencing dissimilar beliefs, due to the effect it may have on their outcomes. Thus, collaboration with these services, including in joint research and lobbying for service provision, may help to gain support for couples experiencing dissimilarity.

Governmental guidelines

NICE guidance for several conditions now incorporate recognition of the need for family/carer involvement, such as epilepsy (NICE, 2016), prostate cancer (NICE, 2014), and motor neurone disease (NICE, 2016). The current NICE guidance available for FM is predominantly based on pharmacological treatment, which has not yet followed the shift to non-pharmacological treatments as outlined in international guidance (Fitzcharles et al., 2012; Macfarlane et al., 2016). International guidance currently suggests several non-pharmacological treatments, including education, exercise, and psychological therapies (Kia & Choy, 2017). However, with the current development of NICE guidelines for persistent pain, registering as an individual stakeholder may enable input as a researcher. The findings from our study suggest that input by the partner may be helpful, particularly regarding the cyclical nature of FM. Thus, by guidelines stipulating this, services may be more aware of involving the partner if needed.

The existence of dissimilarity found in our review also suggests that guidelines for different health conditions may need to be explored and given input at times of their revision. The evidence of this impact will be through its inclusion in NICE guidelines when our findings have shown shared understanding to be important in particular conditions.

Dissemination

In order to disseminate these findings to the relevant academic audience, the most appropriate journals are deemed to be *Psychology & Health* (empirical study) and *Health Psychology Review* (systematic review). Both publications are stringently peer-reviewed, and aim to promote the growth of health psychology. Whilst *Health Psychology Review* focuses on theory-based reviews of empirical studies, *Psychology & Health* endorses the application of psychological approaches and interventions to illness; hence why their different foci seemed relevant for the systematic review and empirical study respectively. The *Health Psychology Review* in particular is the official journal of the European Health Psychology Society, which indicates the ability to disseminate to a wide audience of appropriate members. Both journals are abstracted in leading well-known databases, such as CINAHL, Medline, PsycINFO, and Scopus, which enhances their circulation.

There are also several conferences which may be appropriate for dissemination. These include the 2019 Annual Conference of the European Health Psychology Society, or the British Psychological Society Division of Health Psychology 2019 Annual Conference. Unfortunately, there seem to be few national Fibromyalgia-focused conferences, though there are larger-scale conferences on pain which include research into FM, such as the World Congress on Pain and World Institute of Pain conferences.

To disseminate to service users, firstly, findings from the study will be fed back by lay summary to those who took part in the study. This will take place using the preferred method of contact detailed by the participant. Prior to dissemination, the content of this information sheet, including feedback on the language used, will be

reviewed by at least two service users from FM support groups who had expressed interest in doing so.

Several of the FM support groups who had agreed to post details of the study on their group asked to be made aware of the findings once completed. All Facebook group facilitators will be contacted again, and offered to post a link to an online version of the information sheet for any interested members. This will also be the case for face-to-face support groups and the community pain centre, where either attendance in person, or a copy of the information sheet, will be used to inform them of our findings.

FM charities, including Fibromyalgia Action UK, Fibromyalgia Awareness UK and UK Fibromyalgia, will be contacted regarding the outcomes of the study, and a link given to the online information sheet. Charities will be able to disseminate these findings if, and how, they wish to do so. The opportunity to write an article regarding the findings for their newsletter or magazine will also be offered.

NICE guidelines for persistent pain are currently in the development stage, and at present, only have two Fibromyalgia charities registered as stakeholders. Registering as an individual stakeholder and giving input to the development of these guidelines, due to be finalised by early 2020, could be helpful to contribute towards the psychological considerations of the guidance and to use our findings when appropriate.

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Appendix 1: The Systemic-Transactional Model of dyadic coping (Bodenmann, 1995, 2005)

Who is primarily concerned?	Stressor concerns primarily partner A	Partner A and B are both concerned by stressor	Stressor concerns primarily partner B
Primary appraisals	Individual primary appraisals by partner A (1a, b, c, d)	Joint primary appraisals (partner A and B)	Individual primary appraisals by partner B (1a, b, c, d)
secondary appraisals	Individual secondary appraisals by partner A (2a, b, c)	Joint secondary appraisals (partner A and B)	Individual secondary appraisals by partner B (2a, b, c)
goals	Individual or partner-related goals by partner A	Joint goals by partner A and B	Individual or partner-related goals by partner B
individual and dyadic coping	Individual coping Supportive, delegated, negative dyadic coping by partner A	Common dyadic coping by partner A and B	Individual coping Supportive, delegated, negative dyadic coping by partner B
Outcomes	Psychological and physical well-being Relationship satisfaction, life satisfaction, Performance by partner A	Feeling of we-ness, mutual trust, intimacy and connectedness	Psychological and physical well-being Relationship satisfaction, life satisfaction, Performance by partner A

Appendix 2: Appraisal tool for Cross-Sectional Studies (AXIS)
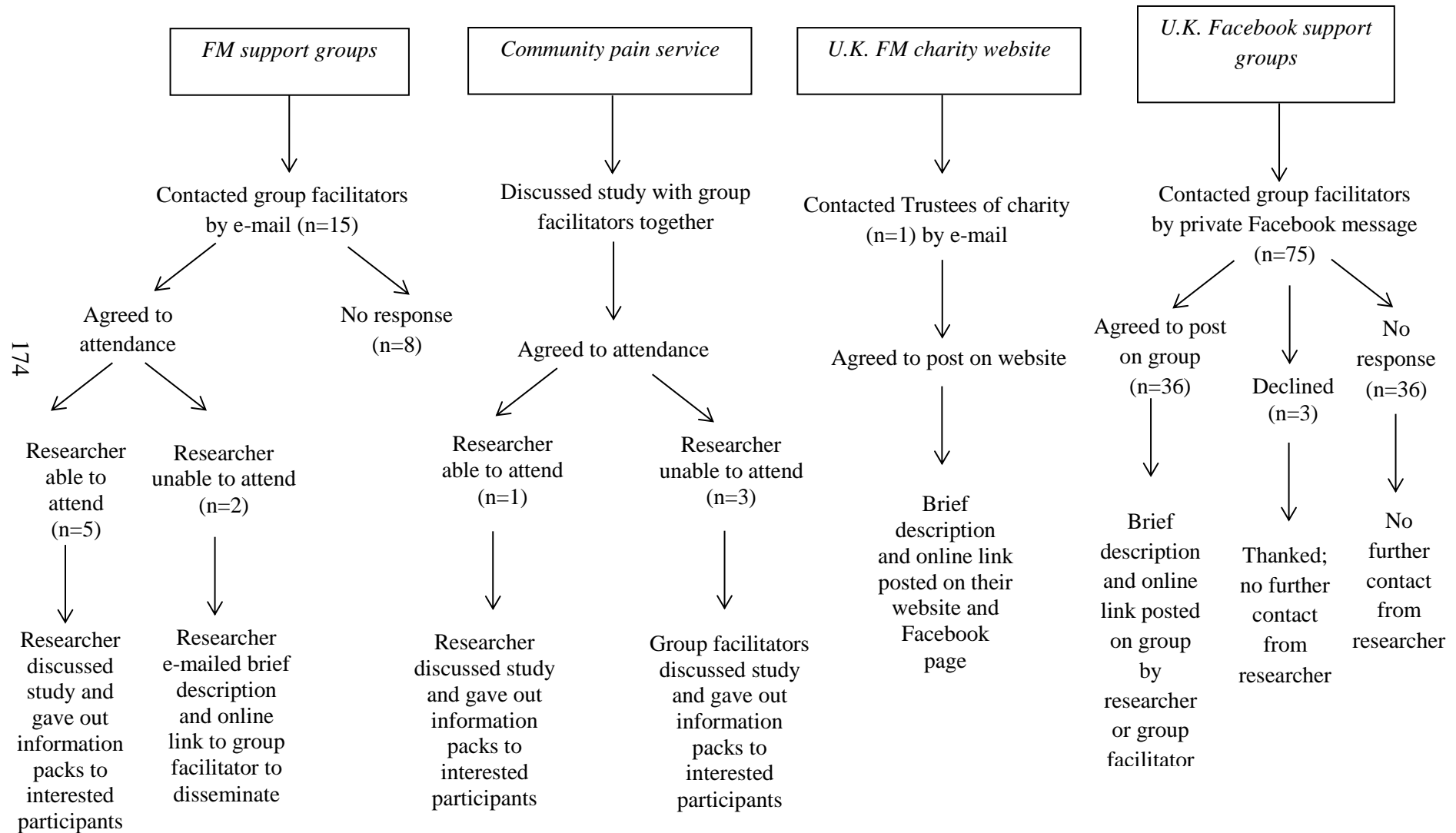
Removed due to copyright

Appendix 3: Copy of approval from Bloomsbury Research Ethics Committee

Removed for confidentiality

Appendix 4: Research Ethics Committee approval for substantial amendment

Removed for confidentiality

Appendix 5: Diagram of recruitment process for all participants (n=92)

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┌─────────────────────┐   ┌─────────────────────┐   ┌─────────────────────┐   ┌─────────────────────┐
│  FM support groups  │   │Community pain service│   │U.K. FM charity website│  │U.K. Facebook support│
│                     │   │                     │   │                     │   │       groups        │
└─────────────────────┘   └─────────────────────┘   └─────────────────────┘   └─────────────────────┘
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FM support groups

Contacted group facilitators by e-mail (n=15)

- Agreed to attendance
  - Researcher able to attend (n=5)
    - Researcher discussed study and gave out information packs to interested participants
  - Researcher unable to attend (n=2)
    - Researcher e-mailed brief description and online link to group facilitator to disseminate
- No response (n=8)

Community pain service

Discussed study with group facilitators together

Agreed to attendance

- Researcher able to attend (n=1)
  - Researcher discussed study and gave out information packs to interested participants
- Researcher unable to attend (n=3)
  - Group facilitators discussed study and gave out information packs to interested participants

U.K. FM charity website

Contacted Trustees of charity (n=1) by e-mail

Agreed to post on website

Brief description and online link posted on their website and Facebook page

U.K. Facebook support groups

Contacted group facilitators by private Facebook message (n=75)

- Agreed to post on group (n=36)
  - Brief description and online link posted on group by researcher or group facilitator
- Declined (n=3)
  - Thanked; no further contact from researcher
- No response (n=36)
  - No further contact from researcher

Appendix 6: E-mail sent to FM face-to-face support group facilitators

Hi,

Apologies for the slightly out-of-the-blue email, but I saw the details of your support group and thought it might be worth getting in touch.

I'm currently in my third year doing a doctorate in Clinical Psychology at Royal Holloway University of London. I'm doing my thesis research on couples' beliefs in Fibromyalgia Syndrome (FMS). There is research in other long-term health conditions about how couples' understanding of the condition can affect the symptoms, its impact, how people manage it, and how much distress it causes people. However there doesn't seem to be any research into FMS as yet. We were hoping that in doing this research, it would give us an idea as to what might be helpful for services to provide couples living with FMS.

The study consists of participants with FMS completing five questionnaires (which should take around 15-20 minutes), and their partner completing two questionnaires (which should take around 10 minutes). Participants can complete the questionnaires either using paper versions of the questionnaires (plus stamped addressed envelope), by telephone with myself, or online using a survey link.

I've attended a few FMS support groups so far, to talk through the study and to give questionnaire packs to people who are interested in taking part. It seems to have helped that I'm available to answer any questions people have about the study, but I am also very aware of emphasising that people are not obliged to take part, and that it doesn't affect their care or support in any way.

Either way, please do let me know your thoughts, and thanks in advance for reading this,

Caitlyn Box

Trainee Clinical Psychologist

Appendix 7: Verbal script utilised in the community pain centre groups

"I've been asked to let you know about a study that is being undertaken by a doctorate student called Caitlyn from Royal Holloway University of London. It's up to you as to whether you would like to take part, but I'll talk first through their reasons behind the study and what it will involve.

It has been found in other long-term health conditions that how a couple makes sense of a condition when one person is ill can affect its symptoms, its impact, how people manage it, and how much distress it causes people. However, there has been little research into couples with FMS, so we don't know how any shared understanding in a relationship affects how people experience their condition. Hopefully this research will help us to know what might be helpful for services to provide people who are in a couple where one person has Fibro.

The study consists of participants completing five questionnaires (which should take around 15-20 minutes), and their partner completing two questionnaires (which should take around 5-10 minutes).

People are eligible for the study if they are over 18, have a diagnosis of Fibromyalgia from a medical practitioner, and have been with their partner for at least six months.

If you are interested, the first thing to do is to read through the information sheet and consent form given with the questionnaire packs. If you would like to go ahead, you and your partner go through the questionnaires by yourselves, then return them in the stamped addressed envelope provided. If you'd rather not complete them by paper, you can also complete the questionnaires by telephone with Caitlyn, or online using a survey link. The link is on the information sheet.

To keep your data confidential, the researchers will randomly assign you and your partner a participant ID number, so that your responses are not tied to your personal data in any way. Any data will be kept on password-protected and encrypted files, then destroyed at a later date.

Please be aware that you are under no obligation to take part in this research, and there will be no impact on your treatment with IPASS either way. You can withdraw at any time in the study without giving a reason, and there will be no detrimental consequences if you do so.

If you have any further questions, please do not hesitate to contact Caitlyn or [supervisor]. Their contact details are on the information sheet."

Appendix 8: Study advertisement on FM charity website and Facebook page

RECRUITMENT FOR RESEARCH STUDY

As part of her doctoral thesis research into couples' beliefs about Fibromyalgia Syndrome, Caitlyn Box (Trainee Clinical Psychologist) and [supervisor] (Clinical Health Psychologist) are currently recruiting couples where one person has Fibromyalgia Syndrome for their study.

Background

It has been found in other long-term health conditions that how a couple makes sense of a condition when one person is ill can affect their symptoms and the impact of the condition. It can also affect how they manage their condition and how much distress it causes.

However, so far, research into Fibromyalgia Syndrome (FMS) has only looked at the person with FMS's beliefs about the illness, but not about how their partner understands the condition. We also don't yet know how any shared understanding between the couple affects how people experience their condition. We would also like to find out how communication affects these outcomes.

What to do next

We are asking people to complete anonymous online questionnaires, which take about between 15-20 minutes. If you are interested in taking part in this study, please click through to this link to the study, where it will explain further about what the study will involve, and how to take part. The study will stay open for 3 months.

Study link: **https://tinyurl.com/ycc27bf4**

Appendix 9: Copy of message sent to Facebook FM support group facilitators

Hi,

Apologies for the slightly out-of-the-blue email, but I saw the details of your support group and thought it might be worth getting in touch.

I'm currently in my third year doing a doctorate in Clinical Psychology at Royal Holloway University of London. I'm doing my thesis research on couples' beliefs in Fibromyalgia Syndrome (FMS). There is research in other long-term health conditions about how couples' understanding of the condition can affect the symptoms, its impact, how people manage it, and how much distress it causes people. However there doesn't seem to be any research into FMS as yet. We were hoping that in doing this research, it would give us an idea as to what might be helpful for services to provide couples living with FMS.

The study consists of participants with FMS completing five questionnaires (which should take around 15-20 minutes), and their partner completing two questionnaires (which should take around 10 minutes). Participants can complete the questionnaires either by telephone with myself, or online using a survey link.

I've attended a few FMS support groups so far, and people have suggested asking if it might be possible to post a description of the study on their Facebook support groups. I've attached a description of the study below if you are satisfied with posting this. However, you are under absolutely no obligation to do so, and it will not affect anything if you decline.

Either way, please do not hesitate to contact me if you have any questions or concerns.

Thanks in advance for reading through this,

Caitlyn Box

Trainee Clinical Psychologist

"RECRUITMENT FOR RESEARCH STUDY

As part of her doctoral thesis research into couples' beliefs about Fibromyalgia Syndrome, Caitlyn Box (Trainee Clinical Psychologist) and [supervisor] (Clinical Health Psychologist) are currently recruiting couples where one person has Fibromyalgia Syndrome for their study.

They are looking for people to complete anonymous online questionnaires, which take between 15-20 minutes. If you are interested in taking part in this study, please click through to the link below, where it will explain further about what the study will involve, and how to take part. You are under no obligation to take part in this research, and it will not affect any care you receive in any way. If you have any questions or concerns, please do not hesitate to contact Caitlyn using the details on the information sheet.

The link to the study is: **https://tinyurl.com/ycc27bf4**"

Appendix 10: Participant information sheet and consent form

Study Title:

Couples' beliefs about Fibromyalgia Syndrome, and how these relate to health outcomes

Invitation:

We would like to invite you and your partner to take part in a research study exploring couples' beliefs around Fibromyalgia Syndrome. Before you decide *whether to take part*, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything unclear or if you would like further information. Take time to decide whether or not you wish to take part.

What is Fibromyalgia Syndrome (FMS)?

"Fibromyalgia is a disorder that causes muscle pain and fatigue. People with fibromyalgia have "tender points" on the body. Tender points are specific places on the neck, shoulders, back, hips, arms, and legs. These points hurt when pressure is put on them. People with fibromyalgia may also have other symptoms, such as:

- Trouble sleeping

- Morning stiffness

- Headaches

- Painful menstrual periods

- Tingling or numbness in hands and feet

- Problems with thinking and memory (sometimes called "fibro fog")

No-one knows what causes fibromyalgia. Anyone can get it, but it is most common in middle-aged women. People with rheumatoid arthritis and other autoimmune diseases are particularly likely to develop fibromyalgia. There is no cure for fibromyalgia, but medicine can help you manage your symptoms. Getting enough sleep, exercising, and eating well may also help." *(Taken from ICD-10; World Health Organisation, 1992)*

The detrimental impact of FMS symptoms has been well-documented, especially upon everyday life, work, and people's overall quality of life. Therefore, research into FMS and directions for possible treatments is of utmost importance.

What is the purpose of the study?

In health psychology, it has been found that how individuals make sense of a health condition (their "illness representations") can affect their physical and psychological symptoms, how they respond to their illness, and its overall impact.

Particular illness representations have been documented in people who experience FMS.

However, it has been increasingly recognised that the partner in a couple's relationship may hold their own beliefs about the person's illness. Some studies have looked at the "congruence" between the individual and their partner's beliefs about their illness. Congruence means the extent to which the beliefs of the two people in a partnership are similar. Greater congruence indicates that there is more similarity between their beliefs, whilst lower congruence suggests there is less similarity. The congruence of couples' beliefs has been found to be associated with outcomes of the person's illness, e.g. their physical symptoms, and how they respond to their illness.

However, this seems to vary across different health conditions, and across different aspects of illness beliefs. To our knowledge, no authors as yet have looked at the congruence of couples' beliefs in FMS and their health outcomes. We would also like to find out if communicating about FMS affects these outcomes.

Why have I been invited, and am I eligible?

We are asking people in NHS pain services, in FMS support groups, and across online FMS networks to take part.

It is important that participants have been diagnosed with FMS by a healthcare professional *prior* to this study. If you have not had a diagnosis and wish to seek further advice, we recommend contacting your GP in the first instance.

You are <u>eligible</u> to take part in the study if you:

- Are aged 18 or over

- Have a diagnosis of FMS from a medical practitioner

- Have been with your partner for at least 6 months

  You are <u>not eligible</u> to take part in the study if you:

- Are under 18

- Do not have a diagnosis of FMS from a medical practitioner

- Have been with your partner for under 6 months

What does taking part involve?

If you decide to take part, we will give you a set of questionnaires to fill out. If we have met you on a face-to-face basis, we will give you paper versions of these questionnaires, as well as a stamped addressed envelope to send these back. We will mark yours and your partner's questionnaires with a matching participant ID number, which will <u>not </u>be related to any personal details.

If you are accessing this link online, we will ask you to complete your answers electronically. Once you have pressed "Submit" at the end of the questionnaires, an e-mail will be automatically be sent to your partner, with their versions of the questionnaires to complete. We will ensure that your questionnaires are linked

electronically, so that we are keeping your questionnaires confidential and anonymous.

There will be five questionnaires in total for you to complete, which should take around 15-20 minutes. Please be advised that it may be recommended to undertake these questionnaires in a private space if possible, due to the nature of the questions.

Your questionnaires will ask questions about your perspective on:

- Your beliefs about your FMS

- The impact of your FMS (its symptoms, impact, and effect upon your functioning)

- How you respond to your FMS in terms of activity

- Your level of distress about FMS

- Your level of communication about FMS with your partner

We will also give your partner two questionnaires to complete, which should take around 15 minutes. These will ask questions about their perspective on:

- Their beliefs about your FMS

- The level of your communication together about your FMS

We will also ask for details about your age, gender, ethnicity, and highest educational level. These will not identify you in any way, but are helpful for us to know about to explore any patterns.

Once you have completed these questionnaires, you will not normally hear back from us. We will not be informing people of their individual results. However, if you would like to know the outcomes of the research, we would ask that you leave your contact details and preferred method of contact at the bottom of this sheet. We will then contact you at the end of the study.

We will also publish the results in academic papers and at academic conferences. There will be no identifiable information about participants in these publications.

What happens when the research study stops?

We will not normally contact people following the study, and will not be informing people of their individual results. However, please do leave your contact details if you would like us to let you know about the findings from the study.

What are the possible disadvantages or risks of taking part?

We recognise that asking about people's health, and asking couples about their relationships, can mean that people start thinking more about these topics. However, because communication is consistently found to help couples' relationships, we would hope that any discussions from our questionnaires would result in a positive impact. If you do feel that the study has impacted you in an unhelpful way, we are enclosing

details for relevant support services. These can be accessed by skipping to the end of the questionnaires.

We are also aware that completing these questionnaires could briefly increase the pain and discomfort that people with FMS already encounter. We would advise you that you take time in completing the questionnaires, and please use any everyday ways that you find helpful when doing things by hand. We are hoping that the long-term benefits of this research will outweigh any increased physical difficulties for people in the short-term. If you are concerned about your participation worsening your symptoms, you are also able to contact the Chief Investigator and complete these by telephone at a designated time instead. Please use the contact details below to do so.

If you would rather access the survey online, please use the survey link at:

https://tinyurl.com/ycc27bf4.

What are the possible benefits of taking part?

By discussing beliefs around your condition, we hope that this should have a beneficial impact upon your FMS and on your relationship in general. We would hope that our findings might stimulate the creation of couples' interventions in healthcare settings to make them more effective for people with FMS.

Do I have to take part in this research?

No, it is completely up to you and your partner. If you both decide to take part, you will be asked to sign and return the consent form (below) or to indicate your consent via tickbox and electronic signature if online. You and/or your partner are free to withdraw at any time, without giving a reason. Your decision has no influence on your treatment by services, or in research in future.

What should I do if I do want to take part in this research?

If you would like to join the study, then all you need to do is to tick the relevant boxes and sign on the consent form to indicate your consent. You are then able to either fill out the questionnaires and return them by post (if paper), or to fill them out electronically (if online). If you have any further questions, please do not hesitate to contact the researchers at any point during the study. Contact details are written below.

How do I withdraw if I want to do so?

You are under no obligation to take part in this research. You can withdraw at any time without giving a reason, and there will be no adverse consequences if you do so.

Will my taking part in the study be confidential?

Yes. If you are returning your questionnaires by paper, we will assign a participant ID number to your data so that you are not identifiable. If you are completing the questionnaires online, we will link your questionnaires automatically once you have given your partner's e-mail address. Information about your partner's e-mail address will only be kept until the end of the study, when it will be disposed of confidentially.

We will not request or use any of yours or your partner's personal information other than this. Your consent form will also be separated from your study questionnaires, so that your name and signature will not be associated with your answers.

If you request to be contacted regarding the outcomes of the study, we will keep these details securely on an electronic database. Nobody other than the researchers will have access to the data, which will be saved securely on password-protected devices and stored securely in accordance with the Data Protection Act 1998.

Contact details of the researchers

Chief investigator	*Co-investigator*
Caitlyn Box	[supervisor]
Trainee Clinical Psychologist	Clinical Health Psychologist
Department of Clinical Psychology	E-mail: [removed]
Bowyer Building	
Royal Holloway University of London	
Egham	
TW20 0EX	
Telephone: 01784 276339	
E-mail: Caitlyn.box.2015@live.rhul.ac.uk	

Who is organising and funding the research?

The study has been set up as part of doctoral thesis research at Royal Holloway University of London, and is funded through this programme.

Can I know the results of the research?

It is not planned to feedback any results from individual questionnaires. However, if you would like to find out about the outcomes of the study, please leave your contact details below.

Contact details (telephone/postal address only):

Who has reviewed/approved the project?

All research in the NHS is reviewed by an independent group called a Research Ethics Committee. This project has been reviewed and approved by NHS London Bloomsbury Research Ethics Committee.

The proposal for this research has also been peer-reviewed by a Course Research Sub-committee at Royal Holloway University of London, and has been amended following two proposal submissions.

Who do I contact if I have any concerns?

The Chief Investigator (Caitlyn Box) will be glad to answer your questions about this study at any time. You may contact her using the contact details above.

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

IRAS ID: 226462

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: *Couples' beliefs about Fibromyalgia Syndrome, and how these relate to health outcomes*

Name of Researcher: *Caitlyn Box*

1. I confirm that I have read the information sheet dated 05/10/2017 (version 1.6) 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 agree to take part in the above study. ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

Appendix 11: Study measures for participant

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Appendix 12: Debriefing information sheet

After the study…

Thank you to you and your partner for taking part. Your participation is hugely valued, and we hope it will contribute significantly towards developing more effective psychological interventions for couples living with Fibromyalgia Syndrome.

If you have any concerns or questions, please contact the principal investigator by using the contact details below.

Principal investigator
Caitlyn Box
Trainee Clinical Psychologist
Department of Clinical Psychology
Bowyer Building
Royal Holloway University of London
Egham
TW20 0EX
Telephone: 01784 276339
E-mail: Caitlyn.box.2015@live.rhul.ac.uk

If the study has raised any other concerns, below are some organisations that may be of help. If you find yourself struggling with your mood, please contact your GP in the first instance.

Fibromyalgia support

- *Fibromyalgia Association UK*
    - o Website: http://www.fmauk.org/
    - o Helpline: 0300 999 3333
- *U.K. Fibromyalgia*
    - o Website: http://ukfibromyalgia.com/
- *Living with Fibromyalgia- Online Support Group*
    - o http://www.livingwithfibro.org/
- *Arthritis Research U.K.*
    - o Website: http://www.arthritisresearchuk.org/arthritis-information/conditions/fibromyalgia.aspx
    - o Helpline: 0800 5200 520

Relationship support
- *Relate*
    - o Website: https://www.relate.org.uk/
    - o Helpline: 0300 100 1234

More general therapeutic support
- *British Association for Counselling and Psychotherapy- Find a Therapist*
    - o Website: http://www.itsgoodtotalk.org.uk/therapists

Appendix 13: Partner information sheet and consent form

Study Title:

Couples' beliefs about Fibromyalgia Syndrome, and how these relate to health outcomes

Invitation:

We have invited your partner to take part in a research study exploring couples' beliefs around Fibromyalgia Syndrome (FMS), and we would like to ask you to take part as well. Before you decide *whether to take part*, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything unclear or if you would like further information. Take time to decide whether or not you wish to take part.

What is Fibromyalgia Syndrome (FMS)?

"Fibromyalgia is a disorder that causes muscle pain and fatigue. People with fibromyalgia have "tender points" on the body. Tender points are specific places on the neck, shoulders, back, hips, arms, and legs. These points hurt when pressure is put on them. People with fibromyalgia may also have other symptoms, such as:

- Trouble sleeping

- Morning stiffness

- Headaches

- Painful menstrual periods

- Tingling or numbness in hands and feet

- Problems with thinking and memory (sometimes called "fibro fog")

No-one knows what causes fibromyalgia. Anyone can get it, but it is most common in middle-aged women. People with rheumatoid arthritis and other autoimmune diseases are particularly likely to develop fibromyalgia. There is no cure for fibromyalgia, but medicine can help you manage your symptoms. Getting enough sleep, exercising, and eating well may also help." *(Taken from ICD-10; World Health Organisation, 1992)*

The detrimental impact of FMS symptoms has been well-documented, especially upon everyday life, work, and people's overall quality of life. Therefore, research into FMS and directions for possible treatments is of utmost importance.

What is the purpose of the study?

In health psychology, it has been found that how individuals make sense of a health condition (their "illness representations") can affect their physical and

psychological symptoms, how they respond to their illness, and its overall impact. Particular illness representations have been documented in people who experience FMS.

However, it has been increasingly recognised that the partner in a couple's relationship may hold their own beliefs about the person's illness. Some studies have looked at the "congruence" between the individual and their partner's beliefs about their illness. Congruence means the extent to which the beliefs of the two people in a partnership are similar. Greater congruence indicates that there is more similarity between their beliefs, whilst lower congruence suggests there is less similarity. The congruence of couples' beliefs has been found to be associated with outcomes of the person's illness, e.g. their physical symptoms, and how they respond to their illness.

However, this seems to vary across different health conditions, and across different aspects of illness beliefs. To our knowledge, no authors as yet have looked at the congruence of couples' beliefs in FMS and their health outcomes. We would also like to find out if communicating about FMS affects these outcomes.

Why have I been invited, and am I eligible?

We are asking people and their partners in NHS pain services, in FMS support groups, and across online FMS networks to take part.

It is important that your partner has received a diagnosis of FMS by a healthcare professional *prior* to this study. If they have not had a diagnosis and wish to seek further advice, we recommend that they contact their GP in the first instance.

You are eligible if you are:

- Aged over 18

- Have been with your partner for at least 6 months

You are <u>not eligible</u> if you:
- Are aged under 18

- Have been with your partner for less than 6 months

What does taking part involve?

If you decide to take part, we will give you two questionnaires to fill out. If we have met your partner on a face-to-face basis, we will give them paper versions of these questionnaires, as well as a stamped addressed envelope to send these back. We will mark yours and your partner's questionnaires with a matching participant ID number, which will <u>not </u>be related to any personal details.

If we have sent your partner this link online, we will ask you to complete your answers electronically. Your link to the study should have been generated when they pressed "Submit" at the end of their questionnaires, and will link automatically to your partner's electronically-assigned ID number.

You will be given two questionnaires to complete, which should take around 5-10 minutes. These will ask questions about your perspective on:

- Your beliefs about your partner's FMS

- The level of your communication together about their FMS

Once you have completed these questionnaires, you will not normally hear back from us. We will not be informing people of their individual results. However, if you would like to know the outcomes of the research, we would ask that you leave your contact details and preferred method of contact at the bottom of this sheet, or at the end of the study if completing electronically. We will then contact you at the end of the study.

We will also publish the results in academic papers and at academic conferences. There will be no identifiable information about participants in these publications.

What are the possible disadvantages or risks of taking part?

We recognise that asking about people's health, and in couples about their relationships, can mean that people start thinking more about these topics. However, because communication is consistently found to help couples' relationships, we would hope that any discussions from our questionnaires would result in a positive impact. If you do feel that the study has impacted you in an unhelpful way, we are enclosing details for relevant support services. These can be accessed by skipping to the end of the questionnaires.

What are the possible benefits of taking part?

By discussing beliefs around your partner's FMS, we hope that this should have a beneficial impact upon their condition and on your relationship in general. We would hope that our findings might stimulate the creation of couples' interventions in healthcare settings to make them more effective for people with FMS.

Do I have to take part in this research?

No, it is completely up to you and your partner. If you both decide to take part, you will be asked to sign and return the consent form (below) or to indicate your consent via tickbox and signature if online. You and/or your partner are free to withdraw at any time, without giving a reason. Your decision has no influence on your treatment by services, or in research in future.

What should I do if I do want to take part in this research?

If you would like to join the study, then all you need to do is to tick the relevant boxes and sign on the consent form to indicate your consent. You are then able to either fill out the questionnaires and return them by post (if paper), or to fill them out electronically (if online). If you have any further questions, please do not hesitate to contact the researchers at any point during the study. Contact details are written below.

How do I withdraw if I want to do so?

You are under no obligation to take part in this research. You can withdraw at any time without giving a reason, and there will be no adverse consequences if you do so.

Will my taking part in the study be confidential?

Yes. If you are returning your questionnaires by paper, we will assign a participant ID number to your data so that you are not identifiable. If you are completing the questionnaires online, we will link your questionnaires automatically once your partner has completed theirs and you have received the study link via your e-mail address. Details of your e-mail address will only be kept until the end of the study, when it will be disposed of confidentially.

We will not request or use any of yours or your partner's personal information other than this. Your consent form will also be separated from your study questionnaires, so that your name and signature will not be associated with your answers.

If you request to be contacted regarding the outcomes of the study, we will keep these details securely on an electronic database. Nobody other than the researchers will have access to the data, which will be saved securely on password-protected devices and stored securely in accordance with the Data Protection Act 1998.

Contact details of the researchers

Principal investigator   *Co-investigator*

Caitlyn Box   [supervisor]

Trainee Clinical Psychologist   Clinical Health Psychologist

Department of Clinical Psychology   E-mail: [removed]

Bowyer Building

Royal Holloway University of London

Egham

TW20 0EX

Telephone: 01784 276339

E-mail: Caitlyn.box.2015@live.rhul.ac.uk

Who is organising and funding the research?

The study has been set up as part of doctoral thesis research at Royal Holloway University of London, and is funded through this programme.

Can I know the results of the research?

It is not planned to feedback any results from individual questionnaires. However, if you would like to find out about the outcomes of the study, please leave your contact details below.

Contact details (telephone/postal address only):

_____

Who has reviewed/approved the project?

All research in the NHS is reviewed by an independent group called a Research Ethics Committee. This project has been reviewed and approved by NHS London Bloomsbury Research Ethics Committee.

The proposal for this research has also been peer-reviewed by a Course Research Sub-committee at Royal Holloway University of London, and has been amended following two proposal submissions.

Who do I contact if I have any concerns?

The Principal Investigator (Caitlyn Box) will be glad to answer your questions about this study at any time. You may contact her using the contact details above.

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

CONSENT FORM

Title of Project: *Couples' beliefs about Fibromyalgia Syndrome, and how these relate to health outcomes*

Name of Researcher: *Caitlyn Box*

4. I confirm that I have read the information sheet dated 05/10/2017 (version 1.6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

5. 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. ☐

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

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

Appendix 14: Study measures for partner

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