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Doctoral Thesis

What are the experiences of caring for a loved one with a chronic condition?

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Abstract

This thesis comprises of a literature review, a research paper and a critical appraisal of the thesis. The main focus of the thesis is on family members’ experiences of caring for loved ones with chronic illnesses. First, a thematic synthesis explored mothers’ experiences of parenting a child with a chronic illness. Thirteen papers (comprising of twelve studies) exploring the experiences of 176 mothers to children with seven different chronic illnesses were included in the synthesis. The thematic synthesis resulted in four themes: the overarching and pervasive sense of responsibility; the altered maternal relationship: the tension between idealised and actual motherhood; counting the costs: dismissing one’s own feelings in order to maintain the ability to care; and becoming the expert. The aim of the research paper was to explore the experiences of partners of people with chronic pain. Interpretative Phenomenological Analysis was used to analyse ten semi-structured interviews of eight men and two women. Five themes were identified: the process of acceptance and adjustment; the challenge of accessing effective support; pain as a personal, independent and malignant force; loss and growth in the relationship; and controlling ones awareness as a means of controlling the impact pain. The first two themes are already documented in the qualitative pain literature and therefore were not discussed in the research paper to allow for more detailed exploration of the novel findings. Finally, a critical appraisal extended the discussion of the research paper and literature review by exploring in more detail the limitations and how future research can further the current findings. Particular attention was paid to the role of gender in the research findings.

Declaration

This thesis presents research submitted in January 2017 as partial fulfilment of the requirements for the Lancaster University Doctorate in Clinical Psychology. The work in this thesis is my own except where due reference has been made to other authors. This thesis has not been submitted for academic award elsewhere.

Name: Laura Smith

Signature:

Date:

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I would like to extend thanks to the partners who generously gave up their time to share their experiences. Their honesty and openness was profoundly touching. I would also like to thank my supervisors, Dr William Sellwood, Dr Jane Simpson and Dr Fiona Eccles for their support, both emotionally and academically. Thank you for continuing to provide support over this extended process.

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Section One: Literature Review

What are Mothers' Experiences of Parenting a Child with Chronic Illness?

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What are Mothers' Experiences of Parenting a Child with Chronic Illness?

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Statement of Contribution

What is already known on this subject?

- Childhood chronic illness negatively impacts on parents in multiple ways.
- Qualitative research has explored the experiences of mothers parenting a child with chronic illness.

What does this study add?

- Mothers experience a strong sense of responsibility that influences their every decision.
- Their need for certainty and control influences their relationship with professionals.
- They experience a discrepancy between ‘normal’ mothering and mothering a chronically ill child.

Abstract

Purpose. Mothers play a vital role in caring for chronically ill children and due to social and cultural gender norms may experience parenting differently from fathers. This review synthesizes empirical research exploring mothers' experiences of parenting a chronically ill child.

Methods. A systematic search of eight databases identified 13 qualitative articles which were analysed using Thomas and Harden's (2008) method of thematic synthesis.

Results. The analysis produced four themes: the overarching and pervasive sense of responsibility; the altered maternal relationship: the tension between idealised and actual motherhood; counting the costs: dismissing one's own feelings to maintain the ability to care; and becoming the expert. Mothers experienced a need to be in control at all times, despite feeling out of control. Their experiences were emotionally traumatic and yet they felt unable to consider their emotions for fear this would stop them being able to mother. They experienced intense guilt and responsibility for their child's illness. As a result of their experiences, mothers employed a variety of methods to regulate their emotions, moving from denial and other emotion-focused strategies to more problem-focused coping strategies.

Conclusions. The themes provide some guidance to practitioners and are in accord with Lazarus and Folkman's (1984) transactional model of stress, appraisal and coping and the self-regulatory model (Leventhal, Nerenz & Steele, 1984; Leventhal, Leventhal & Cameron, 2001).

Keywords: Chronic Illness, Chronic Health, Mothers, Experiences, Thematic Synthesis

Introduction

Many definitions of chronic illness exist (see van der Lee, Mokkink, Grootenhuis, Offringa & Heymans, 2008), however no one definition is universally accepted. Although prevalence rates are hard to estimate given the varying definitions (van der Lee et al., 2007), some of the most common childhood chronic illnesses include asthma, diabetes (Association for Young People's Health, 2015; Torpy, Campbell & Glass, 2010) and cystic fibrosis (Torpy et al., 2010). There are currently an estimated 1.1 million children in the UK with asthma (Asthma UK, 2016), approximately 35,000 with diabetes (Diabetes UK, 2015) and 1 in 2500 new-borns are diagnosed with cystic fibrosis per year (Ratjen & Doring, 2003).

The impact of childhood chronic illness of parents

The impact of childhood chronic illness upon parents is diverse and no two families' experiences are likely to be the same (Cohen, 1995). Quantitative research illustrates that these impacts include emotional and psychological distress (e.g. Raini et al., 2005; Silver, Westbrook & Stein, 1998), altered family functioning (e.g. Long et al., 2013), physical illness (Klassen et al., 2008; Meltzer & Mindell, 2006) and social isolation (Silver, Bauman & Weiss, 1999). The impact on parents' emotional, psychological and physical health is thought to be due to the constant high levels of stress experienced by parents (Sterling & Eyer, 1988). Parents are expected to play an important role in the care of their chronically ill child, ensuring treatment adherence (Gavin & Wysocki, 2006; Wiebe et al., 2005), promoting positive coping strategies (Knafl, Breitmeyer, Gallo & Zoeller, 1996), and acting as intermediaries between the child and healthcare professionals (Starke & Möller, 2002). These additional burdens on parents can cause additive stress over a potentially indefinite time period.

Alongside these findings, qualitative research has provided a detailed understanding of parents' grief responses over the illness trajectory. Diagnosis is typically the most stressful time for parents (Clements, Copeland & Loftus, 1990) when they experience the most intense grief (Lowes, Lyne & Gregory, 2004, 2005) including emotions such as anger, denial, shock, uncertainty and sorrow (Vickers 2005a, 2005b). For some parents, chronic illness can result in situations where there is no resolution for their grief (Lowes et al., 2004, 2005), and thus they experience chronic sorrow, which is a pervasive sadness that does not resolve and may get worse over time (Olsnasky, 1962). This can be triggered even after many years of it not being experienced and has been documented in parents of children with chronic illnesses (e.g. Lowes & Lyne, 2000; Vickers, 2005a).

To gain a comprehensive understanding of the experiences of parenting a chronically ill child both quantitative and qualitative research are needed to provide complementary perspectives. Fisher (2001) reviewed eight qualitative articles exploring the needs of parents with chronically sick children; Coffey (2006) completed a metasynthesis of 11 studies exploring parents' experiences of parenting a child with chronic illness and a follow-up meta-synthesis of Coffey's review by Kepreotes, Keatings and Stone (2010) updated these findings using more recently published articles. These reviews explored both mothers' and fathers' experiences. Themes from these reviews included the initial emotional impact, such as feeling helpless, overwhelmed and intense sadness or grief. Parents described the initial period following diagnosis as a period of "intangible losses" (Coffey, 2006, p. 57). Following these initial feelings there was a process of seeking normality and certainty in an attempt to counteract the initial emotional reaction. This process of adaptation included seeking out additional information, partnership with healthcare providers, reluctantly taking responsibility for their child's healthcare, learning as a family (both immediate and wider family) how to survive the illness and learning to manage the additional impact of the illness during important developmental milestones.

The process of adapting was highlighted as an important aspect of parents' ability to cope with their child's chronic illness in all three reviews. The constant changing nature of chronic illness means parents are unable to ever fully adapt, and must rather exist in a state of continual adaptation (Akre & Suris, 2014). Achieving some adaptation, in particular making adjustments to their family life, allows parents to cope with the additional tasks of caring for a chronically ill child, feel more in control and reduce the impact it has on the family (Jerrett, 1994). Jerrett (1994) also argued that the practical process of reorganising life may be reflective of an internal, emotional "re-organisation of self" (p. 1054). Another facet of the process of reorganising is redefining 'good' parenting, particularly in respect to discipline (MacInver, Jones & Nicol, 2010).

Mothering in the context of chronic illness

The focus on the current review is mothers' experiences of parenting a chronically ill child. The reviews discussed previously clearly demonstrate that childhood chronic illness impacts both mothers and fathers. What is not clear however, is whether mothers and fathers experience, respond to and influence childhood chronic illness differently.

Regarding the parental experience of childhood chronic illness, the evidence is contradictory. Some researchers have suggested that parents share similar views about the impact of the chronic illness (e.g. Costigan & Cox, 2001; McBride et al., 2005). Sallfors & Hallberg (2003) argued that parents share similar views of the impact but approach the process of learning and adapting differently. Others have suggested that mothers and fathers experience childhood chronic illness differently, with women typically experiencing more grief at the diagnosis, experience grief for longer periods of time and have less life satisfaction (Bruce, Shultz & Smymios, 1996; Vance, Boyle, Najman & Thearle, 1995). The reasons for such varied results are unclear however, it may be due to individual differences within couples and across couples, few studies comparing mothers and fathers within the same family or differences across chronic illnesses. Whether mothers and fathers experience the impact of, respond to, or influence childhood chronic illness similarly or not it is likely that they will have differing experiences of parenting due to gender roles and social expectations (Akre & Suris, 2014). There has been much consideration about how mothers experience 'mothering' within the context of illness and healthcare. Caring and motherhood are thought to be inextricably linked (e.g. Anderson & Elfert, 1989; Judson, 2004) and women are typically, although not always, the primary caregivers (Young, Dixon-Woods, Findlay & Heney, 2002). Women construct their caretaking role carefully to ensure they display competence to others, especially to those in positions of power such as healthcare professionals, for example by using the personal pronoun 'I' rather than 'we' when discussing the care of their child and not disclosing information they may be privy to, so as to secure their role as competent and primary caregiver (Anderson & Elfert, 1989; Gallo & Knafl, 1998). Anderson and Elfert (1989) argue that when a child becomes ill, the questioning by healthcare professionals can inadvertently reinforce women's struggles with feeling competent. Additional challenges to competency can occur when a child is hospitalised and others (namely healthcare professionals) are responsible for looking after the child, not the mother (MacDonald, 2007; Sikora & Janusz, 2014), resulting in mothers refusing to relinquish their role as primary caregiver during hospitalisation (Judson, 2004).

In addition to their differing experiences of having a chronically ill child, mothers and fathers may play differing roles in their child's psychological development and adjustment following a chronic illness diagnosis. Paediatric psychology has long been interested in the relationship between the child, their family and the illness (e.g. Sameroff & Chandler; Fiese & Sameroff, 1989), specifically how the family system can support the child to adjust to their chronic illness. Adaptive family relationships and parental psychological adjustment are positively associated with a child's psychological adjustment to their chronic illness (Drotar, 1997). One construct that has been used to explore this relationship is expressed emotion, which is a standardised method of measuring emotion in interactions (Vaughn & Leff, 1976). It has primarily been used within the field of schizophrenia research, but in recent years has been applied to other mental health conditions (e.g. depression; Florin, Nostadt, Reck, Franzen & Jenkins, 1992), non-clinical populations (Vostanis & Nicholls, 1992) and chronic physical health conditions (Brown & Jardesi, 2000). Expressed emotion has been clearly demonstrated to negatively influence treatment compliance in epilepsy (Otero & Hodes, 2000), asthma (Schobinger, Florin, Reichbauer, Lindemann & Zimmer, 1993) and diabetes (Stevenson, Sensky & Petty, 1991) and symptom control in epilepsy (Brown & Jardesi, 2000).

Another construct that has been used is emotion regulation, which is defined as “extrinsic and intrinsic processes responsible for monitoring, evaluating and modifying emotional reactions, especially their intensive and temporal features, to accomplish one’s goals” (Thompson, 1994, pp. 27-28). It is influenced by biological (e.g. cognitive development), psychological (e.g. temperament) and social (e.g. relationships with significant others) factors (Cole, Martin & Dennis, 2004; Eisenberg & Morris, 2002; Goldmsith & Davidson, 2004). In their review of the role of family context in emotion regulation development, Morris, Silk, Steinberg, Myers and Robinson (2007) propose that three specific aspects family context influence emotion regulation in three specific ways; observation of parental emotion regulation strategies, parenting practices and techniques and finally the emotional climate of the family (for example attachment, facial expressions, the marital relationship). Poor emotional regulation abilities has been linked to poor psychological wellbeing (Southam-Gerow & Kendall, 2002; Yap, Allen & Sheeber, 2007).

Mothers and fathers appear to play unique roles in the emotional development and wellbeing of their children. Maternal distress (which could be conceptualised as both emotion expression and emotion regulation) consistently predicts problematic adjustment in children with chronic illness (Drotar, 1997). Mothers also demonstrate higher levels of expressed emotion (specifically emotional over-involvement, critical comments and hostility) towards childen with epilepsy than their healthy siblings (Hodes, Garralda & Schwartz, 1999). Mothers and fathers show different responses to emotional expression in their children and can influence the development of emotion regulation differently. For example, Cassano , Perry-Parrish and Zeman (2007) found that fathers typically respond to sadness by minimising the problem or encouraging the child to inhibit the display of their sadness. Alternatively, mothers were more likely to problem solve and encourage displays of sadness. Additionally, mothers are more likely to discuss the causes of emotions compared to fathers (Fivush, Brotman, Buckner & Goodman, 2007), which may demonstrate that mothers are more typically involved in helping their child develop emotional coping strategies. Finally, childhood emotion regulation is influenced more by maternal factors than paternal factors (Bariola, Hughes & Gullone, 2012; McDowell, Kim, O’Neil & Parke, 2002).

The importance of parents in shaping their child’s emotional development, and therefore their child’s ability to adjust to chronic illness, in addition to the relationship between maternal distress and child health outcomes (such as symptom control and treatment compliance) clearly demonstrates the importance of exploring mothers’ experiences of childhood chronic illness.

To date, only one metasynthesis has been conducted exploring mothers’ experiences, although not specifically with mothers of chronically ill children. Nelson (2002) explored the experiences of “mothering other-than-normal children” (p. 515) including children with chronic illness, disabilities, mental health conditions and other non-chronic conditions such as low birth weight. She reported four themes: becoming the mother of a disabled[1] child; negotiating a new kind of mothering; dealing with life and the process of acceptance and denial. While these results are a crucial step in understanding mothers' experiences, there are likely to be differences between the experiences of mothers of chronically ill children when compared to mothers of children with longstanding mental health difficulties or learning disabilities. The sample of Nelson's metasynthesis may therefore not be homogenous enough to apply the findings to childhood chronic physical health conditions.

In summary, it has been identified that mothers and fathers have differing experiences of parenting a child and parent differently (Cassano, Perry-Parrish & Zeman, 2007). Mothers are typically a child's primary carer and therefore are more likely to be involved in the daily care of a chronically ill child (Young et al., 2002). Parents are expected to play an important role in the care of their chronically ill child, ensuring treatment adherence (Gavin & Wysocki, 2006; Wiebe et al., 2005), promoting positive coping strategies (Knafl, Breitmeyer, Gallo & Zoeller, 1996), and acting as intermediaries between the child and healthcare professionals (Starke & Möller, 2002). It is therefore vital to understand what the experiences of parents are in order to help support them care for their child. Additionally, research suggests that mothers may play a more substantial and important role in supporting their child to develop emotional regulation strategies than fathers (e.g. Fivush et al., 2000; McDowell et al., 2002). Therefore it is particularly important to understand the experiences of mothers. This review will therefore seek to develop an understanding of what mothers' experiences are of childhood chronic illness and parenting a chronically ill child so as to provide guidance on how services can best support mothers of chronically ill children.

Method

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[1] Please note the term "disabled child" is used within the theme title used by Nelson and therefore has not been changed, despite the social model of disability subscribed to by the author.

Methodology

Thomas and Harden's (2008) method of thematic synthesis was chosen as it has previously been used to explore people's experiences about a particular aspect of their lives. Thematic synthesis shares many similarities with meta-ethnography (Noblit & Hare, 1988) and grounded theory (e.g. Eaves, 2001) such as moving from descriptive to analytic themes and creating a new analysis which goes beyond the individual studies included (Barnett-Page & Thomas, 2009). Thematic synthesis differs however, in that an integral aspect of thematic synthesis is the development of a synthesis which can be of benefit for policy makers and intervention developers, unlike other methods of synthesis such as meta ethnography or grounded theory which tends to result in a more intricate and symbolic product (Barnett-Page & Thomas, 2009). As thematic synthesis aims to shape policy, it therefore tends to assume a critical realist perspective, believing that there is a shared reality and results could be replicated by other researchers. It also focuses on exploring similarities within the studies, explaining differences between participants by looking within the studies rather than at the social, historical or theoretical context (Barnett-Page & Thomas, 2009). Thematic synthesis can be conducted with papers from a variety of methodologies, unlike grounded theory for example. The studies included in this review varied in terms of the method, depth and quality of analysis and the depth and quality of reporting. Thematic synthesis was therefore considered the most appropriate method for this review.

Literature search

A systematic literature search was conducted in March 2016 across eight databases (Academic Search Complete, AMED, CINAHL, MEDLINE, PsycARTICLES, PsycINFO, PubMed and Web of Science) in consultation with an academic librarian. These databases were identified as likely to contain articles relevant to the research question. PubMed draws upon similar journals to MEDLINE, but uses more up-to-date articles. Therefore, searching in PubMed was restricted to articles published in 2015-2016. General and specific search terms were used, with specific chronic illnesses being included based on prevalence statistics (Association for Young People's Health, 2015; Torpy et al., 2010). See Table 1 for search terms.

Preliminary searches using only generic terms such as "chronic health" or "chronic illness" returned only a limited range of articles and did not find articles that the author had prior knowledge of. The search strategy was therefore expanded to specifically include the most prevalent chronic illnesses in children (which met the inclusion criteria) to ensure all relevant articles were found.

[Table 1 about here]

Inclusion and Exclusion Criteria

This review considers chronic childhood illness as an incurable physical health condition, occurring in children aged 0 to 18 years, that has been present for longer than three months and is likely to continue to be present in the future. See Table 2 for justifications of the inclusion and exclusion criteria.

Articles were initially screened based on the title and abstract, for example removing studies which were clearly quantitative or did not explore mothers' experiences of parenting a chronically ill child. Full text articles were screened based on the inclusion and exclusion criteria. Studies were included if they explored mothers' experiences of parenting a chronically sick child, the child had been diagnosed with the chronic illness for a minimum of 3 months, contained only the mothers' experiences and were published in English. Studies were excluded if they were not published in peer reviewed journals or included children with cancer or neurodevelopmental conditions. See Figure 1 for a PRISMA diagram (Moher, Liberati, Telzlaff & Altman, 2009). Two studies were included following forward and backward searching.

[Insert Figure 1 and Table 2 about here]

Key features of the studies included in the meta-synthesis

Overall, 176 mothers and 187 interviews were included from 13 papers (4-29 mothers in each study). See tables 2 and 3 for demographic details. The same mothers' interviews were used to explore differing aspects of mother experiences for analysis in Swallow and Jacoby's (2001a, 2001b) papers. The following chronic conditions were included: asthma (Borhani, Asadi & Mohsenpour, 2012; Dowell, 2015; Horner, 1997; MacDonald, 1996; Rydström, Dalheim-Englund, Segesten & Rasmussen, 2004), adrenoleukodystrophy (Lee, Li & Liaw, 2014), cystic fibrosis (Hodgkinson & Lester, 2002; Priddis, Dougall, Balding & Barrett, 2009), diabetes (Abolhassani, Babaee & Eghbali, 2013, Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane & Grey, 2003), congenital heart defects (Bruce, Lilja & Sundin, 2013), chronic renal disease (MacDonald, 1995) and vesicoureteric reflux (Swallow & Jacoby, 2001a, b). Countries in which the research was conducted were Australia (Priddis et al., 2009), USA (Dowell, 2015; Sullivan-Bolyai et al., 2003), Canada (Macdonald, 1995; MacDonald, 1996), Taiwan (Lee et al., 1996), UK (Borhani et al., 2012; Hodgkinson & Lester, 2002; Swallow & Jacoby, 2001a, b), Iran (Abolhassani et al., 2013) and Sweden (Bruce et al., 2013; Rydström et al., 2004). A variety of research methods were used including grounded theory informed methods, ethnographic enquiry, phenomenologically informed methods, naturalistic enquiry and content analysis (see Table 4).

[Tables 3, 4 and 5 about here]

Quality appraisal

The worth and process of assessing of the quality of qualitative articles is highly debated (Barbour, 2001; Spencer, Ritchie, Lewis & Dillon, 2003). However, given the critical realist epistemology of thematic synthesis, quality appraisal is a crucial part of the analysis process (Barnett-Page & Thomas, 2009). As the definition of quality can change over time

(Sandelowski, Docherty & Emden, 1997) studies were not excluded based on the quality appraisal. Instead, the quality assessment was used to weight the studies and monitor the extent to which the studies contributed to the overall analysis (Hannes, 2011).

A widely used quality assessment tool is the Critical Appraisal Skills Programme ([CASP]; Public Health Resource Unit, 2006). The CASP is a 10-item scale, designed to assist researchers to consider the quality of a study. Studies were either scored 'no' for no or a brief mention of the criterion, 'cannot tell' for a limited exploration of the criterion or 'yes' for detailed discussion (see Table 6). No themes relied solely on studies of low quality (e.g. Abolhassani et al., 2013). Any method of quality appraisal is an inexact science based on the researcher's judgement and pre-existing knowledge of research principles. Additionally, research studies rarely fall neatly into exclusive categories and therefore a best judgement decision must be made. To ensure these decisions were as robust as possible, I discussed aspects of the quality appraisal that were controversial or unclear with my research supervisor. Additionally a quality appraisal was conducted by a fellow researcher. Both quality appraisals were conducted separately without discussing our opinions. We then met together to discuss our appraisals and why we had reached those decisions. Where there was divergence of opinion, the final appraisal (see Table 6) was reached by discussion. Ultimately, I made the final decisions as the researcher responsible for this review.

[Table 6 about here]

Data analysis

Thomas and Harden (2008) suggest researchers consider "what counts as data" (p. 48), and in line with their guidelines, all text within the results sections and relevant author interpretations included in the discussion sections were considered data. Thomas and Harden (2008) describe several steps of analysis, however, as with all methods of meta-synthesis this is an iterative, nonlinear process. The analysis process involved repeatedly reading the papers to ensure familiarity with the data and relevant contextual details. Secondly the data were coded and then grouped into descriptive themes. Finally, analytic themes were developed, going beyond mere description and becoming "more than the sum of its parts" (Thorne, Jensen, Kearney, Noblit & Sandelowsi, 2004, p 1358). Throughout the analysis a reflexive journal and detailed audit trail were kept to ensure the researcher did not unduly influence the analysis. This can be especially problematic during the final stage of analysis (Thomas & Harden, 2008). See Appendix 1-A for a worked example of the development of analytic themes and which papers contributed to which themes.

Reliability and validity

To ensure appropriate reliability and validity during each stage of data collection and analysis my supervisor and I met to discuss the analysis process and explore my reflexive journal. This began at the development stage of the review and included discussions about the specific focus of the review, the development of inclusion and exclusion crtieria and the decisions made during the literature search. Examples of coding was taken to supervision, in addition to each iteration of thematic development.

Results

Thirteen papers were included, which generated four themes capturing mothers' experiences of parenting a child with chronic illness. These were: the overarching and pervasive sense of responsibility; the altered maternal relationship: the tension between idealised and actual motherhood; counting the costs: dismissing one's own feelings to maintain the ability to care; and becoming the expert. See figure 2 for a thematic map of the findings.

[Insert figure 2 about here]

The overarching and pervasive sense of responsibility

This main theme permeates and influences all other themes as it drives all actions as a mother. Mothers felt guilty, responsible and blamed themselves for their child's illness and for not seeking medical help sooner. Some were reluctant to accept the responsibility of caring for a chronically unwell child, however, despite this, all mothers embraced the responsibilities. They aimed to be in control of all aspects of their child's care, feeling that nobody could care better than them and that as a mother they must provide the care. This resulted in them finding it difficult to relinquish the tight hold they have to others.

The prevalent sense of responsibility and need to be in control was reported in all studies except Priddis and colleagues (2009). For some mothers they "[longed] to be excused from their role as constant controller" (Rydström et al., 2004, p. 89), although nevertheless took on the responsibility. Some felt they had no choice but to be the one in control, stating "I've had to be the strong one" (Hodgkinson & Lester, 2002, p. 380) because "there is no-one else" (Dowell, 2015, p. 846). They felt obliged to be responsible and to cope as they were the central source of strength in the family. One mother stated "I have shouldered the responsibility myself" (Rydström et al., 2004, p. 90) however, whether this was through choice, a sense of obligation, or lack of available others was at times unclear. Mothers' perceptions that there was nobody else who could care for their child as well as themselves perpetuated their sense of responsibility and their need for control.

One specific area of responsibility mothers experienced was feeling responsible for their child's illness. This was if genetic factors were present (Hodgkinson & Lester, 2002; Lee et al., 2014; Swallow & Jacoby, 2001b), for not realising their child was unwell, and therefore for delaying seeking medical help (Borhani et al., 2012; Lee et al., 2014), and for having respite (MacDonald, 1995). For example:

> If we hadn't been selfish and gone in for a child [chosen to have a child] perhaps it wouldn't have happened. We just had this terrible feeling of guilt, which I think, 13 years later, you still carry round with you (Hodgkinson & Lester, 2002, p. 380).

Mothers discussed their guilt in a way that suggested they believed they were not only responsible for caring for the child, but also for the child's illness. This sense of guilt about the cause of the illness may have influenced mothers' beliefs about their responsibility towards caring for their child.

Subtheme: Control as a method of coping with the sense of responsibility

The pervasive sense of responsibility mothers experienced permeated all aspects of mothers' lives, thus driving mothers to find ways in mitigate this feeling. For all mothers in the review, control was the most prevalent method of compensating for their sense of guilt and responsibility. Mothers controlled all aspects of their child's life, and described themselves as controllers, planners and managers (Borhani et al., 2012; Bruce et al., 2013; Rydström et al., 2004). They were responsible for organising all aspects of their child's healthcare needs, including communicating with the healthcare professionals (MacDonald, 1995), educating school and the wider family (Bruce et al., 2013; Hodgkinson & Lester, 2002) and educating the chronically ill child (Hodgkinson & Lester, 2002). Mothers felt they were responsible for organising these issues, however, for most mothers this also provided them with a belief that they were proactively doing something, a sense of achievement that aspects of their child's care had been arranged and also allowed them to organise things their own way. This resulted in mothers feeling more in control of their child's illness and therefore able to tolerate the sense of responsibility they experience.

Despite the immense amount of responsibility mothers had, whether through choice or obligation, some struggled to relinquish the responsibility, even when their partner was caring for their child. For example MacDonald (1995) summarised that "even when they [mothers] allowed the spouse to take over, they would lie awake and listen. They did not ever turn themselves off from the needs of the child" (p. 505). Additionally, hospitalisation did not alleviate mothers' sense of being responsible, or need to be in control (MacDonald, 1995). Mothers appeared to find comfort in their role as overall controller. Mothers only discussed this reluctance to relinquish responsibility when talking about their male partners. It is not clear however, whether mothers may experience this same reluctance if they were leaving their child with their own mother for example. Additionally, the reluctance to relinquish control is culturally, and socially, influenced. Mothers in Dowell's (2015) study had to leave their children more frequently due to socio-economic factors. It may be that these mothers experienced the same reluctance, but circumstance forced them to accept the situation.

The altered maternal relationship: the tension between idealised and actual motherhood

This theme details the altered relationship mothers feel they have with their chronically ill child. Their additional caring role fulfilled the essence of motherhood, albeit in a non-traditional way, and yet mothers felt they were not the type of mother they envisioned. They felt 'less of' a mother to their other children and 'less of' a spouse to their partner. Mothers worked hard to try and maintain normalcy, through activities, discipline and schooling but ultimately felt that they were living a not-normal life. Uncertainty about their competence and role, in addition to the pervasive sense of responsibility and involvement of healthcare professionals, challenged mothers' sense of being responsible for, and in control of, the care of their child.

Mothering was experienced as distorted as a result of their child's chronic illness (Borhani et al., 2012; Bruce et al., 2013; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; 1996; Priddis et al., 2009; Rydström et al., 2004; Swallow & Jacoby, 2001b). They feared they were not good enough mothers (Borhani et al., 2012) and experienced high levels of uncertainty about their ability to mother a chronically ill child (Borhani et al., 2012; MacDonald, 1995, 1996; Rydström et al., 2004; Swallow & Jacoby, 2001b). Some mothers described being physically and emotionally very close to their child (MacDonald, 1995; Rydström et al., 2004), placing their child's needs above all other aspects of their lives. The need for closeness appeared to be as a result of the sense of responsibility mothers experienced, and the use of control as a coping strategy for this (see Theme 1). However, this closeness was a two edged sword, with mothers reporting feeling both happy to do so but also trapped by doing so:

> This relationship is a little bit different. Because of the child's disease I had to stay with him at the hospital a great deal of time…you learn to know this child in another way. It (the relationship) becomes closer, it will be a little bit different. You try not to have it in this way, but it still becomes a little bit different (Rydström et al., 2004, p 89).

For other mothers, their child's chronic illness created a physical proximity due to the additional care required, but also an emotional distance. One mother in Priddis and colleagues (2009) study explained "I love her passionately 80% of the time but I'm holding back on the 20% I guess...I feel it in my heart that I'm too scared to love her completely" (p. 22). For this mother she distanced herself from her child to protect herself from the emotions she expected to experience when her child with cystic fibrosis died.

Mothers were aware of their altered maternal relationship with the child and sought to promote normalcy even in the face of the abnormality of their everyday life (Borhani et al., 2012; Hodgkinson & Lester, 2002; MacDonald, 1995; Rydström et al., 2014). Mothers did this by a variety of means including encouraging separation between the child and themselves

(MacDonald, 1995) and trying to ensure their child was not given too much attention for example: “I probably discipline her more because I’m just very aware that everybody else is so lenient and I want her to be liked” (Hodgkinson & Lester, 2002, p. 380).

For some mothers, the overarching and pervasive sense of responsibility mother experience (see Theme 1) results in the act of placing the child’s needs above all else, which may have been influenced by societal gender norms and external shame, which subtly perpetuate the idea that mothers are not allowed to take time away from their caring role: “the mothers perceived that they were confined to their homes and judged irresponsible if they socialised” (MacDonald, 1995, p. 505).

Chronic illness was reported not only to affect the parents and affected child, but also the wider family. Mothers worried about the impact the chronic illness had on their partnership, other children and wider family (Bruce et al., 2013; Lee et al., 2014; MacDonald, 1995; Rydström et al., 2004). They experienced guilt, about the impact of the chronic illness on their healthy children (Bruce et al., 2013; MacDonald, 1995; Rydström et al., 2004). Due to hospital visits and stays and the emotional burden mothers experienced, they felt both physically and emotionally unavailable for their healthy child(ren). They experienced shame and guilt that they were not being the mothers they felt they should be and felt personally responsible for the impact their child’s illness had on the wider family unit. In particular, mothers in Lee and colleagues (2014) study worried about their other children’s genetic risk of being a carrier of the adrenoleukodystrophy gene and the social stigma that might result.

Counting the costs: dismissing one’s own feelings to maintain the ability to care.

This theme details the attempts to regulate the emotions mothers experience so as to continue with life and most importantly, to continue caring for their child. There was a sense of maintaining the façade that everything is ok, despite things not being ok. Things that might help mothers cope with their emotions, for example time away from their child or social support, were difficult to do because of their caring responsibilities. However, other families with chronically ill children were described as an excellent source of emotional and practical support. Mothers' need to be in control and be responsible (theme one) drove their need to dismiss their own feelings in order to continue caring for their child.

The emotional turmoil experienced by mothers of chronically ill children was evident across all studies. Mothers described a range of negative emotions and experiences. They experienced negative physical and mental health effects including depression, weight gain and severe sleep deprivation (Abolhassani et al., 2013; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1996; Priddis et al., 2009; Sullivan-Bolyai et al., 2003). For some mothers the emotions were so intense they considered suicide because "Nobody understood what I have been through" (Lee et al., 2014, p. 201). Mothers reported revisiting these emotions, in some cases as flashbacks. Mothers described the trauma associated with fearing their child may die noting: "I am so afraid because I think my child will suffocate at any moment. It is really difficult for me, in such a way that life has become unbearable for me" (Borhani et al., 2012).

Mothers also experienced negative emotions towards their new found role as carer (Borhani et al., 2012; Hodgkinson & Lester, 2002; MacDonald, 1995, 1996; Rydström et al., 2004) and described caring for their child as "confin[ing]" and "monotonous" (MacDonald, 1995, p. 505). Despite feeling negatively about it, mothers felt there was no other choice but to accept it. Despite the overwhelmingly negative emotions and experiences, mothers knew they must continue to provide care to their child. For the majority of mothers, it could be argued that the intense, traumatic and overwhelming emotions and experiences were easier to cope with if kept repressed or ignored. It was too frightening to allow themselves to experience fully the magnitude of their experiences and emotions. They therefore could not allow themselves to reflect on their feelings, but instead coped with them by choosing not to think about them or by busying themselves with learning. For one mother, she explained that she "just pretty much went blank for probably six months to eight months I think, until, until I sort of snapped out of it a bit. I just, I functioned I suppose, but on a pretty basic level" (Priddis et al., 2009 p. 22). There was also perhaps a fear that if they were to open up to their feelings, they would be unable to function and continue the day to day management of their child's condition, and therefore their child's survival depended on their ability to ignore their feelings and not express them until in an appropriate context and time. One mother explained:

> When I get the feeling…that doesn't happen very often, but you feel like you're going to panic…that engulfs you…I can't stay in that place…it's too awful. I'm too weak a person to get into emotions that I can't handle (MacDonald, 1995, p. 505).

Mothers were forced to find coping strategies to manage the intense emotions they experienced so as to be able to continue caring effectively for their child. This need to find coping strategies was driven by the overwhelming sense of responsibility mothers experienced. In order to fulfil their obligations and responsibilities mothers must find methods to manage their emotions. For most mothers, there were very few coping mechanisms available for them, and so instead they engaged in denial or dismissal of their emotions and the impact of the illness. This can be conceptualised as mothers exerting control, as illustrated in the subtheme control as a method odf coping with the sense of responsibility. Mothers instead channelled their energy into learning how to care for their child and finding certainty, as illustrated by themes one and four.

Mothers did have some methods of coping other than exerting control over their emotions. One method was to choose to focus on a positive perspective, which for some involved relying upon faith (Abolhassani et al., 2013; Borhani et al., 2012; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995). Mothers described finding meaning in their experiences, stating a shift in priorities stating "it does make you more aware of the important things in life" (Hodgkinson & Lester, 2002, p. 380).

Other mothers turned to social support to help them cope. Some reported feeling supported by their family (e.g. Borhani et al., 2012; Bruce et al., 2013; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; Macdonald, 1995; Sullivan-Bolyai et al., 2003). Others simultaneously experienced increasing social isolation, the inability of their social network to help support them, the lack of professional support or the obstacles in accessing social support (Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; Rydström et al., 2004; Sullivan-Bolyai et al., 2003). Even for those mothers who had support, it was either not enough, or difficult to access, for example: "I was so exhausted in the beginning, when we got home and…I turned off the phone to… all friends, they wanted to call and ask and, well like almost every day and I said 'I can't take it'" (Bruce et al., 2013, p. 60).

Mothers valued the support of fellow parents of chronically ill children (Bruce et al., 2013; Lee et al., 2014; MacDonald, 1995; Sullivan-Bolyai et al., 2003). This support from fellow mothers included the sharing of information, in particular about the disease and sources of help (Lee et al., 2014) and the support that came from sharing an experience and being able to communicate, without words, their experiences to people who are "in the same boat" (Lee et al., 2014, p. 201) (Bruce et al., 2013; MacDonald, 1995).

Becoming the expert

This theme describes mothers' attempts to become the expert in their child's care, as a means of reducing their sense of incompetence and uncertainty, but also as way to counteract their perceived lack of competence in healthcare professionals. During the initial phase mothers relied heavily on healthcare professionals. This initially eased their uncertainty, however ultimately it resulted in them feeling incompetent, unknowledgeable and ultimately out of control of their child's healthcare. In an attempt to reassert their dominance and quell the intense uncertainty they sought out information, and thus competence. As mothers developed a sense of competence and expertise, they lost their naïve trust in professionals and the system. This further propelled mothers to become expert at caring for their child.

Uncertainty was a prevalent feeling throughout the journey of caring for a child with chronic illness in all studies except Priddis and colleagues (2009). Indeed, MacDonald's (1995) overarching theme when exploring mothers' experiences of childhood asthma was "mastering uncertainty" (p. 55), reflecting the powerful nature of uncertainty for mothers, and their journey to gain some perceived control over it. Uncertainty was highest during the process of diagnosis (Bruce et al., 2013; Lee et al., 2014). Diagnosis became a definitive fact to hold on to and a means of gaining more information; however the relief was short lived. Mothers described their desire to learn more so as to feel more competent and certain, so as to effectively fulfil their perceived sense of responsibly (Abolhassani et al., 2013; Bruce et al., 2013; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; Rydström et al., 2004). This need for certainty and competency (and therefore control) was heightened by mothers' feelings that they were expected to learn the necessary skills quickly for example "they give you a bag of supplies and say 'ok take her home, you'll be fine, right!'" (Sullivan-Bolyai et al., 2003 p. 25), further increasing their feelings of incompetence.

Seeking medical support was one way mothers sought certainty, for example "I was constantly looking for medicine, antibiotics and the doctors. Now I see a doctor regularly and I'm a little calmer" (Borhani et al., 2012, p. 118). This could be perceived as mothers' attempts to pass the responsibility they feel onto healthcare professionals. This provided only temporary relief as mothers were ultimately still unknowledgeable about their child's condition and therefore could not help their child when medical support was unavailable.

Mothers therefore sought to educate themselves to increase their competence and sense of control (Dowell, 2015; MacDonald, 1996).

As mothers became more informed and competent they learned to "take hold" of the illness and feel more certain and confident, and therefore in control (MacDonald, 1996, p. 58). They learned to take risks by introducing flexibility into the treatment regime (Bruce et al., 2013; Rydström et al., 2004; Sullivan-Bolyai et al., 2003), trust themselves (MacDonald, 1996) and find a sense of satisfaction in their new knowledge (Bruce et al., 2013). MacDonald (1996) described the end result of this process as a "mastered uncertainty" (p. 55) and a realisation that they can cope with their child's condition.

During the process of gaining new knowledge and competency, mothers lost their trust in the healthcare professionals and modern medicine (Bruce et al., 2013; Dowell, 2015; MacDonald, 1995, 1996, Swallow & Jacoby, 2001a). Mothers initially placed their trust in the healthcare providers, but that trust was easily shattered (MacDonald, 1995, 1996), especially when mothers realised that they did not have the answers (Bruce et al., 2013) or when they did not meet the mothers' demands (Swallow & Jacoby, 2001a, 2001b).

The relationship between mothers and healthcare professionals was a complex and varied one. Mothers reported mixed experiences with healthcare professionals. They valued the specialised knowledge and support (Bruce et al., 2013, Borhani et al., 2012; Dowell, 2015; Hodgkinson & Lester, 2002; MacDonald, 1995, 1996; Swallow & Jacoby, 2001a, 2001b). However, mothers also felt threatened, judged, let down and dismissed by them (Bruce et al., 2013; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995, 1996; Priddis et al., 2009; Swallow & Jacoby, 2001a, 2001b). Their role as a mother (i.e. primary caregiver and decision maker) was challenged by the healthcare professionals. This was particularly challenging as they experienced an overwhelming sense of responsibility, while simultaneously having that responsibility dismissed by professionals. Mothers wanted their expertise to be recognised, for example "I've been living with this for three years, I know what I'm talking about" (MacDonald, 1995, p. 506) and "I'm the expert on my child. Nobody else knows what she was like last night" (MacDonald, 1996, p. 58) but felt it was often dismissed. As mothers became increasingly knowledgeable and competent, they became more aware of the fallibility of the system and healthcare providers. This resulted in them feeling more able to challenge the system when they felt their needs were not being met (Borhani et al., 2012; MacDonald, 1996; Swallow & Jacoby, 2001a, 2001b). This allowed them to resume their role as the one in control, evidencing the role of the overarching theme of responsibility and control.

Discussion

The aim of the present synthesis was to gain an understanding of the experiences of mothers with chronically ill children. Thematic synthesis was used to analyse 13 papers looking at mothers' experiences of parenting a chronically ill child. Four themes were identified, specifically: the overarching and pervasive sense of responsibility; the altered maternal relationship: the tension between idealised and actual motherhood; counting the costs: dismissing one's own feelings to maintain the ability to care; and becoming the expert.

The two main theories that will be used to interpret the current findings are Lazarus and Folkman's (1984) transactional model of stress, appraisal and coping and the self-regulatory model (Leventhal, Nerenz & Steele, 1984; Leventhal, Leventhal & Cameron, 2001). In light of both models, all mothers perceived the situation as threatening; the threat of their child's illness, of not being able to be a 'good' mother and not being able to handle their own emotions. Additionally, the overwhelming sense of guilt mothers experienced could be conceptualised as a threat. This appraisal resulted in mothers initially feeling powerless, although they acknowledged that healthcare professionals could control or manage the situation, suggesting that mothers' helplessness was not global helplessness but rather specifically related to their own ability to alter the outcome. They engaged in emotion-focused coping, specifically by avoiding or denying their emotional reactions to the situation. Denying their emotional reactions clearly allowed mothers to cope with the uncertainty experienced, while also maintaining their hope that the threat (their child's chronic illness) could be overcome. Denial is viewed with mixed opinion by researchers and clinicians (Livneh, 2009), however for these mothers it was an integral and beneficial aspect of their coping. The emotional turmoil experienced by mothers is supported by findings from previous reviews (Coffey, 2006; Nelson, 2002). Coping is a dynamic process, meaning that people choose and change coping styles based on their appraisals and reappraisals of the situation (Folkman & Lazarus, 1980; 1988; Lazarus & Folkman, 1984). While mothers initially used denial and other emotion-focused strategies in the initial stages, this did not allow them to feel competent and in control so they adapted their coping strategies to better meet their needs. As mothers' perceptions of the illness and their coping strategies changed over the course of time, their emotional responses changed, from overwhelmed and avoidant, to more confident and competent. This illustrates how the emotional response to a situation is mediated by cognitive factors (appraisals and perceptions) and behavioural strategies (coping strategies) (Lazarus & Folkman, 1984; Leventhal, Meyer & Nerenz, 1980).

One mediating factor which influenced mothers' perceptions, appraisals and coping strategies of choice was control. In the current study, mothers initially experienced a sense of complete lack of control over their child's illness and their own emotional response to the situation. This resulted in them desiring and seeking control. The need for mothers to feel in control, in order to cope with their child's chronic illness, is well documented in other reviews (e.g. Coffey, 2006; Fisher, 2001). As mothers adapted and became knowledgeable about their child's condition and treatment, their sense of perceived control, perceived self-efficacy and sense of mastery improved. Mothers' emotional well-being appeared to be at its lowest when their perceptions of control were lowest (see Hagger & Orbell, 2003). Unfortunately, this relationship is not fully understood and there are likely to be many confounding variables which influence it (Helgeson, 1992). Given the overarching theme of responsibility, it follows that mothers would feel their primary objective would be to improve the situation. To do so, they need to experience a sense of control over the situation. Within the current synthesis, when mothers perceptions of control were at their lowest they were less likely to seek out ways to develop their sense of competence (for example by learning about the illness, challenging professionals, making decisions etc.). The act of taking control is a coping strategy for mothers. While it does not reduce the negative feelings they experience, it does allow them to cope with the challenges they face. This may explain why emotional wellbeing is low when perceived sense of control is low. It must be noted however, that mothers' taking control (both emotionally and practically) may also be an attempt to display competence as a mother in a setting which can be perceived as threatening to their competence (Anderson & Elfert, 1989). The cultural and societal expectations of mothers as carers (e.g. Bem, 1981) may mean that mothers feel pressured to cope (and therefore care well) at all times. It may be that mothers' desires to appear like 'good mothers' influence their coping strategies of choice.

One specific way that mothers took charge was their changing relationship with professionals. This developed in conjunction with their increasing knowledge and expertise. The need to be viewed as a partner by professionals (and the challenges in managing this) is supported by other syntheses on parents of chronically ill children (Coffey, 2006; Fisher, 2001; Nelson 2002). The process mothers went through mirrors Gibson's (1995) theory of the process of empowerment in mothers of chronically ill children. This process of feeling empowered was a vital part of mothers' development as a parent and carer, which also enabled them to cope with their situation.

Reflections on inter-rated reliability during the data collection and analysis

The process of having a second person to review and discuss each stage of my data collection and analysis allowed me to delve deeper in my analysis, to notice things I might not have done on my own. It also provided a counterbalance to situations where my own life experience and perspective may have coloured the analysis. During supervision I would bring my reflexive journal and discuss its contents. These discussions allowed me to bracket, or separate, my own life experiences as much as possible, in line with Thomas and Hardens (2008) advice. An example of this was my experience as a mother. While my child does not have health problems, it was at times difficult to not imagine myself in the mothers' positions during the analysis. This process ensured both transparency and a high level of quality during the analysis.

Reflections on the impact of the heterogeneity of the studies

As with many literature reviews, the inclusion of multiple papers resulted in heterogeneity between mothers. While all attempts were made to ensure homogeneity through the use of inclusion and exclusion criteria there will inevitably be areas where divergence exists between participants. Within the current study there several areas of heterogeneity which may have influenced the results. It is important to note however, that while heterogeneity can limit the application of results, it does also allow a less restrictive understanding of a variety of perspectives. Specifically these are ethnicity/culture/religion, disease type and timing since diagnosis.

First, culture, religion and ethnicity were widely represented within the current study. Papers were conducted in seven countries (Iran, UK, USA, Canada, Taiwan, Sweden and Australia). They included a variety of ethnicities, for example Dowell (2015) only included African-American mothers, Lee et al. (2014) only included Taiwanese mothers and some papers included a variety of ethnicities e.g. Sullivan-Bolyai et al. (2003). They also included mothers with a variety of religious beliefs. This variance influenced the results in specific ways. For example, mothers in Lee et al.’s (2014) study discussed the role of faith in coping (illustrating the influence of religious beliefs), but also discussed the cultural shame and stigma of having their other (healthy) children genetically tested and the implications that might have for their eligibility for marriage. While genetic testing was discussed in other papers, the cultural aspects of shame and stigma were not, suggesting this specific finding may be specific to Lee et al.’s study and Taiwanese mothers. Dowell (2015) focused on African-American mothers from low income families. These mothers felt the same sense of responsibility and control as mothers in other studies. However, despite their need to be responsible for, and in control of, every aspect of their child’s life and their reluctance to allow others to care for their child, they were forced to leave their children in the care of others (family or childcare staff) in order to work. This specific finding was discussed less in other studies, suggesting it is influenced by lower socio-economic status (which in turn may be influenced by ethnicity). Finally, the culture of healthcare provision may have influenced findings. For example, within the UK, healthcare is almost entirely state funded, in USA parents must obtain health insurance and in other countries (Australia for example) there is a mid-way provision of partially state funded healthcare. The necessity of having to obtain healthcare insurance may have influenced mother’s sense of responsibility (due to the financial burden a sick child may place on the family) but also the need to be in control of healthcare provision (that they are paying for). The role of healthcare funding was not explored adequately within the individual papers however, making it difficult to draw conclusions. While mothers report broadly similar experiences, culture and religion do clearly exert an influence. Services would benefit from being culturally and religiously aware and sensitive to mother’s needs when diagnosing and treating children.

Secondly, a variety of illnesses were included within the review, specifically diabetes, asthma, congenital heart defects, cystic fibrosis, adrenoleukodystrophy and chronic kidney disease (including vesicoureteric reflux). Overall, mothers reported surprisingly similar experiences irrespective of their child's condition, however there were some minor differences. For example, mothers of children with cystic fibrosis and adrenoleukodystrophy had to consider the genetic implications of their child's illness (including implications for the wider family), whilst other mothers did not. Mothers of children with respiratory illnesses (asthma and cystic fibrosis) discussed the emotional burden of having to watch their child struggle to breathe, which was not an experience other mothers shared. Mothers did not however, report greatly differing experiences, suggesting that broadly speaking, the experiences of parenting a chronically ill child are similar, irrespective of illness type. Despite this generally similar experience, healthcare providers should be aware of the unique challenges of chronic health conditions present for mothers.

Finally, the timing since diagnosis may have influenced the results of the current review. It was difficult to ascertain within the original papers how long it had been since their child was diagnosed with a chronic condition and so determining the role this may have played in the findings is challenging.

Limitations

The vast majority of the studies were conducted in western societies. There was some ethnic diversity (e.g. Abolhassani et al., 2013; Borhani et al., 2012; Dowell, 2015; Lee et al., 2014) within the studies included; however it was evident that mothers from different cultural and ethnic backgrounds had different experiences. For example, mothers in Dowell's study discussed having to leave their children in childcare or with family due for financial reasons as they themselves had to go out to work. Furthermore, single mothers were in the minority of participants, and to the author's awareness, no mothers in a same-sex relationship were included in the studies. Future research should therefore ensure that minority groups' experiences are heard and explore the differences and similarities between these and groups already studied. Additionally, there were some minor discrepancies between mothers experiences related to their child's condition. For example, guilt was more prevalent in mothers whose children had genetic conditions.

With specific regard to the literature searching process there were a number of potential limitations. First, while forward and backward literature searching was conducted, only two additional articles were identified. Forwards and backwards searching identified two further papers not found through the search strategy. This small number may indicate that although there is a risk of relevant papers not being identified, it is fairly unlikely. Furthermore, the decision was made to exclude grey literature, due to the time consuming nature of identifying it and the lack of peer review process. There may therefore be additional sources of data not included in the review. Additionally, there was no double sorting or inter-rater reliability checks on the decision making during the review of search results.

Finally, it must be acknowledged that any inclusion and exclusion criteria will influence the results. This review has specifically focused on mothers whose children have a physical health condition, and therefore must be applied to mothers whose children have mental health conditions and neurodevelopmental conditions with caution. Additionally, I chose to exclude mothers of children with cancer due to the difficulties in determining whether the child's cancer was terminal or not. Please see Table 2 for more details on this justification. The application of inclusion and exclusion criteria is a carefully considered process in literature reviews; however every decision made creates the potential for biases within the results. The decisions made within the current review were made to ensure the studies were as homogenous and as high quality as possible.

Implications

Based on the current findings there are numerous potential clinical implications. Mothers experience intense negative emotions and a sense of helplessness and powerlessness when their child is chronically ill. For mothers in the current synthesis denying, or ignoring, these feelings was a coping strategy that allowed them to continue to care for their child. Therefore intervention for mothers initially that challenge this particular strategy is likely to be detrimental. It may be more beneficial to provide information on where mothers can access support (e.g. parent support groups, medical professionals, a clinical psychologist etc.) when they feel able to do so. Healthcare professionals must be aware of the various stages of coping mothers are at and adapt how they interact. For example, in the early stages of diagnosis mothers feel unable to take in information and take control and need the professional to be stable and in control. Repeating information at later appointments, providing written information and methods for mothers to ask questions away from appointments (such as an email address or phone number) may be beneficial for them. However, mothers soon want to take control and gain information, which requires professionals adapting their interactions. Training (and refresher) sessions for mothers could be offered on a regular basis for mothers to opt into. This would allow them the opportunity to seek clarification, knowledge and improve their competence. Healthcare professionals would benefit from considering at what stage of adaption mothers are at and providing a safe and secure environment for mothers to improve their knowledge and sense of competence and to take control of their child's illness by being included in decisions.

Family centred care is recommended in healthcare settings (Franck & Callery, 2004) and should theoretically encourage mothers to be involved in their child's care. The findings of this study suggest however, that it is either not adequately implemented or that it does not fulfil mothers' needs. Further research exploring the implementation, impact and experience of family centred care would be beneficial. One possibility is that is not what family centred care does, but rather how it does it. Ensuring that mothers are not stigmatised inadvertently is vital to their wellbeing and possibly that of the child they care for. In addition, handing over case management tasks at later stages, after appropriate coaching, might enhance their sense of control whilst allowing mothers to gain appropriate support without being undermined.

Peer support may be beneficial for mothers and was identified as a potential source of support by the mothers in this review. Peers understand the challenges mothers experience and may prove a non-threatening arena to disclose their strong emotional reactions, intense sense of responsibility and sense of incompetence. It may be that mothers cannot disclose these feelings to healthcare professionals for fear of being viewed as a 'bad mother' but can to fellow mothers of chronically ill children. Additionally, mothers could be trained as peer educators/peer supporters and act as a formal source of support that sits between friends/family and professionals (Dennis, 2003). They could assist in education sessions, help provide training to healthcare professionals, be involved in service development and delivery and support parents to access additional support where necessary.

Providing access to a clinical psychologist would likely be of benefit to mothers. Clinical psychologists are increasingly working within physical health settings (British Psychological Society, 2008), and can provide an array of skills to both the parents and the healthcare professionals. Clinical psychologists could help monitor mothers' mental health and grief response, help establish peer support for mothers, offer training and guidance to staff on how to communicate with mothers at various stages of the illness trajectory based on theoretical knowledge (for example, grief response theories (e.g. Kubler-Ross, 1972), information storage and recall theories (e.g. Craik & Lockhart, 1972)) and provide interventions to both mothers and children to help adjust to living with a chronic illness. Mothers could also be supported to work through the guilt and shame they experience using compassion focused interventions (Gilbert, 2009). This is not to say that mothers' behaviours should be pathologised. The message that they should receive is that they are being offered support or coaching because they are in a difficult situation that is difficult for anyone in that situation.

Future research

There is a small, but slowly growing, evidence base exploring fathers’ experiences of parenting a child with chronic illness (e.g. Hobson & Noyes, 2011; Waite-Jones & Madill, 2008). Future research could focus on developing this evidence base and conducting a systematic literature review to summarise the research. This would allow exploration of whether mothers and fathers share experiences and which experiences may be dissimilar.

Conclusion

In conclusion, this study explored mothers’ experiences of parenting a child with chronic illness. Mothers felt an overwhelming sense of responsibility and the need to be in control at all times (because of feeling emotionally out of control). Mothers described their experiences as emotionally traumatic, during the early stages of the illness and for many years after. Mothers felt unable to cease mothering to deal with these emotions, and therefore employed any methods possible to regulate their emotions to allow them to continue mothering. Finally, they experienced an altered sense of mothering, with the illness shaping their experiences. The current findings emphasise the importance of healthcare providers being aware of mothers’ emotional reactions to their child’s illness and offering support at each stage of the illness. They also highlight the importance of providing information using multiple methods, at multiple times, as well as focusing on developing a strong, positive and collaborative relationship with mothers.

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Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science Medicine,* 55, 1835-47. http://dx.doi.org/10.1016/S0277-9536(01)00318-5

Table 1.

Search syntax

Database	**Syntax**
Academic Search Complete AMED Web of Science	((‘Mother*’ OR ‘maternal’ OR ‘parent’) AND (‘experience*’ OR ‘perspective*’ OR ‘view*’ OR ‘perception*’ OR ‘attitude*’) AND (‘chronic health’ OR ‘chronic illness’ OR ‘chronic disease’ OR ‘chronic condition’ OR ‘long term health’ OR ‘asthma’ OR ‘diabetes’ OR ‘cystic fibrosis’) AND (‘qualitative’) NOT (‘disabilit*’ OR ‘neurodevelopment*’ OR ‘ADHD’ OR ‘autism’ OR ‘cerebral palsy’ OR ‘spina bifida’ OR ‘cancer’))
CINAHL MEDLINE PubMed	NB terms in bold were searched as MESH terms ((‘**Mother***’ OR ‘maternal’ OR ‘parent’) AND (‘experience*’ OR ‘perspective*’ OR ‘view*’ OR ‘perception*’ OR ‘attitude*’) AND (‘chronic health’ OR ‘chronic illness’ OR ‘**chronic disease’** OR ‘chronic condition’ OR ‘long term health’ OR ‘asthma’ OR ‘diabetes’

	OR 'cystic fibrosis') AND (**'qualitative studies'**) NOT ('disabilit*' OR 'neurodevelopment*' OR 'ADHD' OR 'autism' OR 'cerebral palsy' OR 'spina bifida' OR 'cancer'))
PsycArticles PsycInfo	NB terms in bold were searched as major concepts (('**Mother***' OR 'maternal' OR 'parent') AND ('experience*' OR 'perspective*' OR 'view*' OR 'perception*' OR 'attitude*') AND ('chronic health' OR 'chronic illness' OR '**chronic disease'** OR 'chronic condition' OR 'long term health' OR 'asthma' OR 'diabetes' OR 'cystic fibrosis') AND ('qualitative') NOT ('disabilit*' OR 'neurodevelopment*' OR 'ADHD' OR 'autism' OR 'cerebral palsy' OR 'spina bifida' OR 'cancer'))

Table 2.

Details of inclusion and exclusion criteria and the justification for these.

	Criterion	**Justification**
Inclusion	Qualitative papers	The aim of the study was to explore mothers' in depth experiences of parenting a chronically ill child. It is difficult to fully understand a person's experience using quantitative methodologies and therefore qualitative studies were most appropriate to the aim of the review. Given that most methods of literature synthetisation allow for multiple methodologies to be included, the broad category of qualitative research was applied, rather than specific methodologies.
	Minimum of three months diagnosis	Most definitions of chronic illness require symptoms to be present for a minimum of three months, although some extend that to six months or a specified number of hospital visits within a year (see van der Lee et al., 2008). Specifying a minimum of three months ensured parents of children who were acutely ill were not included in the study.
	English	The researcher is not fluent in any other languages. Additionally, translating studies is both costly and can result to the loss of detail. It was therefore considered appropriate to only include studies published in English.

	Mothers	As explored in the introduction, mothers’ experiences of parenting are likely to be different to those of fathers. The aim of the research was to explore specifically what mothers’ experiences of parenting a chronically ill child are, and therefore papers must include mothers’ experiences.
Exclusion	Published in a non-peer reviewed journal	In order to ensure the data included were of as high quality as possible, only studies published in peer-review journals were included. Publication in a peer reviewed journal is not a guarantee of quality; however it does ensure that an element of quality checking has occurred. Additionally quality appraisal was conducted as part of the analysis process.
	Cancer	Mothers of children with cancer were excluded because it was felt that the experiences of mothering a child with untreatable, terminal cancer may be different to parenting a child with treatable cancer. Unfortunately, it was not always possible to conclude whether the child’s cancer was treatable or not and so it was felt more appropriate to exclude all studies exploring mothers’ experiences of cancer to ensure consistency.
	Neurodevelopmental conditions	Neurodevelopmental conditions or intellectual disabilities were not included for two reasons. First, Nelson (2002) has already conducted a meta-ethnography on a sample that primarily consisted of mothers whose children had neurodevelopmental conditions. Second, the lived

	experience of mothers with a child with a neurodevelopmental condition might be different to mothers of physically chronically ill children. For example, being faced with their child’s personality and capabilities being changed following a brain injury (e.g. Kirk, Fallon, Fraser, Robinson & Vassallo, 2015) and challenging behaviour (Lecavelier, Leone & Wiltz, 2006).
Mental health	The specific focus of the review was mothers of children with physical chronic health problems and therefore mothers of children with mental health problems were excluded. It could be argued that mothers’ experiences may be similar, irrespective of whether their child has physical or mental health difficulties, however, in the interest of trying to produce as homogenous sample as possible, mental health conditions were excluded.
Included others’ experiences	It could be argued that studies that included mothers as well as other individuals (e.g. fathers, healthcare professionals) could provide useful data. However, many of the studies included did not distinguish between experiences of mothers and others, often combining them during the analysis process. This means that those results are not focusing exclusively on mothers’ experiences. Excluding studies which included multiple perspectives ensured the data were as homogenous as possible, therefore ensuring the purity of the final themes.

Table 3.

Details of Studies Included in the Meta-Synthesis.

Study	Sample	Location	Disease
Abolhassani et al., 2013.	11 mothers	Iran	Diabetes
Borhani et al., 2012	10 mothers	UK	Asthma
Bruce et al., 2013	10 mothers	Sweden	Congenital heart defects
Dowell, 2015	15 mothers	USA	Asthma
Hodgkinson & Lester, 2002	17 mothers	UK	Cystic Fibrosis
Lee et al., 2014	8 mothers	Taiwan/Canada[2]	Adrenoleukodystrophy
MacDonald, 1995	8 mothers	Canada	Chronic kidney disease
MacDonald, 1996	4 mothers	Canada	Asthma

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[2] The study interviewed Taiwanese mothers but the study was completed and written in Canada

Priddis et al., 2009	19 mothers	Australia	Cystic Fibrosis
Rydström et al., 2004	17 mothers	Sweden	Asthma
Sullivan-Bolyai et al., 2003	28 mothers	USA	Diabetes
Swallow & Jacoby, 2001a	29 mothers	UK	Vesicoureteric reflux (VUR)
Swallow & Jacoby, 2001b	29 mothers	UK	Vesicoureteric reflux (VUR)

Table 4.

Demographic Details of Participants Included in the Meta-Synthesis.

Study	**Age of mother**	**Age of child**	**Other children**	**Ethnicity**	**Employment**	**Education**	**Relationship status**	**Religion**	**Time since diagnosis**
Abolhassani et al., 2013.	28-42 years old	4-16 years old	Not disclosed	Iranian	Not disclosed	5 high school education or higher 5 diploma or less 1 illiterate	All married	Not disclosed	Not disclosed
Borhani et al., 2012	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed

Bruce et al., 2013	Mean age 38	3-12 years old	Not disclosed	Not disclosed	1 unemployed 1 early retirement 8 employed	6 university education 4 upper secondary education	Not disclosed	Not disclosed	Not disclosed
Dowell, 2015	22-52 years old	2-14 years old	Yes but number not disclosed	African American mothers	53% employed (deliberately recruited those considered low income)	60% college education 40% finished high school	27% married 27% unmarried 20% divorced 13% living with partner 13%	Not disclosed	Not disclosed

							separated		
Hodgkinson & Lester, 2002	24-48 years old	2-13 years old	Mean other children 1.88	West-Midlands of UK	58.8% unemployed 35.5% part time employment 5.9% full time employment	23.5% no GCSE's 35/3% GCSEs 23.5% A Levels 17.6% Degree	88.2% nuclear family 11.8% single parent	Not disclosed	Not disclosed
Lee et al., 2014	33-52 years old	Not specified	Not disclosed	Taiwanese mothers	1 worked outside the home	2 junior high 2 senior high	Not disclosed	3 Taoist 2 Christian 2 Buddhist 2 non-	3-10 years

						2 college 1 university 1 undergrad		religious	
MacDonald, 1995	Not specified	3-4.5 years old	Not disclosed	Not disclosed	Not disclosed	Not disclosed	All married	Not disclosed	Not disclosed
MacDonald, 1996	26-47 years old	3-10 years old	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	3-10 years
Priddis et al., 2009	Not specified	Mean age 3.46 years old (SD, 1.97)	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed
Rydström et al., 2004	Not specified	Not specified	Unclear but at least 14 mothers	Not disclosed	Not disclosed	Not disclosed	14 lived with biological	Not disclosed	Not disclosed

			had other children				father 3 single parents		
Sullivan-Bolyai et al., 2003	Mean age 33 (SD 5.24) years	Mean age 2.9 (SD 0.6) years	Not disclosed	89% white	15 mothers were housewives	Mean educated was 15 (SD 2.5) years	86% married	Not disclosed	Mean duration 1.25 (SD 0.7) years
Swallow & Jacoby, 2001a	Not disclosed	Not specified	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed
Swallow & Jacoby, 2001b	Not disclosed	Not specified	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed	Not disclosed

Table 5.

Key Features of Studies Included in the Meta-Synthesis

Study	Main focus	Data collection	Analysis	Main themes
Abolhassani et al., 2013.	The experiences of mothers with children with diabetes	11 1:1 semi-structured interviews in person	Content analysis	Reaction at the time of diagnosis Disease consequences
Borhani et al., 2012	The experiences of mothers with children with asthma	10 1:1 semi-structured interviews in person	Content analysis	Constant concern The feeling of having an unusual life The need for help from others The desire to constantly monitor the child Feelings of guilt
Bruce et al.,	The lived	10 1:1 semi-structured	Phenomenologic	Requesting privacy as support

2013	experiences of support of mothers with children with congenital heart defects	interviews in person	al-hermentic interpretative method	Supportive confirmation
Dowell, 2015	The experiences, functioning and needs of low income African-American mothers with children with asthma	15 1:1 semi-structured interviews in person	Content analysis	Managing the symptoms as a parent Cultural beliefs and values of the mother influence the day to day Professional/cultural competence of the HCP
Hodgkinson & Lester, 2002	Stresses and coping strategies of mothers with children with cystic fibrosis	17 1:1 semi-structured interviews in person	Influenced by grounded theory	Psychosocial consequences of caring for a child with CF Coping strategies

				Relationship with HCPs
Lee et al., 2014	Mothers experiences of having a child with adrenoleukodystrophy	8 1:1 semi-structured interviews in person	Phenomenologically informed approach	Difficult confirming diagnosis Powerlessness toward unsatisfactory treatment Guilt about being a carrier Struggles with decisions around carrier testing Support from family members/other parents with a child with ALD Lack of integrated resources and support
MacDonald, 1995	Mothers experiences of having a child with chronic renal disease	10 1:1 semi-structured interviews in person of 4 mothers. Three mothers were interviewed three		

		times.		
MacDonald, 1996	Mastering uncertainty as a mother of a child with asthma	13 1:1 semi-structured interviews of 8 mothers in person. 5 mothers were interviewed twice	Influenced by Ethnographic enquiry	Mastering uncertainty Actions Internal self Passage of time
Priddis et al., 2009	Cystic fibrosis diagnosis: impact on mothers of affected Australian children	19 1:1 semi structured interviews in person	Content analysis	Trauma upon learning of the child's diagnosis Ongoing feelings of grief and loss Process of adjustment Relationship with the hospital Family relationships

Rydström et al., 2004	Relations governed by uncertainty: part of life of families of a child with asthma	17 1:1 semi-structured interviews in person	Grounded theory	Being governed by disease engendered uncertainty Mothers being available for the child with asthma Mothers being less available for other family members
Sullivan-Bolyai et al., 2003	Constant vigilance in mothers of young children (under 4) with type 1 diabetes	28 1:1 semi-structured interviews in person	Naturalistic enquiry	Constant vigilance (central theme) Day to day concerns Day to day management Supportive resources Burden of constant vigilance on mothers physical and emotional health
Swallow & Jacoby, 2001a	Mothers' evolving relationships with doctors and nurses	29 1:1 semi-structured interviews in person	Framework technique to content analysis	Before the diagnosis: being taken seriously Making the transition to diagnosis: communication

	during the chronic childhood illness trajectory			between mothers and staff After the diagnosis: managing the relationships
Swallow & Jacoby, 2001b	Mothers’ coping in chronic childhood illness: the effect of presymptomatic diagnosis of vesicoureteric reflux	29 1:1 semi-structured interviews in person	Framework technique to content analysis	Pre-diagnosis phase Diagnosis phase Post-diagnosis phase

Table 6.

Quality Appraisal Using the CASP[1]

Study	**Statement of aims**	**Appropriate methodology**	**Research design**	**Recruitment strategy**	**Data collection**	**Researcher reflexivity**	**Ethical issues**	**Data Analysis**	**Results**	**Value of findings**
Abolhassani et al., 2013.	Yes	Yes	Yes	Cannot tell	Yes	No	Cannot tell	No	Cannot tell	Cannot tell
Borhani et al., 2012	Yes	Yes	Yes	Yes	Yes	No	Cannot tell	Yes	Yes	Yes
Bruce et al., 2013	Yes	Yes	Yes	Cannot tell	Yes	No	Cannot tell	Yes	Yes	Yes
Dowell, 2015	Yes	Yes	Cannot tell	Yes	Yes	No	Cannot tell	Yes	Yes	Yes

Hodgkinson & Lester, 2002	Yes	Yes	No	No	No	No	Cannot tell	Yes	Yes	Yes
Lee et al., 2014	Yes	Yes	Yes	Yes	Yes	No	Cannot tell	Yes	Yes	Yes
MacDonald, 1995	Yes	Yes	Yes	Yes	Yes	No	Cannot tell	Yes	Yes	Yes
MacDonald, 1996	Yes	Yes	Yes	Yes	Yes	No	Cannot tell	Yes	Yes	Yes
Priddis et al., 2009	Yes	Yes	Yes	Cannot tell	Yes	No	Cannot tell	Yes	yes	yes
Rydström et al., 2004	Yes	Yes	Yes	Cannot tell	Yes	No	Cannot tell	Yes	Yes	Yes

Swallow & Jacoby, 2001a	Yes	Yes	Yes	Yes	Yes	No	Cannot tell	Yes	Yes	Yes
Swallow & Jacoby, 2001b	Yes	Yes	Cannot tell	Yes	Yes	No	Cannot tell	Yes	Yes	Yes

[1] CASP responses. Criterion were scored 'yes' when the criterion in question was present and clearly reported, 'no' when the criterion in question was not described adequately or was absent from the paper and 'cannot tell' when the criterion were referred to but there was not enough detail to confirm adequacy.

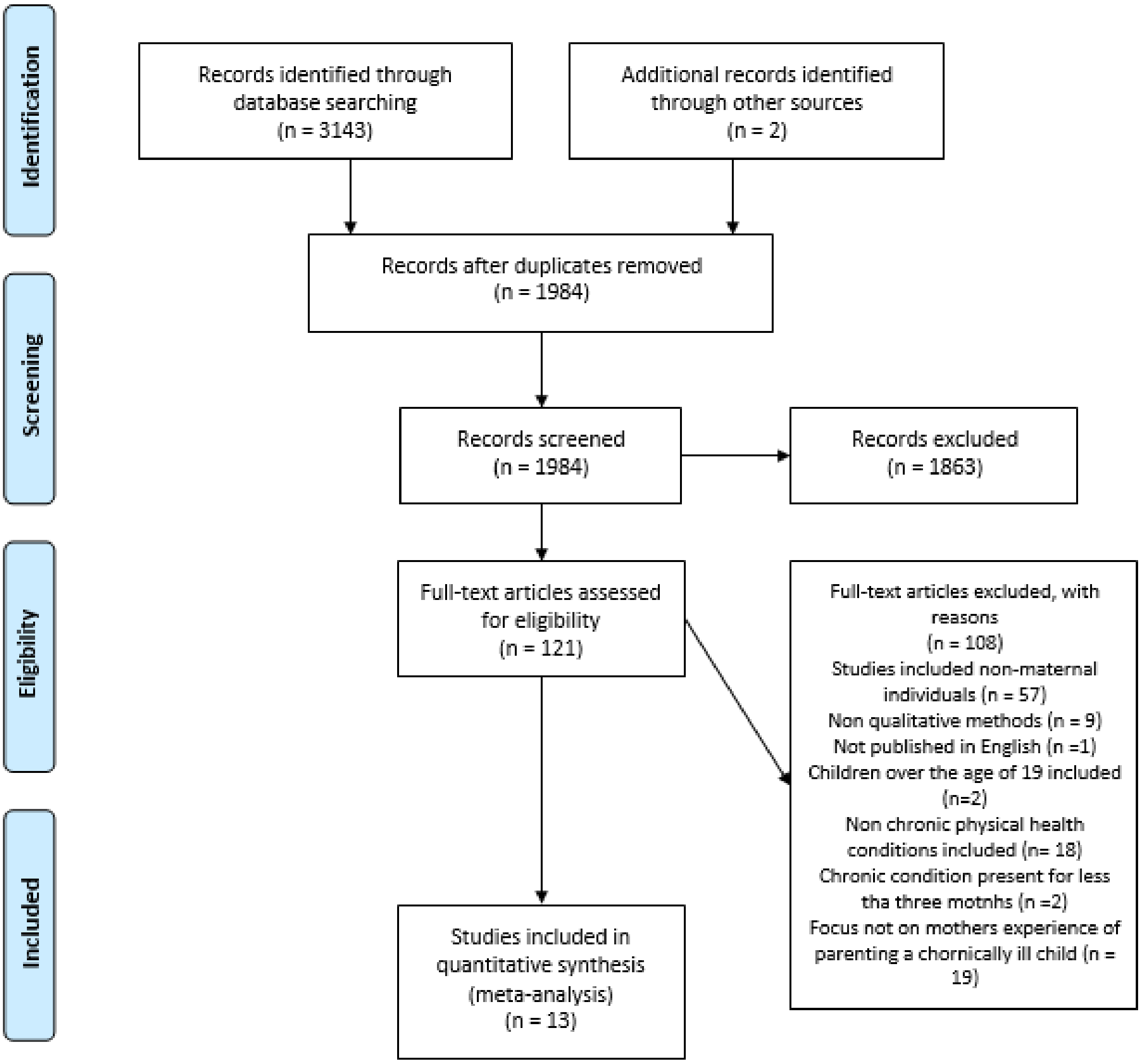
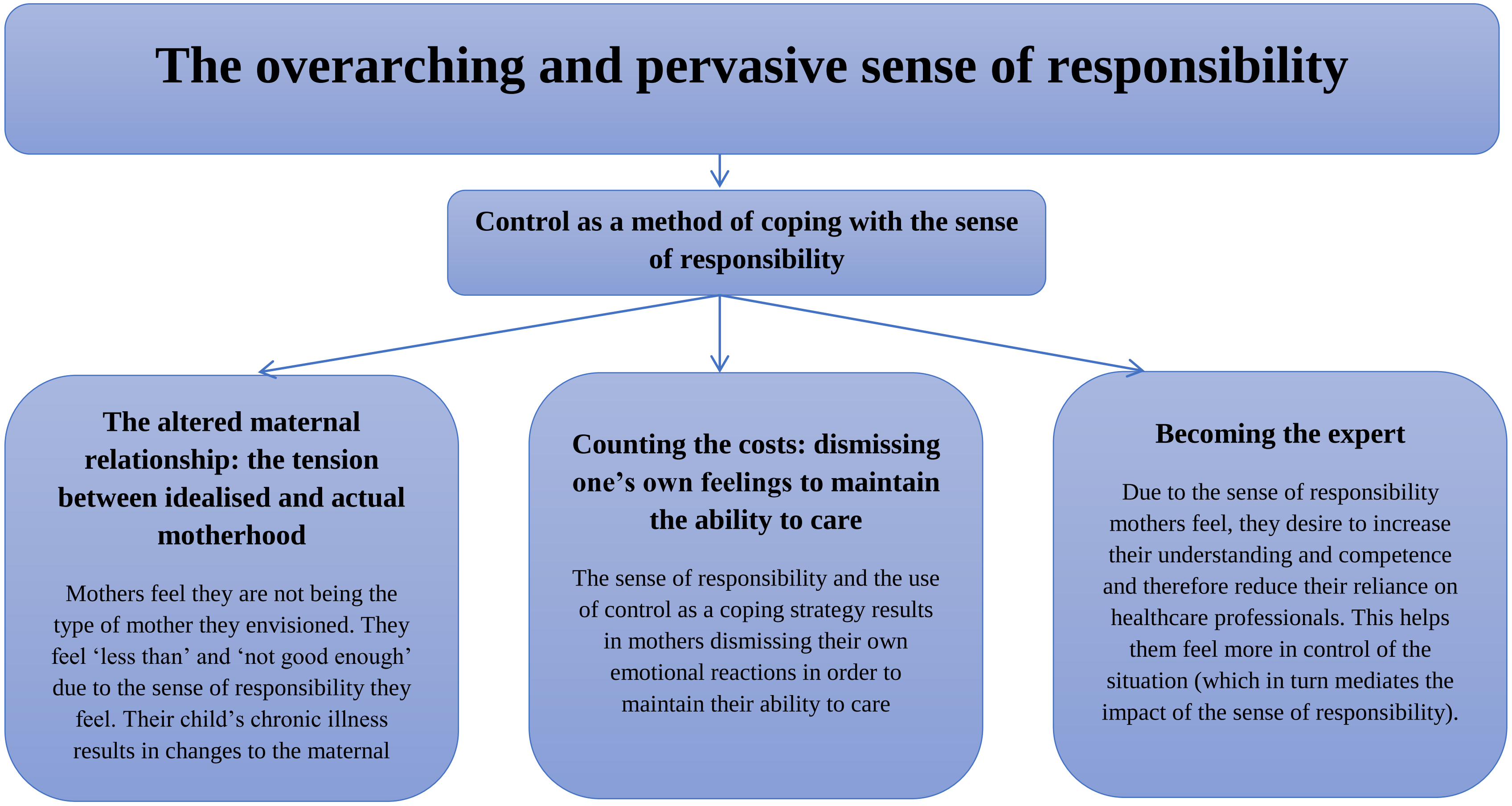


Figure 1.

PRISMA diagram



The overarching and pervasive sense of responsibility

Control as a method of coping with the sense of responsibility

The altered maternal relationship: the tension between idealised and actual motherhood

Mothers feel they are not being the type of mother they envisioned. They feel ‘less than’ and ‘not good enough’ due to the sense of responsibility they feel. Their child’s chronic illness results in changes to the maternal

Counting the costs: dismissing one’s own feelings to maintain the ability to care

The sense of responsibility and the use of control as a coping strategy results in mothers dismissing their own emotional reactions in order to maintain their ability to care

Becoming the expert

Due to the sense of responsibility mothers feel, they desire to increase their understanding and competence and therefore reduce their reliance on healthcare professionals. This helps them feel more in control of the situation (which in turn mediates the impact of the sense of responsibility).

Figure 2.

Thematic map of findings

Appendix 1-A

Worked Example of the Development of the Analytic Themes

Descriptive Themes	**First Iteration**	**Second Iteration**	**Final Theme**	**Papers which contribute to the theme**
Feeling of having to cope Not wanting the responsibility but feeling obliged Guilt/self-blame Responsibility and control Feeling of having to	Responsibility is an obligation. It is unescapable. The need to control all aspects of a child's life helps mitigate the overwhelming sense of responsibility they experience.	Responsibility permeates all aspects of mothers experiences of living and parenting. They employ control as a coping technique to mitigate this experience.	**The overarching and pervasive sense of responsibility** **Sub theme: Control as a method of coping with the sense of responsibility**	Abolhassani et al., 2013; Borhani et al., 2012; Bruce et al., 2013; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; 1996; Rydström et al., 2004; Sullivan-Bolyai et al., 2003; Swallow & Jacoby, 2001a,

cope Not wanting the responsibility but feeling obliged Guilt/self-blame Responsibility and control				2001b
Trying to maintain normalcy The maternal relationship Fear of the child dying	Mothering the chronically ill child is different/difficult	The maternal relationship is altered due to the chronic illness. They have to make different/difficult choices (e.g.	**The altered maternal relationship: the tension between idealised and actual motherhood**	Borhani et al., 2012; Bruce et al., 2013; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; 1996; Priddis et al., 2009; Rydström et al., 2004;
Impact on the wider	Mothering other siblings is			

family	also difficult/different. Other relationships are also affected	relationship with spouse/other children).		Swallow & Jacoby, 2001b
Parents in a similar position are a good source of support Social support Lack of social support An unwanted life of high cost, low gain Emotional trauma Importance of faith/positive	The importance of social support. Social support is sometimes not there/does not meet their needs Great emotional impact Coping strategies	Mothers attempts to cope with/control their (great) emotional reactions. Emotional (dys)regulation -	**Counting the costs: dismissing one’s own feelings to maintain the ability to care.**	Abolhassani et al., 2013; Borhani et al., 2012; Bruce et al., 2013; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995; 1996; Priddis et al., 2009; Rydström et al., 2004; Sullivan-Bolyai et al., 2003; Swallow & Jacoby, 2001a, 2001b

perspective Defence mechanisms				
A lack of information and competence Motivation to learn more Acquiring information and competence Certainty and uncertainty	Mother's feel unskilled/incompetent and so seek out information/skills	Moving from uncertainty to certainty	**Becoming the expert**	Abolhassani et al., 2013; Borhani et al., 2012; Bruce et al., 2013; Dowell, 2015; Hodgkinson & Lester, 2002; Lee et al., 2014; MacDonald, 1995, 1996; Rydström et al., 2004; Sullivan-Bolyai et al., 2003; Swallow & Jacoby, 2001a, 2001b
Loosing trust in the system	Challenging the system (as their new found			

Challenging the system	competence/skills/information shakes their confidence
The complexity of the healthcare professional-mother relationship	

Section Two: Research Paper

What are Partners Experiences of Living with Someone with Chronic Pain?

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Doctorate in Clinical Psychology

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What are Partners Experiences of Living with Someone with Chronic Pain?

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Word count (exc. figures/tables): 7691

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Statement of Contribution

What is already known on this subject?

- Chronic pain impacts on the individual and their family in many ways.
- Chronic pain has a marked impact on partners of those affected
- Partners of those with chronic pain experience multiple negative experiences including poor physical and emotional wellbeing

What does this study add?

- Coping is associated with partners' perceptions of pain as an independent and malignant force.
- The perception of pain as independent and malignant is a result of partners personalising pain.
- Feeling in control was achieved via the searching out or avoidance of information.

Abstract

Purpose. Partners of those affected by chronic pain experience negative consequences, including financial difficulties, reduced leisure time (Kemler & Furnee, 2002), altered family life (Smith, 1998), deterioration in marital satisfaction (Soderberg & Lundman, 2001) and poor physical and mental health (Currie & Wang, 2004). This in turn, affects the individual with chronic pain. However, an in depth analysis of these experiences is required. This paper aims to explore the experiences of partners living with someone with chronic pain.

Methods. An Interpretative phenomenological analysis (IPA) of ten interviews with partners was conducted.

Results. Findings suggested that chronic pain exerts a strong influence on all aspects of partners' lives, however, that experience is not universal and some participants were able to develop strategies to lessen the impact pain had on their life. Five themes were identified: the process of acceptance and adjustment; the challenge of accessing effective support; pain as a personal, independent, malignant force; loss and growth in the relationship and controlling one's awareness as a means of controlling the impact of pain. As the first two themes are already well documented they were not discussed to allow the novel data to be explored in detail.

Conclusions. Findings demonstrate the impact on partners and support recommendations for professional support to be provided to partners of individuals with chronic pain.

Key Words: partners; experiences; qualitative; chronic pain; IPA.

Introduction

Pain is defined as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (International Association for the Study of Pain [IASP], 1994; p.210). More specifically, chronic pain is defined as pain that "persists beyond the normal tissue healing time" which is generally considered to be 3 months (IASP, 1986 p. 6). It is often medically unexplained, meaning a diagnosable organic cause is difficult to find (Gatchel, Peng, Peters, Fuchs & Turk, 2007; Harris, Morley & Barton, 2003). European large scale surveys estimate the prevalence of chronic pain as between 12 and 30% (Breivik, Collettt, Ventafridda, Cohen & Gallacher, 2006), and around 6.4% of the UK population being estimated to experience chronic pain (National Pain Audit, 2012). Women are more likely to experience chronic pain than men (van Hecke, Torrance & Smith, 2013).

The role of partners

There were 5.4 million unpaid carers in England in 2011 (Office for National Statistics, 2012) and carers are reported to contribute to significant social care savings (Carers UK, 2015). However, caring for a loved one can incur personal costs, including physical health problems, emotional or mental health difficulties and injuries (The Princess Royal Trust for Carers, 2011). These negative health consequences appear to incrementally increase as the number of hours a person is responsible for caring for a loved one increases (Department of Health, 2014).

Of specific importance is how partners of somebody with chronic pain view their caring role. A carer is defined as "someone who without payment provides help and support to a relative, friend or neighbour who could not manage to stay at home without their help due to age, sickness, addiction or disability" (The Princess Royal Trust for Carers, 2011, p.5). However, not everybody who meets the definition of a carer considers themselves to be such, often considering it a normal aspect of a relationship (Cleary, Freeman & Walter, 2006; Social Care Institute for Excellence, 2007). Indeed, for many, it is the relationship not the label that is important (Arskey, Heaton & Sloper, 1998; Fine & Glendinning, 2005; O’Connor, 2007).

Chronic pain has an impact on partners, and partners, in turn, can affect the experiences of pain (Leonard, Cano & Johansen, 2006). Multiple theoretical perspectives might explain the role of partners in reducing or exacerbating the impact of chronic pain. The three most universally cited theories are the biopsychosocial model, behavioural theories and cognitive-behavioural theories (Vasudevan, 2015). These theories are not incompatible with each other and can indeed be considered complimentary and clearly demonstrate that partners can exert an influence over both the experience of, adjustment to, and coping with, chronic pain in their partners.

The biopsychosocial model of pain

As chronic pain often does not have a clear organic cause, biological causes cannot entirely explain it, and thus psychological and social factors must play a role in its development, expression and maintenance. Pain is said to occur due to the interaction of biological, psychological and social factors (Jensen, Ehde, Hoffman, Patterson, Czerniecki & Robinson, 2002; Turk & Okifuji, 2002; Hanley, Jensen, Ehde, Patternson & Robinson, 2004; Gatchel, Peng, Peters, Fuchs & Turk, 2007). The biopsychosocial model of pain is widely accepted within research and interventions (Gatchel et al. 2007) and much of the evidence supporting other theories can be applied to the biopsychosocial model too. Despite the general acceptance of the model, research tends to focus more on the biological and psychological aspects of the biopsychosocial model, with the social aspects being less well considered and explored.

Behavioural theory of pain.

The operant conditioning model of pain suggests that pain behaviours (behaviours which communicate that the ICP is in pain, for example grimacing, moaning, guarding) can be punished or rewarded by a partner (Fordyce, 1976, Leonard et al., 2006; Flor, Kerns & Turk, 1987). It could also potentially be argued that they could be ignored and thus extinguished. Operant models of pain are supported by observational research (Cano & Williams, 2010; Goubert et al., 2005; Newton-John, & Williams, 2006). Pain behaviours are likely to be reinforced unconsciously as part of a family's inclination to comfort one another when pain behaviours are displayed. This then can release the ICP from their responsibilities (e.g. cleaning, going to work), thus creating a benefit or reward to pain behaviours which perpetuates their expression (Turk et al., 1987, Flor et al., 1987). Leonard et al. (2006) conducted a systematic review into the role of couples in chronic pain and found support for behavioural theories. There are strong links between partners' responses to pain behaviours and ICP's pain experience. Partner's responses to an ICP are often divided into highly solicitous and non-solicitous responses. Solicitous behaviour predicts ICP's self-reported pain levels (Kerns, Haythornthwaite, Rosenberg, Southwick, Giller & Jacob, 1991) and activity levels (Flor et al., 1987; Romano et al., 1995). Marital satisfaction appears to moderate the relationship between partners solicitous behaviour and ratings of pain severity in ICP's, however evidence is currently mixed and the relationship appears present only in some groups (married men and unmarried women) (Leonard et al., 2006). Additionally higher levels of solicitous behaviour are associated with low activity levels in ICP's (Flor, Kerns & Turk, 1987).

Cognitive behavioural theory of pain

Cognitive behavioural theories of pain argue that partners' attitudes and beliefs about pain can influence how they think about and act towards the ICP and their treatment, which in turn influences the ICP's attitudes, beliefs and behaviours (Leonard et al., 2006; Turk, Meichenbaum & Genest, 1983). The pain communication model (Hadjistavropoulos et al., 2011) shares similarities with cognitive behavioural theories of pain. It suggests that ICPs send messages which are decoded by the receiver (their partner). The process of decoding depends upon the partner's cognitions about the message being received, resulting in behavioural responses which in turn impact the pain and disability of the ICP (e.g. paper 16 Leieux, Bergeron, Steben & Lambert, 2013; Leonard & Cano, 2006; Metalsky, Halberstadt & Abramson, 1987). An example of the influence of a partner's pain cognition would be pain catastrophising, which has been found to be positively associated with increased ICP pain (e.g. Kerns, Turk & Rudy, 1985; Leieux, Bergeron, Steben & Lambert, 2013; Leonard & Cano, 2006). Leonard et al (2006), in their systematic review, found that there is also support for cognitive-behavioural theories of pain. In support of cognitive theories Schwartz, Slater and Birchler (1996) found that partners who describe their feelings towards the ICP's pain as negative are more likely to respond punitively to an ICP's pain behaviours. This in turn is associated with greater reported pain severity by an ICP and greater physical and psychological impairment (Schwartz et al. 1996).

Research supporting theories involving partners.

Numerous studies have explored the role of partners in the maintenance of chronic pain, as argued by the theories described above, however results are varying and often contradictory (Leonard, Cano & Johansen, 2006). Researchers have examined the role of support (e.g. Holztman, Newth & Delongis, 2004), communication (e.g. Lyons, Jones, Bennett, Hiatt & Sayer, 2013), relationship quality (Campbell, Jordan & Dunn, 2012) and the involvement of partners in interventions (e.g. Martire et al., 2007). Leonard et al. (2006) conducted a systematic review concerning the role of partners. They found that overall, there appears to be a consistent positive relationship between solicitous partner responses and ICP self-reported pain severity and pain behaviours. However they state that gender and marital satisfaction may impact the relationship. They reported inconsistent evidence for a relationship between marital satisfaction and support on ICP self-reported pain severity and disability; however marital dissatisfaction does appear to be negatively correlated with pain behaviours. Leonard et al. summarise that it is pain specific aspects of functioning, rather than marital satisfaction per say that influences ICP's pain experience. That is marital satisfaction may indirectly influence pain severity through via partners' responses.

The impact of chronic pain on partners

Partners may be required to undertake additional domestic tasks resulting in less personal leisure time (Kemler & Furnee, 2002; Soderberg & Lundman, 2001), as well as less shared leisure time with their spouse (Kuyper & Wester, 1998), friends and family (Kemler & Furnee, 2002). It can also result in financial difficulties, due to the individual with chronic pain having to reduce or cease paid employment and the increased cost of living due to the chronic pain, for example paying for medications (Kemler & Furnee, 2002). Family life can also be influenced by chronic pain, with traditional family roles (Blanchard, Hodgson, Lamson & Dosser, 2009) and parenting (Smith, 1998) being impacted. A deterioration in marital satisfaction and sexual functioning are as a further consequence of chronic pain (Soderberg & Lundman, 2001; Soderberg, Strand, Haapala & Lundman, 2003). Specifically there is a decrease in sexual desire, sexual frequency and the importance of sex (Schantz-Laursen, Overvad, Olesen, Delmar & Arendt-Nielsen, 2006). Finally, chronic pain can have a detrimental impact on partners' health, particularly their emotional health (Currie & Wang, 2004).

While it is important to understand the impact of chronic pain on partners, it is equally important to understand how partners cope. There are numerous theoretical frameworks which could explain how partners cope with a variety of physical and mental health conditions, however perhaps the most widely used is Lazarus and Folkman's (1984) transactional model of stress and coping. They aimed to challenge existing beliefs about coping, specifically that it is linked to mastery and that it was a personally trait (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). They argue that individuals cognitively evaluate a situation via primary appraisal (whether the situation is harmful, threatening or challenging) and secondary appraisal (whether action would improve the situation and if so, what action would be most appropriate). Following these appraisals, individuals employ coping strategies. They define coping as a dynamic process and "constantly changing cognitive behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984, p. 141). Coping strategies can be broadly separated into two forms; emotion-focused and problem-focused coping. Emotion-focused coping aims to regulate the emotional distress an individual experiences, whereas problem-focused coping is action orientated and aims to control the situation or others to reduce the emotional distress. Individuals then appraise whether their coping strategies of choice are effective and adapt the coping strategies as necessary. While Lazarus and Folkman's (1984) coping theory is widely accepted, it is important to consider whether it can be applied to partners of those with chronic pain.

Two qualitative studies have explored partners' experiences of living with somebody with chronic pain. West, Usher, Foster and Stewart (2012) conducted a thematic analysis of nine interviews with partners of people with chronic pain and reported four main themes. These were family loss; life changes; emotional impacts and future plans. However, there was limited detail as to what these themes were comprised of (West et al., 2012). Miller and Timson (2004) explored partners' experiences using a mixed methods grounded theory to explore 26 individuals' journals and nine individuals' focus group interviews. This resulted in three themes: coping with the pain; perceptions of healthcare and the dominance of the illness over their social contacts. There are a number of methodological issues however. For example, no model was developed, and the results resemble thematic analysis more than grounded theory. Secondly, there was a discrepancy between the type of information disclosed between the two data collection methods, with the authors acknowledging that those participants in the focus group tended to discuss more emotional, cognitive and psychological issues rather than the functional day to day issues that were discussed in the journals.

One frequent criticism of pain research is that while there is a comprehensive list of the various impacts of pain on a partner and the ways in which partners can influence pain, there is little understanding of why pain exerts such a strong impact, or the specific mechanisms through which partners can reduce or exacerbate pain (Leonard & Cano 2006; Osborn & Smith, 1998; Roy, 2010). Additionally, it is widely recognised that pain is an individual and subjective experience, so it therefore must follow that being a partner of an individual with pain must also be an individual and subjective experience, and yet little research has been conducted exploring this. The qualitative evidence base is limited and lacks in depth analysis of carers' experiences. Consequently there is a lack of understanding about partners' lived experiences of living with someone with chronic pain, and in particular how partners' interpretations of chronic pain influence their ability to cope with chronic pain. This study will therefore explore what partners' experiences are of living with someone with chronic pain, with the aim to develop recommendations for services as to how best to support them. Given this, a qualitative methodology was deemed most appropriate, specifically, the use of interpretative phenomenological analysis (IPA). IPA allows for a detailed and idiographic understanding of partners' experiences and interpretations. Additionally, it produces a higher level of analysis due to its interpretative nature (Smith, Flowers & Larkin, 2009). The idiographic understanding of partners' understandings may inform targeted interventions and support, as well as quantitative models of appraisal and coping.

Method

Study Design

Data were collected using semi-structured interviews that were conducted and analysed in accordance with the Smith et al. (2009) approach to IPA. As the focus of the research was to explore partners' experiences of living with an individual who has chronic pain, IPA was considered the best method of analysis as it allows for an exploration of how individuals make sense of their experiences (Starks & Trinidad, 2014; Smith et al., 2009) providing in depth analysis and building upon the existing research (Smith et al., 2009). It also allows account to be taken of the experiences and expectations of researchers (Smith et al., 2009). Other methods that were considered included thematic analysis and grounded theory. While thematic analysis would have allowed for an exploration of how participants make sense of their experiences, thematic analysis typically focuses on patterns across data (Braun & Clarke, 2012) and therefore the individual experiences and accounts can be lost. Alternatively, IPA allows for exploration within and across participants, which I felt was an important consideration during the study. Grounded theory could have been used to conduct the current study, however the aim of the research was to explore participants experiences and not to develop a theoretical understanding and model of their experiences (Charmaz, 2006), therefore making IPA a more suitable option.

Participants

In accordance with IPA guidance, a small homogenous sample was purposefully selected to allow for the exploration of shared experiences (Smith et al., 2009; Smith & Osborn, 2008). Inclusion criteria required participants to be over 18 years old, to be able to communicate adequately in English with little or no adaptations and to be cohabiting with their partner for a minimum of 12 months. Non-cohabiting partners may have qualitatively different experiences and so were also excluded from the study. The impact of chronic pain may be additive, becoming more burdensome for the whole family the longer it is present (Parris Stephens, Martire, Cremeans-Smith, Fruley & Wojno, 2006). Therefore it was decided that pain must be present for a minimum of twelve months. A maximum timeframe was not established as essentially once pain is defined as chronic (more than six months) the circumstances of the participants was assumed to be stable and thus an upper limit on duration was not set. Additionally, it is not customary within the chronic pain literature to set a maximum time frame (e.g. Osborne & Smith, 1998; Snelgrove & Liossi, 2009)

Participants were required to have been in a relationship for a minimum of twelve months to be eligible for participation to allow the participant to have had time to experience the impact of chronic pain. Finally, participants were excluded if their partner was experiencing chronic pain as a temporary side effect of medical treatment, for example surgery or chemotherapy. The lack of information around causation, progression and treatment of chronic pain has been cited as challenging (Osborn & Smith, 1998). It was therefore felt that there was likely to be qualitative differences in experiences of pain that is chronic but likely to resolve and pain that is chronic and unlikely to resolve.

Ten participants, eight men and two women, were recruited, all in heterosexual married relationships. See Table 1 for participant details. Participants ranged in age from 24 to 63 years. The duration of chronic pain ranged from 1.5 to 34 years and the duration of the relationship ranged from 46 months to 34 years. Reported pain conditions included mixed connective tissue disease, osteoarthritis, fibromyalgia, myalgic encephalopathy (ME), endometriosis, adenomyosis, rheumatoid arthritis, migraine, ankylosing spondylitis, cervical spondylosis and queried migraine or cluster headaches.

[Table 1 about here].

Ethics

Ethical approval was obtained from Lancaster University Faculty of Health and Medicine Ethics Committee. Advice was sought from supervisors and members the ethics committee to ensure ethical practice throughout the duration of the study. For example, Trish[1] is registered legally blind, meaning obtaining signed consent was impossible. She offered to get her husband to sign it, however, I felt this was not appropriate and therefore, after seeking advice, I recorded myself reading the statements on the consent form and Trish replying "I agree".

Procedure

Multiple recruitment strategies were employed simultaneously. Social media have proved to be an effective recruitment strategy ensuring a far wider reach than traditional face to face recruitment while also being time effective (O'Connor, Jackson, Goldsmith & Skirton, 2014). Relevant pain related online forums, Twitter accounts and online support groups were contacted via email requesting advertisement of the study information. A web link to the participant information sheet and the poster was posted on Twitter along with a request to share the information. At the interview, consent and consent for future contact forms were signed. Participants were offered a choice of interview locations; four chose to be interviewed via Skype, five by telephone and one in person. Interviews were audio recorded and lasted between 32 and 110 minutes using a semi structured topic guide. See Section 4 for recruitment documentation.

Researcher's Context and Epistemological Stance

The process of developing and conducting research is influenced by the researcher's epistemological stance, specifically my critical realist perspective. Additionally, my experience of working within pain management will have undoubtedly influenced my thoughts and understanding of partners' experiences of living with somebody with chronic

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[1] Please note pseudonyms have been used throughout the study

pain. Completely detaching from our beliefs, both personally and theoretically, is not possible, and is it not recommended in IPA (Dahlberg, 2006; Probst, 2015). A reflexive journal was used to encourage reflective awareness (see Appendix 1-A for exert; Cresswell, 2012; Finlay, 2002).

Data analysis

The interviews were transcribed verbatim by the researcher to ensure familiarity and immersion in the transcripts. To ensure accuracy, participants were given the opportunity to comment on their transcript before analysis occurred. All participants read their transcripts but none made any recommendations for changes or clarifications. Smith et al.’s (2009) guidance on conducting IPA was followed. Transcripts were analysed in isolation to retain the idiographic aspects of individual accounts (Snelgrove, 2014) to allow for idiographic comparisons later on. Stage one of analysis involved listening to the audio recording and reading the transcripts several times. Stage two consisted of making three types of notations detailing participants’ experiences and beliefs. These included descriptive notations (descriptions of participants’ experiences), linguistic notations (how the use of language helps describe experiences) and conceptual notations (interpretative comments on participants’ experiences). Stage three included grouping these notations into first iteration themes by exploring the connections between them, thus reducing the data into concise statements (Smith et al., 2009). See Table 2 for an example of stage two and three. During stage four the data were explored further to develop superordinate themes using polarisation (looking for opposing or contrasting relationships), abstraction (looking for similar pieces of data together) and subsumption (looking for emerging superordinate themes that help bring related themes together) (Smith et al., 2009). See Table 3.

This process was repeated for each transcript resulting in ten groups of superordinate themes. “Bracketing” (Smith et al., 2009 p.100) was used during this process to consider each transcript individually, ensuring the idiographic nature of IPA was maintained. A reflexive journal was used to make notes about contrasts and comparisons between participants.

The sixth and final stage of analysis involved considering the entire data set to develop an understanding of how the super-ordinate themes could be meaningfully organised into one coherent whole. See Table 4 and 5.

[Insert tables 2, 3, 4 and 5 about here]

Reliability and validity

To ensure appropriate reliability and validity during each stage of the study my supervisor and I met regularly and explore my reflexive journal. This began at the development stage of the study and included discussions about the specific focus of the study, the development of inclusion and exclusion criteria and the development of the interview schedule. The transcript from the first interview was taken to supervision and amendments were made to the interview schedule where necessary. Feedback on my interview technique was also provided. Coding examples were taken to supervision, in addition to each iteration of thematic development. An example of this was in the development of theme one 'pain as a personal, independent and malignant force'. The concept of pain as an independent entity came from my supervision highlighting that I personified pain during our discussions. After checking the transcripts and my reflective diary I was able to ascertain that this personification originated with the participants.

Results

Five themes were identified. Pain as a personal, independent and malignant force describes partners' interpretations of pain. Loss and growth in the relationship details the cost and gains experienced within the relationship. Controlling ones awareness as a means of controlling the impact of pain describes partners' attempts to control the impact of pain by either avoiding, or seeking, awareness and understanding of pain and its impact. The process of acceptance and adjustment highlights partners’ various stages of processing their emotional experiences. This theme has been documented within qualitative pain research (e.g. Fernandez, Reid & Dzuirawiec, 1992; Miller & Timson, 2004; West et al., 2012). Finally, the challenge of accessing effective support demonstrates the absence of support that meets the partners’ needs. This theme has also been documented within the qualitative pain research (e.g. Miller & Timson, 2004; West et al., 2012). Yardley (2000; 2008) argues that, in order to ensure the rigour of qualitative research, findings should be novel and add to the existing knowledge base, and therefore this paper will discuss the first three themes.

The process of acceptance and adjustment

Participants described learning to accept and cope with chronic pain as a process. Initially they held on to the hope that the chronic pain condition could be cured, however, overtime as they developed a medical and experiential knowledge about the condition they realised the pain was unlikely to be cured. It must be noted however, that participants appeared to never fully accept this and would still hope for a cure. The process is an individual one, varying in time and ease for participants, for example some participants felt able to adjust easily whereas others felt forced into accepting the chronic nature of their partner’s pain. The process is mediated by whether they knew their partner before the onset of chronic pain, the speed of the onset of the pain, the frequency and severity of the pain and how well their partner adjusts. Accepting and adjusting to chronic pain affects how well partners are able to cope with the pain and the impact that pain has on their lives. Specifically, those who accept pain as a long term part of their life appear to experience fewer negative aspects of pain. As previously stated, this theme has already been well documented and therefore will not be explored in detail within the current study.

The challenge of accessing effective support demonstrates the absence of support that meets the partners’ needs.

Partners had varying experiences of feeling supported and unsupported by various people, both throughout the data set and within individual participants’ accounts. Most participants reported feeling generally supported personally, by friends, family and managers at work. There was however a tone of feeling unsupported, even when citing sources of personal support. This lack of support appears to be as a result of a lack of understanding from people, in particular the chronic and inescapable nature of their partner’s pain and the significant impact it could have on all members of the family. As a result, participants would limit their disclosure, reducing their ability to access social support.

Fewer participants reported feeling professionally supported however, with most participants praising individual professionals but feeling that overall the ‘system’ had let them down. Specific examples included the difficulty in obtaining benefits and accessing appointments in a timely manner.

Pain as a personal, independent and malignant force

This theme details the way partners personalise pain and construe it as an independent, malignant force in their lives. These partners typically described pain as having a greater impact on their lives compared to those who viewed pain as powerful, but not a personal, independent or malignant force. For most participants pain was a shared experience. The emotional pain participants experienced by being a partner of an individual with chronic pain mirrors the partner’s physical pain. For example in Nathan’s comment below, he (the partner) could be mistaken for the one with pain: “There is not one activity that me and Ava can do that pain isn’t a part of.” The personal nature of the chronic pain refers to both the shared experience of chronic pain (specifically that they feel they are in (emotional) pain because of their partners’ chronic pain) but also the perception of pain as a combative force that is going to damage them, as well as their partner. The personalisation of pain was found only among participants who viewed pain as an independent malignant force. Additionally, these participants were those who experienced difficulties in accepting and adjusting to the impact pain has.

For all participants pain played an important role in shaping their lives. Pain was viewed as having an identity of its own (independent), which was inherently negative and destructive (malignant). For example pain was personified by Trish as the “third person” in her marriage. Pain was tangibly in participants’ lives and was described as a living, growing part of their experience. During the interviews there was a sense of participants experiencing pain as threatening.

Pain was described as a “constant” (Liam) aspect of life that is “never going to get any easier” (Nathan). The implied hopelessness participants experienced further strengthened their perception of pain as malignant. The perception of pain as all-consuming was most prominent when the individual with chronic pain experienced constant chronic pain with the partner’s emotional pain mirroring the physical pain. Compounding this was the additional workload or burdens that pain entailed. Partners described themselves as having a “full time job, [being] a full time carer and a full time parent” (Liam) and that the “burden is all on me” (Michael). Juggling the additional domestic and parenting workload was more difficult for those who also worked full time.

Pain was also described as incredibly powerful and strong which resulted in partners feeling powerless. Participants’ beliefs about the power of pain stemmed from the feeling that it could, and did, influence all aspects of life. It “dominate[s] everything” (Jane), becoming “central” (Nathan) whether individuals want it to or not. One way pain exerted its power was by the restrictions it placed on life and the impact it exerted on life. Some male participants likened the feelings of being a partner to an individual with chronic pain as being impotent feeling unable to help make their partner’s lives better. For example, Sean commented:

> I don’t have Bupa healthcare, I don’t have funds to take her to America where these magical drugs are, I’m impotent, I can’t fix it. I can’t bloody fix it. How am I going to spend the rest of my life, [how] is she going to spend the rest of her life? Are we going to spend the rest of our lives trying to deal with this? (Sean)

While women did express some helplessness, it was most prevalent in men. This is perhaps due to cultural gender expectations, specifically that men are providers, protectors and problems solvers.

Perceiving pain as personal, independent and malignant negatively impacts partners’ ability to cope with pain and results in pain having a larger influence over partners’ lives. Those partners who did not view pain as independent or malignant tended not to personalise pain and it did not appear to impact on their lives as significantly as for other participants. For example:

> Instead of trying to rail against it and think ‘oh I could be doing this’ or ‘I could be doing that’ you have to learn to accept the limitations of your partner and deal with that yourself because they’re the ones [who are] suffering. (Thomas)

By taking steps to be cognisant of their partners’ suffering and focusing on accepting the existence of pain, partners can neutralise the potentially malignant impact of pain and thus feel more able to cope.

Loss and growth in the relationship

This theme reflects the losses and growth pain creates within the relationship and the role of the relationship satisfaction in how those losses and growth are perceived. Those who are dissatisfied with their relationship perceive the losses as much greater and more costly.

Pain is something that will “either bring you closer together or pull you apart.” (Warrior). This theme is influenced by the stage of acceptance the partner is at, with those who are more accepting of chronic pain’s presence in their lives reporting less negative impacts of pain on the relationship and describing caring for their partner as a privilege rather than an obligation. Additionally, the perceived quality of the relationship was associated with the partner’s perceived ability to cope such that those with apparently stronger relationships seemed to cope better with chronic pain.

The impact of chronic pain on the relationship was evident throughout all the interviews with the exception of Jane’s. However the importance it was given, and which aspects where discussed by partners, varied. The impact of chronic pain on intimacy and affection was discussed by Michael and Sean. They both discussed the impact of pain on the frequency and “spontaneity” of their sexual relationship. There may also have been a loss of attraction, or femininity for example: “This is an old person’s disease. What’s my young wife got to do with a ‘wrinklies’ (sic) disease?” (Michael). Pain resulted in them feeling more vulnerable when initiating sex due to the fear of rejection. There was also a loss of affection reported by multiple participants. For Sean the loss of affection was more important than the loss of intimacy, for example:

> She's just too tired to do anything to even, I don't know, to even entertain...I'm not talking [about] sexual [intercourse], just to be happy with each other a little bit more...just a little bit more touchy feely a little bit more intimate with each other without being sexual...it just doesn’t occur to her. It doesn't maybe cross her mind.

The impact of pain extends to the wider family unit. Those who discussed the impact of chronic pain on their family were those with children under the age of 18 (Sean, Michael and Simon), suggesting that the specific impact on parenting may be most relevant when children are younger, and therefore require more practical and physical care. For example, as children get older, they are more able to look after themselves, the individual with chronic pain, "understand [pain] a bit better" and "do more around the house" (Michael). There was a sense of male participants having to learn how to parent when chronic pain was part of your family. They discussed having to protect their children from seeing the consequences of pain, to "soften the blow" and to "shield them" (Simon) from the consequences of pain.

Pain altered communication between the couple, producing a detrimental impact on the relationship, especially when tensions were high. Partners described feeling obliged to back down during arguments or discussions as pain is a "trump card" (Warrior) that changes what is considered acceptable behaviour. This altered communication further perpetuates the difficulties that pain can create within a relationship. For example:

> It's almost become the norm that she talks to people like that and there is only so much of it I can take. I have moments where I think to myself 'what are you doing, this woman's not well, and it's not her fault' and I know it's not her fault but I get to a point where I think I can't do it anymore. (Sean)

Finally, there was a sense of the marriage, or the partner, being changed because of pain. This was particularly true for Sean, who said "it almost feels like our relationship is over." For example one participant reported feeling that pain "has had a profound effect on her personality" and has "dulled their spark" (Simon) and their role within the marriage. For example "[I feel] like I'm her carer more than her husband" (Liam). This was reported exclusively by those where the onset of pain was after the relationship began.

Despite the negative impact pain can have on the relationship, pain can also improve the relationship, or help highlight the positive aspects of the relationship. It must be noted however that this was the exception within the current population. For example, partners felt their relationship was actually stronger than before, specifically that the pain "strengthens [the] relationship" (Thomas) and felt they "love[d] [their partner] more because [they are] struggling" (Liam). There was a tangible sense for some participants that caring for their partner was an honour, for example: "I don't see it as a chore, it's a pleasure, it's a privilege to do that" (Warrior). Additionally, some partners described feeling like a better person due to their experiences, such as becoming more "tolerant" (Michael) and developing a "sensitivity" towards others' suffering (Alfonso). Partners who were able to acknowledge the improvement or strengths in their relationship were also those partners who were further along the process of accepting the chronic pain. This did not appear to be a temporal issue as these partners described a quick acceptance and adjustment to their partner's chronic pain. It may be that these partners naturally placed value in being able to provide care for their partner, rather than just receive care. It may also be that these partners held more fluid expectations for their quality of life and so were more able to adapt to the challenges within their relationship. This appeared especially true in relation to gender roles.

It is difficult to clearly establish the direction of causality between the relationship quality and partners' acceptance and ability to cope with chronic pain, and indeed it is not for qualitative research to make firm predictions, but rather suggest avenues for further research. The direction of causality appeared most clear for those partners who described pain being an impetus for improving their relationship. Specifically, those partners described a positive and strong marital relationship prior to the onset of pain, which in turn influenced their ability to adjust to and accept the limitations and consequences chronic pain produces. For those partners who reported relationship difficulties following the onset of chronic pain, the picture was less clear. Some of those participants made reference to pre-existing difficulties that may have been exacerbated by chronic pain. Others however, described a strong relationship prior to chronic pain. It is unclear whether there were difficulties which were perhaps more easily hidden until the development of chronic pain, or whether the relationship is less clearly defined. Further research exploring this would be both beneficial and interesting.

Controlling ones awareness as a means of controlling the impact of pain

This theme details the balance each individual experienced between having too much and too little information. There was a clear division between participants who sought out information in order to feel able to cope and those who preferred to know less. For all participants there was a desire for information but the degree of information, the type and function of information differed. Information creates potential hope for partners, specifically that there may be hope for a cure, new treatments, or new coping strategies. Information also provided partners with a sense of certainty, which was difficult to find following the individual's chronic pain diagnosis. For example, Michael said "I wanted answers and you get sort of a little bit frustrated with not getting the answers." When information is provided, specifically in the form of a diagnosis it was described as a "milestone" (Alfonso), a "framework" (Alfonso) to explain their partners' symptoms and experiences and allowing for the couple "to able to form a plan and say 'ok let's try this, this and this, and if that doesn't work then we can try this'" (Thomas). The lack of information was particularly challenging for men who found "not being able to offer a solution" (Sean).

On the other hand, for some participants information was not considered helpful or desirable. Not all information is good and participants had developed their own understanding as to what sources were beneficial for them and what were not. In particular "Googling (sic) it" (Liam) and friends and family's "medical opinions" (Michael) were identified as unhelpful. These attitudes appeared specifically linked to knowing the worst possible outcomes of the pain conditions, such as "shortened life" (Michael) and knowing the information would "scare the hell out of me" (Liam). By limiting the knowledge they had and the sources from which they sought information, partners were able to not only reduce the intrusive thoughts and worries, in particular about the future trajectory of the pain, they were able to continue to cope with pain, care for their partner and maintain a positive perspective. For the majority of participants maintaining a positive outlook and not considering the potential outcomes (another form of information avoidance) were an important factor in their attempts to cope with the day to day impact of chronic pain.

For example:

> I sometimes feel guilty that I'm so forgetful or absentminded about the pain she is under and I feel like maybe I should be conscious of it, but honestly if I was more conscious I don't think I could do anything. (Alfonso)

> If I read everything on it I would have blown my own mind to start with and it would be like I would be waiting maybe for that to happen or be sat there thinking 'ooh she's got that but she doesn't have that'. (Liam)

In addition to the lack of information about the disease, some partners chose to not consider their emotional responses in the face of pain and it was clear they were steering the conversation away from the emotional aspects of being a partner to someone with pain. This can be considered an additional type of avoidance, specifically about their personal state. This was particularly evident in four participants' interviews: Jane, Trish, Thomas and Alfonso whom all chose to focus on the practical aspects rather than the emotional aspects of living with an individual with chronic pain. Partners controlled the impact of pain but controlling their awareness of the situation, whether that be knowing as much as possible or as little as possible.

Discussion

The aim of the present study was to gain an understanding of the experiences of partners of people affected by chronic pain. To this end, ten participants completed interviews and IPA was used to analyse the transcriptions. This resulted in five themes: the process of acceptance and adjustment; the challenge of accessing effective support; pain as a personal, independent and malignant force; loss and growth in the relationship and controlling ones awareness as a means of controlling the impact of pain. The first two themes are already documented in the literature and therefore were only briefly discussed.

Clearly, the present study was not really aimed at developing a model of how partners cope with the sequelae of chronic pain, but it is instructive to relate the findings to the two most widely used relevant models. Thus the current findings have been viewed through the lenses of the transactional model of stress and appraisal (Lazarus & Folkman, 1984) and the self-regulatory model (Leventhal, Nerenz & Steele, 1984; Leventhal, Leventhal & Cameron, 2001). See Figures 1 and 2 for representation of how the current findings fit with the existing theoretical frameworks. First, considering the self-regulatory model (Leventhal et al, 1984; 2001), the current findings clearly demonstrate that partners’ cognitive and emotional representations influence their coping responses, which subsequently influence health and emotional outcomes. Specifically, partners who viewed chronic pain as uncontrollable tended to attempt to find means to control the pain (specifically by medical interventions). This tended to have the opposite effect than desired, resulting in partners feeling even less unable to control pain and thus producing numerous psychological, social and physical consequences. These were also the partners who viewed pain as a personal, independent, malignant force. The smaller group of participants still considered chronic pain to be a serious condition which resulted in high emotional, physical, social and economic consequences. The primary difference however, was that these partners perceived the impact of chronic pain as controllable. Specifically, they re-evaluated their life goals, took steps to minimise the impact of chronic pain without trying to prevent pain and did not resist the impact of pain, but rather embraced the changes required to live well with chronic pain. This difference proved significant and (probably) resulted in better health and emotional outcomes for both the partner and the individual experienced chronic pain.

In regards to the transactional model of stress and appraisal (Lazarus & Folkman, 1984) participants shared broadly similar primary appraisals of chronic pain. Specifically all participants viewed their partner as having a low susceptibility of developing chronic pain, that chronic pain had a significant potential severity and high motivational relevance. Participants typically considered pain to be caused by medical malpractice (specifically doctors not intervening quickly enough to prevent acute pain developing into chronic pain) or “just one of those things”. The main difference between those participants who coped well with their partners’ chronic pain and those that did not was that those who coped well, tended to have a higher sense of perceived self-control and self-efficacy. These participants’ also tended to have a strong dispositional sense of self control (rather than believing others are in control) and tended to focus on the practical day to day tasks rather than information seeking as a dispositional coping style. These participants’ tended to prefer problem focused and meaning focused coping strategies, and reported better emotional and health outcomes both personally and for their partners. They tended to encourage their partner to accept and adapt to the chronic pain condition and reported a higher quality of life. The majority of participants’ however, tended towards emotion focused coping. Those participants reported poorer emotional and health outcomes personally and in their partner. They were more likely to discourage acceptance and encourage seeking medical cure/alleviation, and described reinforcing pain behaviours. The difference in appraisals and coping strategies explains the differences between males found in the current study.

The current seem to be consistent with the existing theoretical frameworks, namely the transactional model of stress and coping (Lazarus & Folkman 1984) and the self-regulatory model (Leventhal et al, 1984; 2001). As far as the author is aware, this is the first time findings concerning partners have been applied to partners of somebody with a chronic illness, which is an important development for the model. However, the value of IPA goes beyond merely supporting existing theories, instead also allowing for the development of a rich, detailed understanding of the personal experiences of individuals that theory alone cannot provide.

[Figures 1 and 2 about here]

The majority of partners appraised pain as a threatening or challenging situation and appraised their resources for coping as low. Due to their appraisals of the situation and their coping resources, their loved one's chronic pain was perceived as a stressful, challenging and overwhelming situation (Lazarus & Folkman, 1984) to the extent that it was viewed as a malignant force. Leventhal et al. (2001) proposed that individuals use five disease specific illness representations to make sense of a threatening situation. These include the identity of the illness; the expected timeline or progression; the cause of the illness; illness consequences and the potential for a cure or controlling the illness. For the majority of the partners in this study the identity and consequences of the chronic pain was powerful malignance, beyond anyone's control (global learned helplessness). Lack of perceived control has been associated with decreased wellbeing and increased distress (Affleck, Tennen, Pfeiffer & Finfield, 1987; Helgeson, 1992; Shapiro, Schwartz & Astin, 1996) which may explain why partners who perceived pain as beyond control also discussed the consequences of pain more negatively.

The overwhelming nature of chronic pain is comprised of the burden it produces (Kemler & Furnee, 2002; Miller & Timson, 2004; Soderberg et al., 2003) and the sense of powerlessness and helplessness (Miller & Timson, 2004; West et al., 2012) evoked. In an IPA study of those with chronic low back pain, the theme of "pain as a threat" in which participants described pain as something which was taking over their bodies was highlighted (Snelgrove and Liossi, 2009 p. 741). They also employed cognitive distancing, referring to pain as "the pain" and "it" (p. 741). This is similar to the findings in the current study, where pain was described as a distinct entity that was powerful and took over their lives.

Those participants who did not view pain as personal, independent or malignant appeared to cope more successfully with pain. They were also partners who described being less reliant on professional or personal support systems (as linked to the theme 'the challenge of accessing effective support demonstrates the absence of support that meets the partners' needs) and further along the process of acceptance and adjustment.These partners were able to find positive meaning in caring and be more cognitively and practically flexible, which has been associated with more successful coping (Dickson et al, 2012; Folkman & Moskowitz, 2000). Their appraisals of pain as more controllable and less threatening, along with their appraisals of their coping resources may have resulted in less psychological stress and better perceived coping.

Information played a crucial role in participants' emotional responses to dealing with chronic pain. For some, a deliberate choice to avoid information allowed them to distance themselves from the uncertainty and emotional distress and focus on aspects of life they could control or influence. Others desired information as a means of seeking certainty. As previously discussed, the transactional model of stress and coping (Lazarus & Folkman, 1984), the cognitive-behavioural transactional model of health (Turk & Kerns, 1985) and the self-regulatory model (Leventhal et al, 1984; 2001) can explain why some participants desired information and why others did not. It may be that there was a difference in how participants appraised the significance of the threat chronic pain posed, in how they appraised their responses and in what coping strategy they chose to use. Alternatively, it may be reflective of the differing needs for information partners have at different stages of their journey with chronic pain. In their systemic review of caregivers' informational needs, Washington, Meadows, Elliot and Koopman (2011) found that they change over time, moving from more general knowledge to specific information tailored to their particular situation.

An alternative, and yet complimentary, theoretical model that could explain the dual role of information to both reassure and cause concern is the uncertainty management theory (Hogan & Brashers, 2009). According to Hogan and Brashers (2009) "interacting with information can reduce, maintain or increase uncertainty" (p. 48). Individuals will then decide on whether to avoid or interact with information based on how they appraise the likely result of the information. For those who avoid information there will be multiple factors that drive their decisions. For example, a desire to avoid feeling overwhelmed, a desire to appear able to cope, and managing their other responsibilities result in it being difficult to meet their information needs (Barbour, Rintamaki, Ramsey & Brashers, 2012). In the current study Liam attributed his desire to avoid information to fear of being overwhelmed and concerned by it. This illustrates the importance of professionals being aware of the differing information needs partners might have (Wackerbath & Johnson, 2002). Washington et al. (2011) found that carers need help to process the information provided by medical professionals. It may be that this type of support would be beneficial for some participants who felt overwhelmed.

The impact of pain upon the relationship was discussed almost universally throughout the interviews. Pain had negative consequences for relationships, although for some, supporting their partner was a positive experience. It seemed that the quality of the relationship was a protective factor and helped with coping. The beneficial effect of a positive relationship in chronic pain is well documented (Becver, 2007). Additionally, couples who experience congruence in their coping, adjustment and cognitive appraisals are more likely to experience positive coping (Burg & Upchurch, 2007). Love for the individual with pain and finding positive meaning and pride in the caregiving role can act as buffers against the impact of chronic pain (Roy, 2010). Those who described their relationship more positively also did not experience as many negative consequences of pain and described caring as an honour.

For a minority of participants, being a partner to an individual with chronic pain resulted in growth, both personally and within the relationship. This may be akin to post traumatic growth, which is the positive change people may experience following a traumatic or adverse event (Tedeschi & Calhoun, 1995). This can include a changed view of oneself, being able to relate to others differently and a re-evaluation of priorities and appreciation of life (Calhoun & Tedeschi, 2014), all of which were discussed by participants. In addition to the personal growth experienced, the same participants also discussed the growth in their relationship, which is consistent with the existing empirical literature (Becver, 2007; Soderberg et al., 2003). Those participants who discussed their personally and relational growth tended to be those who described themselves as further along the process of acceptance and adjustment. It may be that personal growth is only able to occur once participants are able to accept the presence of chronic pain.

The negative impact pain can exert on a partner was clear. Coping with chronic pain requires couples to make multiple and continual adjustments (Blanchard et al., 2009; Grey, Knafl & McCorkle, 2006; West et al., 2012). The reversal of gender roles was discussed and has been documented elsewhere (e.g. West et al., 2012). This will be explored in more detail in Section 3. Pain can also negatively impact upon the relationship. Partners described how pain detrimentally changed their marriage, for example by altering communication, reciprocal affection and intimacy. A loss of effective communication sometimes occurs within a couple who experience chronic pain. Couples stop communicating as a method of protective buffering (Druley, Stephens & Coyne, 1997; Roy, 2010). Positive communication is associated with a stronger, more positive adjustment (Druley et al., 1997) and greater marital satisfaction (Acitelly & Badr, 2005). In addition, marital conflict increases pain behaviours in the individual with pain, which in turn results in spousal punishment and an increase in pain related impairment in the individual (Schwartz, Slater & Birchler, 1996). For those partners in the study who reported a negative impact on their relationship, it may be that a vicious cycle exists for those who are not satisfied within their relationship whereby their unhappiness increases the negative impact of pain, which in turn increases their unhappiness.

Pain affects levels of intimacy (Schantz-Laursen et al., 2006; Soderberg & Lundman, 2001; Soderberg et al., 2003). Lack of physical intimacy can also result in a deterioration of marital satisfaction (West et al., 2012). Only two participants discussed this, which may be due to gender issues, particularly as the sample was predominantly male and therefore may have felt uncomfortable discussing their sexuality with a younger, female researcher. Alternatively, it may be that those participants felt more comfortable discussing it as they were interviewed by telephone, not face-to-face or via Skype.

Reflections on inter-rated reliability during the data collection and analysis

Review and discussion at each stage of data collection and analysis proved to be vital. It allowed a more on depth analysis and appraisal of issues that were missed on initial formation of themes. During supervision personal experiences were related to the data collected as well as reflexive commentaries. This allowed bracketing, of life experiences as much as possible, in line with Thomas and Hardens (2008) advice. For example, the conceptualisation of pain as a personified entity became apparent during supervisory discussions. It was further supported by how I talked about pain in my reflexive journal. Thus, supervision ensured both transparency and a high quality analysis.

Implications

The current findings clearly demonstrate that chronic pain has a significant impact on partners. The majority of partners personalised pain and viewed it as an independent and malignant force in their lives. This resulted in them perceiving the impact of pain as greater and more negative than partners who viewed pain more neutrally. Partners also experienced pain as something that was detrimental to their relationship. There was evidence however, of the protective role the relationship could play in lessening the impact of pain. Those partners who described a more positive relationship were more able to buffer the impact of pain on their relationship. Interventions such as cognitive behavioural therapy, mindfulness, acceptance and commitment therapy or a combination of all three are commonly used within physical health settings to help people identify unhelpful thinking, develop their ability to pay attention and help accept and adjust to a chronic condition while living a value-based life. These interventions, in addition to education would allow partners to reflect on the impact pain has on them, to understand what chronic pain is, the impact of pain and strategies to handle pain (e.g. Scottish Intercollegiate Guidelines Network, 2013). Offering these interventions through pain management programmes would likely be beneficial as it would allow for both individuals in the relationship to develop a shared understanding. Additionally, systemic intervention as a couple may be beneficial.

Some partners did not view pain as a personal, independent and malignant force and did not describe the impact of chronic pain on their life as negatively, as a result of their appraisals and coping strategies (see figures 1 and 2). These partners are therefore less likely to need, or potentially want, intervention to help them tolerate the impact of chronic pain.

Indeed, intervention might be detrimental for these partners. Any intervention provided therefore must be tailored to partners’ needs and coping strategies.

In addition to therapeutic implications, there are also wider implications for the public education and public health spheres. Robust and accurate information about public health must be developed and made easily accessible. The majority of participants discussed the need for information, which was especially true in the early stages of diagnosis. Participants described having to seek out information and finding accurate information difficult to find (for example Liam learnt to not Google information). Adequate information may help to alleviate partners’ fears and prevent misinformation. It may also help the social support system to understand the situation. In addition to public health information, public education also appears to be necessary. Despite partners reporting having a good social support system, they felt the support offered did not meet their needs. Chronic pain is a poorly understood condition, which is made more difficult by the fact that the various chronic pain conditions vary so greatly. A robust public education programme would not only directly benefit partners, but also help the work place, social support networks and even healthcare professionals to support those affected by chronic pain (both directly and indirectly).

Limitations

The sample of participants may limit how the current results can be applied to other contexts. The sample entirely consisted of married heterosexual couples. No same-sex or non-married couples enquired about the study. Care was taken to use ‘partner’ as it was considered to be free from implications of marital or orientation status. Secondly, the sample is predominantly male (eight males). Chronic pain is more prevalent in women (van Hecke et al., 2013) and thus the predominance of males is reflective of the pain population. Finally, all participants were recruited entirely online. Attempts were made to recruit through support groups, however this was not possible.

IPA is an approach that relies on an in depth analysis of the experiences of small homogenous groups (Smith et al). The present study was planned so as to be consistent with this demand. However, there were four key sources of heterogeneity. First, a variety of a chronic pain conditions were involved. The type of pain condition will may influence both the individual and their partners’ experiences. For example, gynaecological pain, such as endometriosis, may have more implications on sexual intimacy and reproductive abilities than a rheumatology condition. Additionally, migraines may not be present on a daily basis, unlike back pain, which may be experienced as constant. Second, there was variance between the lengths of time individuals had experienced chronic pain, due to the lack of a maximum cut off in the inclusion and exclusion criteria. This may have resulted in varying experiences between partners. However, partners’ accounts did not vary greatly between pain conditions or length of pain, and it is commonplace to not include a maximum cut off within the chronic pain literature, therefore suggesting this was not a problematic source of heterogeneity. What appeared to be more important was how partners understood and perceived the chronic pain and the role it played in their life. This was not dependent upon condition or length of time, but rather seemed dependent on individual variables within participants such as preferred coping style-, resilience, expectations of life etc.

There did seem to be a clear impact of whether relationships started before or after the onset of pain. For example partners who knew their partner had a chronic pain condition before beginning the relationship did not report as many difficulties adjusting to the consequences of pain. This was not true for all participants however; for example Nathan had known his wife since childhood and was aware of her chronic pain conditions. Despite this, he did not describe adjusting the chronic pain easily or effectively. Conversely, Warrior and Thomas had been in a relationship with their partners prior to the development of chronic pain and yet reported a much easier adjustment process. As previously stated, the differences found between participants appear to result from individual differences between partners rather than differences between chronic pain. This therefore suggests that the heterogeneity within the current sample of partners' was not problematic.

Finally, there were some minor discrepancies in topics discussed based on the interview medium, specifically the only participants who discussed their intimate relationship were those interviewed over telephone.

Future Research

Given that there is little existing research exploring partners' experiences of chronic pain, a number of potential avenues exist for future research. Further support and exploration of the current study is required. As previously mentioned future research would do well to ensure that diversity within relationships is explored; for example whether sexual orientation, gender, relationship status and whether the relationship began prior to the onset of pain. Finally, technology such as Skype is allowing research to be conducted more easily (Hanna, 2012). Researchers would benefit from exploring whether the interview medium (i.e. Skype, face-to-face and telephone calls) influence what participants discuss.

Conclusion

The findings of this study build upon the two existing qualitative studies exploring partners' experiences of living with an individual with chronic pain as well as adding a qualitative understanding of the impact chronic pain has upon partners. Specifically, the current study highlights the novel finding that the personalisation of pain as an independent and malignant force can influence how partners cope with the impact of pain in their lives. The current study also provided support to the evidence base highlighting the importance of the spousal relationship and the impact the quality of the relationship can have by acting as a buffer to the impact of chronic pain and the use understanding or avoidance as a method of coping. Additionally, two themes describing the process of acceptance and adjustment, and the difficulty in accessing effective support were developed, but not discussed. Finally, what was clearly demonstrated by the results was that partners vary in their interpretations of the meaning of pain, which in terms influences their perspective of pain and how they in turn cope with its impact. The study provides a detailed, personal perspective on partner’s experiences of living with someone with chronic pain. Support for partners is recommended, specifically through pain management clinics and programmes.

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Table 1.

Participant demographic details.

Participant pseudonym	Partners pseudonym	Age	Relationship status	Length of relationship	Length of cohabitation	Partners chronic pain condition	Length of pain condition	Participant's personal pain	Children
Alfonso	Bethan	30	Married	3 years 10 months	1 year	Mixed connective tissue disease	10 years	No	No
Warrior	Princess	57	Married	34 years	33 years	Osteoarthritis, fibromyalgia and ME	16 years	No	2 (0 at home)
Thomas	Sarah	32	Married	16 years	13 years	Endometriosis and adenomyosis	16 years	No	No
Sean	Lauren	45	Married	13 years	12 years	? Migraine/cluster	7 years	No	3 (2 at

						headaches			home)
Liam	Charlotte	39	Married	6 years 5 months	4 years 6 months	Rheumatoid arthritis and endometriosis	18 months (endometriosis present for longer, but unsure of specific length)	Migraine	2 (2 at home)
Simon	Samantha	41	Married	19 years	18 years	Migraine	34 years	No	2 (2 at home)
Trish	Christopher	63	Married	20 years	18 years	Ankylosing spondylitis and cervical spondylosis	31 years	No	Did not answer
Jane	Jonathon	58	Married	21 years	21 years	Neuropathic	15 years	Migraine	2

						pain			(1 at home)
Michael	Lisa	42	Married	20 years	15 years	Rheumatoid arthritis	10 years	No	2 (2 at home)
Nathan	Ava	23	Married	8 years	3 years	Osteoarthritis & cluster migraines	16 years	No	2 (2 at home)

Table 2.

Table illustrating examples of exploratory comments and emergent themes for an exert of the transcript of the interview with Michael

Emergent Themes	Transcript	Exploratory Comments
Shared experience of the impact of pain (shared success, shared impact)	R: yeah it is erm...you know she has gone through she’s gone through real peaks and troughs in terms of the condition one of the peaks for example was she ran the 10k with me erm I: wow R: Manchester 10k from not being where she was to I: that’s a massive achievement	Repetition Impact of pain on life – especially achievements. ? Does pain make it harder to have success/achievements in life/does it alter what counts as an achievement? Included himself in the achievement - ?could she have done it without him She was in a bad place – strengthens achievement Sense of pride in his wife Medication considered an important part of coping with pain - ? Is medication responsible for the success not her?
Constantly trying to balance/control the impact of pain. Uncertainty of living with pain. Pain exerts power over their lives/them	R: medication was awesome it was working well and erm...she did it and we did it together which was a really really good achievement and that time when she was pushing herself you knew she could do it because things were in balance and you know the the progression was sort of in remission erm but then when I see her you know I I notice all the signs now the tiredness and sometimes her colour changes or whatever or the mood becomes a bit sharper and I then know things are verging on a bit of a flare or whatever I: yeah R: it’s just a balancing act really and you know what I regularly	Was –past tense, not working now? Uncertainty, constant change Joint success – shares her achievement. Sense during interview that he was more proud that he helped her do it than he was about his individual achievement Repetition of word Certainty – is uncertainty more common in their lives? Balance – requires work to achieve. Controlled, managed. Some cost/downside of pain but also managing to live life with pleasure. Controlled – but still there lurking in the background. ?cancer/other potentially terminal diseases Switch from “you” to “I” – making it personal Now – didn’t always notice. Had to learn the signs. Responsibility to watch/know? “Or whatever” – dismissal? Casual – he is in control? Sharper – sense of threat? (piercing, knife), ?tense Verging – links to in balance before – balancing on a knife edge all of the time Whatever – dismissal ?casual – he is in control

Having to develop the skills to manage the impact of pain.	get it wrong I'm not the best I'm not saying I'm perfect in anyway if I'm I also get frustrated with it and I've I've blamed the RA for a number of things in the past I think sometimes I've probably used the quote a couple of times since she's had the condition it's not easy to understand myself you know it's not that easy I hate the disease all that sort of stuff you know	Balancing again – important concept Regularly – common occurrence – pain (and his mistakes) are often there. ?sense of failure. He is trying – requires effort Trial and error, not natural, requires learning. "It" "the RA" "the disease"– pain as distinct/separate personification. Able to direct his wife's behaviour Separating the pain from his wife ? Sense of needing permission to struggle with it ? his experience/understanding is separate to hers
	I: yeah	Vague – not going into specific details
	R: so that's been that's been hard to sort of gauge it really	
Understanding/information is a more objective, consistent and achievable thing than "coping" with the impact of pain.	I: how, what is your understanding of RA and the impact it has	Difficult to do Gauge it – understand, measure,
	R: erm...you mean the actual condition you mean how well do I understand it	Clarification – was my question not clear enough, has he not thought of the impact of it, was it thinking of the impact on him/her?
	I: well I suppose the condition from a medical point of view but then how it impacts of her	
?Impact on romantic relationship	R: erm...I think I've got a very very firm understanding of it because when she was first diagnosed I had exactly the same view as everyone else bloody hell this is an old persons disease you know	Repetition of word Firm – in opposition to previous use of "gauge" "balance" etc. His misunderstanding/assumption is understandable as everyone else thinks the same way?
	I: yeah	"You know" – seeking clarification/support?
	R: what's my woma- what's my young wife got to do with a wrinklies disease that's my initial reaction so I've done a lot of research and we're very active in erm...ARUK so we're actually	Age related – disease didn't "fit" with his view of his wife? Loss of femininity? Impact on attraction/sexuality perhaps? My woman – possessive. Stops self saying "my woman" – self inhibiting? Initial reaction – suggests now changed. Research to

Information is a means to feel in control of pain	we ran a branch for that in the local area so we we had instant access to a lot of support and we went to a lot of forums and stuff to understand the condition so I think I've got a very sound understanding of how it progresses and how it the regimes	correct initial reaction/make sense – research as a way to be in control? Seeking out information – seeking out certainty/control? We – joint, shared experience Support – helped make sense of experience. Support/understanding not from doctors
? pain and the treatment of pain can cause damage (physical and ?emotional)	behind it are and how they are meant to treat and what they are supposed to be doing so I understand you know the medication and what its potentially doing to her body and sometimes the the negative positions in later life that the RA can affect	Move from we to I again Sound – firm – again in contradiction to balance/gauge. Information/understanding is a concrete/complete thing? It – separate, personification? "meant" "supposed" – medications aren't doing their job ?disappointed/failed by medication Uncertainty When considering the side effects he is more tentative. Pain is damaging her now and in the future
	I: yeah	
	R: so I do understand it erm how much can I understand of living with it well just from watching Lisa she doesn't tell me everything she doesn't indicate everything and I will very often have to say to her where are you at pain wise today or what's the are you alright that's the stock phrase everyday how are you doing today	Repeating the question – summarising? Keeping on track? Not fully answered Uncertainty. Having to be on alert all the time to notice small cues. Having to ask/check – again having to make sure to ask as she won't tell him. Importance of communication (from his point of view, as she is holding communication back). – Priority?
	I: yeah	
Constant uncertainty Importance of communication	R: to gauge like this morning she has her Fridays off this morning how are you doing today are you ok to take the kids to school alright I'm off I'm going to I knew she was ok she was fine she gave me the signal and off I went so its understanding by asking the right questions how they're doing you know	Gauge – guess, estimate – uncertain Importance of communication Element of constant uncertainty – pain can control the whole family's day Having to learn – developed understanding over time

	I: yeah R: erm and actually having a having a.... a lot of years into it understanding it I: yeah	Developed over time – skill? Practice/
Being a partner to someone with pain requires skills developed over time The tentative sense of being in control of pain. Trying to find a way to be in control of pain (even if only tentatively).	R: erm and I know she's got a friend of hers whose recently been diagnosed and her you know her her partner is going though it and she just doesn't know where she is at with it and I remember that confusion and scared and now it's become quite a big part of our life you just have to get on with it as do our kids as they get older as well erm and you know its manageable I'm **honest** with you its manageable I: yeah R: there's always peaks and toughs I could go home tonight and she could have hit a downer for whatever reason but who knows but you know I would say those periods are less frequent than they certainly were in the early days	Difficult – process/journey? Confusing/disorientating I remember – suggests he is past that phase. ?shared experience all partners go through Quite – pain has an impact but suggests limited impact? Our life – its impact is shared/joint. No choice about pain and the impact – helpless to some extent. Only area of control is how you cope Repetition Manageable – impression of just about keeping control during the interview. Wasn't said with confidence, more of a sense of careful balance that could be so easily lost Honest - has he been dishonest? If so with who? Unpredictable, varied, situation changes quickly – reason not always known/obvious Sense of progress/change as they learn to cope/manage the pain
Pain impacts on social activities	I: how do you cope with the predictability of never knowing how she is going to be R: it's never going to get any easier is it erm you know you can I can count on more than two hands where we've had to cancel things that we wanted to do erm and done different things	Questioning – hoping for comfort that it might get better? Resigned acceptance Change from distant to personal – you to I Pain controls decisions/social activities Disappointment

Pain impacts on parenting/family life	rather than the ones we wanted to do it's a case of for example in the early days when she when it was really bad we turned it into a good thing for the kids for example we'd say right ok oh we were going to go for a picnic today day and not today we're having a duvet day where we are going to read as many books as we can or watch movies or whatever	Shared decision making, shared loss/cost Sense of progress/things have got easier – not always the case Really bad – significant/great impact of pain We – joint decisions/joint responsibility to make it better for kids Trying to minimise the impact Pain impacts on whole family/parenting
Pain can control the whole families life/activities	I: yeah	
	R: and then Lisa can still be part of that you can turn it into another adventure you know	Trying to include wife Trying to find the positive/keep things positive
	I: yeah	
Impact on marriage/relationship.	R; but then if you lose a concert of you don't go to a erm weekend away or go out for dinner than you'd scheduled to do that's quite hard you just try and I don't know have a snuggle on the sofa or whatever have a take away at home or whatever just cause	Lose – interesting choice of word. Lessens the impact compared to cancel? Less of a choice? Impact seems greater when it's an activity the children aren't part of – make it fun for them (e.g. duvet day) but when it's an adult/couple activity it seems they compromise but the impact is felt more
	I: yeah	
	R: you just turn it into you just try not to make a big issue of it it was I'm trying to say	Try – doesn't always succeed? Suggests it is a big issue?
	I: yeah	Feels point isn't being made/received/understood?
	R: I can be as accommodating as does Lia of course	Of course – ensuring her role is understood. Making sure he doesn't seem like the reasonable one? ?after thought?

Table 3.

Table demonstrating the development of super-ordinate themes within Nathan's transcript of his interview.

Super-ordinate Themes	Emergent Themes	Exemplar Quotes from Transcript
Coming to terms with chronic pain is a process- one I don't have much choice in This theme relates to Nathans experience of trying to come to terms with his partner's pain. He described the process of going from having hope to having no hope. He hoped that the pain could be cured, or could be controlled by medications/surgery. However, after trying various treatments, all of which had minimal impact, he began to realise the pain was unlikely to stop. This resulted in the beginnings of Nathan attempting to accept and adjust to the chronic pain. For Nathan, this was a challenging process and one he had had limited success with. He discussed the process of trying to adjust to the pain and trying to learn to cope with the pain. For Nathan, this process of acceptance and adjustment was one he felt obliged, or forced into doing. He felt he had no other choice but to learn how to accept the pain. He had resigned himself to the knowledge that pain was an unwelcome intruder in his life.	Moving from hope to no hope	"So there is a lot going on with the joints…they said of all the checklist she was on the minimum possible and they said they wouldn't bother treating her for it"
	Hoping for a cure	"I still have a little bit of hope that they will find a surgery or erm her medication regime would help alleviate her problems, actually get diagnosed and treated properly, have it managed so that to give us that bit of freedom back"
	The process of acceptance and adjustment	
	Learning to cope over time	"To be honest when something new comes along we just roll our eyes and go 'oh something else to moan about' so it's just…it's just so much of it, it's just like…hmmm…more…"
	Having to accept the presence of pain	"I do what needs to be done. I just focus on what needs to be done and I try to do it. I try to ignore how I feel…and just be how I need to be at that point"

Pain is all consuming and dominant This theme was the most prevalent for Nathan, and in fact all participants. It details the feeling Nathan had that pain was all consuming and was the biggest aspect of his life. Pain was described as strong, creating multiple problems, additional tasks, obstacles etc. all of which made Nathan feel weak, helpless and out of control. Pain felt constant and relentless. Nathan described feeling worn down by pains adversarial nature. Pain was described as being a separate entity.	Pain changes how you view your partner Forced to keep on going – put your head down and carry on Pain is strong and it's overwhelming, adversarial nature makes Nathan feel weak. He is unable to fight it, it is a losing battle. Pain is burdensome. It creates additional physical and emotional work. Pain is constant, there is no hope of escaping its effects. It creates a sense of hopelessness and helplessness that means even when their partner isn't in pain, they are in emotional pain.	"I haven't always known her in pain. When we used to play out together she was running, jumping, skipping. She…I was tied to a tree by some local bullies once and she kind of fought them off and untied me from the tree. She was the superhero. …Now it's like the complete other way round. I'm taking care of her and that's really weird when you think about it. …but it was very weird to think about…I'm not married to that girl (sighs)." "I'd say pain is…that there is not one activity I can do, or me and Ava can do, that pain isn't a part of" "It's literally one thing after another. There isn't, there hasn't been a time in the past year or two, where she hasn't had something that is like attacking her." "It takes it out of you, the simplest little task that just drains you of energy. It would be nice if Ava could help with some tasks but I know because of the pain it's very difficult for her. At the same time it's exhausting for me but you don't really think of pain, you think it's just an arbitrary thing that is there for some people. When you've banged yourself or you've done something silly as a reminder. But for us it's like a constant clod of erm every day. Truly it literally permeates everything. It dictates what we can and cannot do as a family and these other families are doing these things and its every day. (sighs) It's just another thing on the list if I'm honest. "There are times when you are literally just thinking, just a break, just a nice break from the pain to feel…just two weeks with no pain would be completely…"
Desiring support but feeling judged or unable to access that support This theme relates to Nathans intense desire to	Feeling judged or misunderstood by others	"You can feel them judging you because like because of Ava's joint pain she can't exercise, you know what I mean? So because she can't exercise she has put a little bit of weight on, but it's through completely no fault of

feel supported by friends, family and medical professionals. Despite this desire, and his attempts to access support, he felt either misunderstood, dismissed or judged by people. This feeling was particularly prevalent in relationship to medical professionals, in particular their GP. Being unable to obtain a specific diagnosis in a timely manner, in addition to accessing medications, resulted in Nathan feeling dismissed and failed by medics.	Wanting to be understood by others and be supported in the correct way Feeling unsupported and undervalued by professionals (especially around the difficulty in being diagnosed and accessing treatment) Being unable to access support due to pain	her own, but still she will get people giving her dagger glares and stuff like that. They’re making pointed comments like ‘oh if you lost a bit of weight maybe your joints would feel better’. But they don’t seem to realise that the joint pain has caused the weight not the other way round.” “Cause you get those people it’s really difficult because you’re friends with this person, but they don’t understand the level of pain that is in your life at that particular moment. They say ‘oh why don’t you just do this’ and ‘why don’t you just do that’. If only it was that simple but then it is and… (Sighs) they don’t understand because they haven’t been in this situation. They don’t appreciate what we go through and I find that a very difficult obstacle to overcome. “But yeah it’s a long process and half the doctors don’t take her seriously” “A lot of doctors sort of…not ignore but kind of brush it under the carpet. ‘Nah it’s not too much, it’s not important’. It’s completely demoralising. All we want is a doctor to see the problem…”

Table 4.

Comparison of themes across participants[2]

Third iteration: Super ordinate themes			
	Pain as a personal, independent and malignant force	*Loss and growth in the relationship*	*Controlling one's awareness as a means of controlling the impact of pain*
Second iteration: Themes across participants			
	Pain is powerful, constant and destructive *Pain impacts on the partner just as much as the individual* *Pain impacts (and restricts) all aspects of life* *Pain is like a 'living entity'*	*Pain alters communication between partners* *Pain alters the sexual relationship* *Caring for your partner is the 'right thing to do'* *Pain produces challenges, and opportunities for personal development*	*Information is used to provide certainty (which helps people cope)* *Avoiding information also helps people cope* *For some partners however, avoiding information (both in terms of the pain and their own emotions) is more beneficial*
First iteration: original themes for each participant			
Alfonso	*Pain is powerful, but I've learnt to control it* Pain was undoubtedly powerful in Alfonso's life. It was ever present, created additional work and made accessing rest difficult. Pain forced him to reconsider his future plans, change his routine, and take on traditional gender roles he did not want to take on. Despite the powerful nature of pain, Alfonso felt able to	*Caring as an honour* Caring was something viewed with reverence by Alfonso. It was something he enjoyed doing and something which was an important part of his life. It was a way of demonstrating the magnitude of his love for his wife. *Caring confers personal benefits* Alfonso described the numerous	*Information as a way to provide certainty and solutions – which reduces the emotional experience* Information provides clarity and certainty, which reduces the emotional turmoil experienced. Information is the lens through which Alfonso makes sense of his experiences, feelings etc. Information produces practical solutions which allow him to focus his attention on action orientated coping strategies while avoiding

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[2] Please not this table is only for the themes reported in the study. Please see Table 5 for details of the two unreported themes.

	control pain, to reduce its impact on him. Rather than resisting its impact, he went with it. He learnt to think of the future in flexible terms, rather than fixed terms. He embraced the change in routine and viewed it as a chance to learn new hobbies and skills. By doing this, pain remained powerful but he felt in control of it.	personal benefits he experienced from caring for his partner. He described the personal development he experienced, for example becoming more patient. He also described the revelations he experienced about his personality, for example, he realised he was a kind person. For Alfonso these personal developments were incentives to continue caring.	thinking about his situation.
Warrior	*Pain is relentless and exhausting. To cope I have to find "time off"* Pain was constant with no hope of escape. It created additional tasks and burdens (both emotional and practical) that drained Warriors limited resources. His attempts to be a good partner meant he had to sacrifice a lot. He felt he was unable to take time off alone to recuperate as he could not leave his partner alone with her pain. Even work, which he considered a form of respite, was not safe from pain as his wife would contact him while at work. To combat this, Warrior prioritised holidays with his wife. These gave him something to hope for and allowed him to take time out for himself. His wife's pain was generally better while on holiday reducing the guilt her felt when	*Pain can make or break your relationship* Warrior described the impact of pain on his relationship both negatively and positively. Pain was described as a "trump card" which altered communication, especially during arguments. It altered how he viewed his partner (in particular that she was somehow weaker or less). It caused challenges in their relationship. However, it also caused positive growth, both for him as a person and them as a couple. The thing that kept him going and helped him continue to prioritise keeping their relationship strong was the belief that caring was the right thing to do as a partner.	

	resting. Holidays, and rest, gave him good memories to help him get through the bad times.		
Thomas	*Pain as the reason for every decision we make. But by embracing that the impact is minimised.* Pain is the central component of Thomas’s life and work. It was the reason for every choice he made in life. It was constant and therefore there was no escape from it. He could never relax from the impact pain had. Thomas never made any plans or hopes for the future for fear of pain preventing them from happening. Despite this, he did not view pain as negative or powerful. By embracing rather than resisting the pain he was able to minimise the impact he felt pain had on his life.	*The costs of being a partner to someone with chronic pain cannot compare to having chronic pain. It is part of a partner’s duty and one that comes with personal gain.* For Thomas, he felt his personal experiences could not ever compare to his wife’s experiences of pain. He felt it was part of his role as a partner to put his needs second endure personal sacrifice. He felt caring was the “right thing to do” for his wife. He reported numerous personal gains from his caring role, in particular feeling like he was a better person, being able to be more compassionate to others and a stronger, more connected relationship with his wife.	*Information as a means of personal protection* Having lots of information (personal, medical and professional) allows emotional distancing which in turn allows him to cope. Information reduces the sense of helplessness and uncertainty. It allows Thomas to have a “realistic” perspective which allows him to plan for the worst, so as to never be “taken off guard”. Additionally, for Thomas, information allowed him to develop a sense of power, whereby he viewed himself as different to/better than other partners.
Sean	*Living with pain is a battle, one I’m losing.* For Sean, living with pain was a battle and one he felt unable to win. Pain created a lot of additional work for Sean, especially in terms of domestic tasks and caring for the children. Pain dominated their lives constantly. Pain had a significant impact on the	*Pain has fundamentally and irreversibly changed our relationship for the worst.* Pain had an enormous impact on Sean’s marriage. He described doubting his partner’s pain at times. He felt his partner no longer resembled the woman he married and was no longer the mother she used to be. He described his marriage as destroyed, probably beyond	*Coping with chronic pain is dependent upon robust information* Sean had very little information about his wife’s condition, and they were still waiting for a specific diagnosis. This left Sean feeling helpless, hopeless and unable to understand the impact pain had on his life (and his wife’s). Without information, Sean was unable to seek out a

	family's financial status and this resulted in Sean feeling "impotent" and unable to help. He felt helpless against the immense power of pain. Sean was overwhelmed, powerless and felt unable to admit how difficult things were. He felt in competition with his wife over whose life was worse. He felt he was running out of resources to cope and was losing the battle against pain.	repair. He felt trapped in the marriage, he longed to leave but felt unable to be the type of man who leaves a sick wife. Pain had altered their communication, especially around arguments. He felt unable to argue back because she was 'sick' and so would hold his frustration in. He experienced a loss of intimacy and affection. This, especially the loss of affection, resulted in him feeling lonely and rejected.	cure/solutions to help. He was also unable to assign blame for his wife's pain without knowing what had caused the pain.
Liam	*Pain is a destructive force in my life* Pain was viewed as a destructive part of Liam's life. He felt it destroyed his partner, aging her and making old before her time. It destroyed his good memories of their relationship. He described pain as a violent, difficult, growing thing that was intruding in their life. Its constant and destructive nature meant that he was unable to ever escape from it. This, alongside the additional workload it created, means he was unable to rest or escape, meaning that he felt he was being destroyed by the pain too.	*Pain instigates personal and relational growth* Liam described experiencing growth personally; specifically that he felt he had become a 'better' person because of his circumstances. Pain had forced him to try new things and learn new skills (e.g. cooking and cleaning). He felt their relationship had grown in many ways. He described feeling more in love with his wife. *Feeling like a carer, not a partner* Liam's wedding vows were an important reason for his caring. He repeatedly cited "in sickness and in health" during the interview. He felt like caring reflected on him as a partner, specifically that doing a bad job of	*Avoiding information, and prioritising personal knowledge, as a means of coping.* Liam carefully selected sources of information, in particular avoiding generic, medical sources of information. These sources of information were considered frightening and unhelpful. Instead, Liam valued the personal knowledge he had curated about his partner. This allowed him to be an expert in his partner, rather than Rheumatoid Arthritis.

		caring meant he was a bad partner. While he did not begrudge or object to caring for his wife, he discussed feeling more like a carer than a partner and that his relationship with his wife was fundamentally changed because of the pain.	
Simon	*Pain has changed my partner* Pain was so powerful it was able to change his partner. He described it as eroding her personality and spark. *Pain restricts and alters all areas of my life* Pain was a constant and burdensome aspect of his life. It impacted on every aspect of his life, but most noticeably his family, his work and his social activities. Simon felt forced into taking on "female" tasks at home (caring, cleaning etc.) while also having to juggle being the main wage earner. The most difficult aspect for Simon was the impact on his social activities. He tried not to plan around the pain, but would find himself having to make contingency plans or cancelling activities. He found the "waiting game" (waiting to see if his wife's migraines would improve so he	*Pain alters communication between partners* Pain created 'flashpoints' within the relationship, which were often caused due to disrupted communication between partners. These flashpoints were made more difficult when both individuals did not share the same understanding of pain. Simon would describe getting angry at the pain (which he viewed as separate to his wife), but this was interpreted by his wife as him being angry at her.	

	could go out) the most difficult. During these times he felt totally helpless and controlled by pain.		
Trish	*Pain is restricting and demanding* Despite Trish's 'stiff upper lip' approach to dealing with pain, she was still clearly affected by it. She described pain as burdensome, creating additional work for her. She prioritised her partner's needs over hers at all costs; however this was exhausting for her. She longed for respite, and was able to access it; however it created additional work to get that rest. Pain restricted many of their life decisions, reducing their perceived quality of life.		*Having a shared understanding of disability* Trish and her husband both had disabilities (details not included for anonymity). This personal experience (a form of information) shaped her interactions with her partner and professionals. In particular not being defined by a disability and not giving up on someone because of it. *Having an expert, business-like approach to dealing with pain* Trish dealt with the consequences of pain with an expert, business-like approach. She focused entirely on the practical side and discussed her experiences with an element of emotional disconnect. She took on the expert role and focused on developing her sense of competence and control at the exclusion of her emotions.
Jane			*Choosing to avoid an awareness of her emotions by focusing on the practical aspects of daily life* Jane described her experiences in terms of the practical impact pain had on her. When

			questioned about the emotional experiences she was unable to provide any information. Jane described focusing on learning how to practically help her husband, and herself. She distanced herself from other partners, describing how she did not need support and was coping well. She sought information, but only if she felt it would help her practically assist her.
Michael	*Pain creates strong dark emotions* Feelings such as hopelessness, helplessness, being unable to fix the situation, feeling angry at your situation. He feared his children would develop rheumatoid arthritis and felt he had to always be on the lookout for symptoms in them. *Pain controls all aspects of my life* Michael described pain as a constant aspect of his life, with the consequences (emotional and practical) still present when pain was not. Pain was described as a powerful entity in his life, one that he was too weak to combat. For Michael pain exerted its power in two specific ways: creating competing demands/tasks (especially parenting/housework/work) and	*Learning to parent in the face of pain* The challenge of protecting your children, while ensuring your partner is not excluded from parenting is a difficult balance. Learning to be the primary caregiver, but only during certain (sometimes unexpected periods) is challenging. *The sexual relationship becomes more challenging and 'risky'.* Pain reduces the frequency of sexual intercourse. However, it's most significant impact is reducing affection and the ease of communication around sex and increasing the vulnerability he experiences in his sexual relationship. The caring role he undertakes for his wife makes him desire sex more, possibly as a reward for his caring, or as an extension of his caring.	*Information is a tool to help you, and your partner, cope with pain* Information is a multi-tool. Information, or the lack of it, is important in searching for, and accessing treatment options. It allows him to best support his partner and children. It allows him to develop his own coping strategies. It allows him to prepare for the future. Information allowed Michael to move from panic to planning. However, not all information was considered good, or beneficial. In particular information that was perceived as negative, or unsolicited information caused more harm than good.

	forcing him to cancel his personal activities/plan his life around the pain.		
Nathan	*See Table 2*		

Table 5.

Comparison of themes across participants for those themes not reported in the current paper[3]

Third iteration: Super ordinate themes		
The challenge of accessing effective support		*The process of acceptance and adjustment*
Second iteration: Themes across participants		
Feeling let down by the system and professionals *Feeling alone and unsupported* *Others judgement and lack of understanding makes support hard to access*		*Learning to cope with pain is a process* *Learning to come to terms with pain (or not) is linked to coping*
First iteration: original themes for each participant		
Alfonso	*Being aware of others judgements and choosing carefully what, and how, to disclose to others.* Alfonso was very aware of others judgements. These judgements could be both positive (e.g. how good of a partner he was) and negative (e.g. why would be begin a relationship with someone who was sick). He was aware of the judgements others made about his partner (especially around employment) and so chose carefully when, how and what to disclose to people. This included close friends.	
Warrior	*The tension between wanting support, having support and feeling that you are not supported enough.* Warrior had what he described as good support from friends, family and work colleagues. However, despite this support,	*Acceptance is mediated by the severity and experience of the pain* Warrior underwent a process of coming to terms with his wife's pain. This process involved trialling out medical

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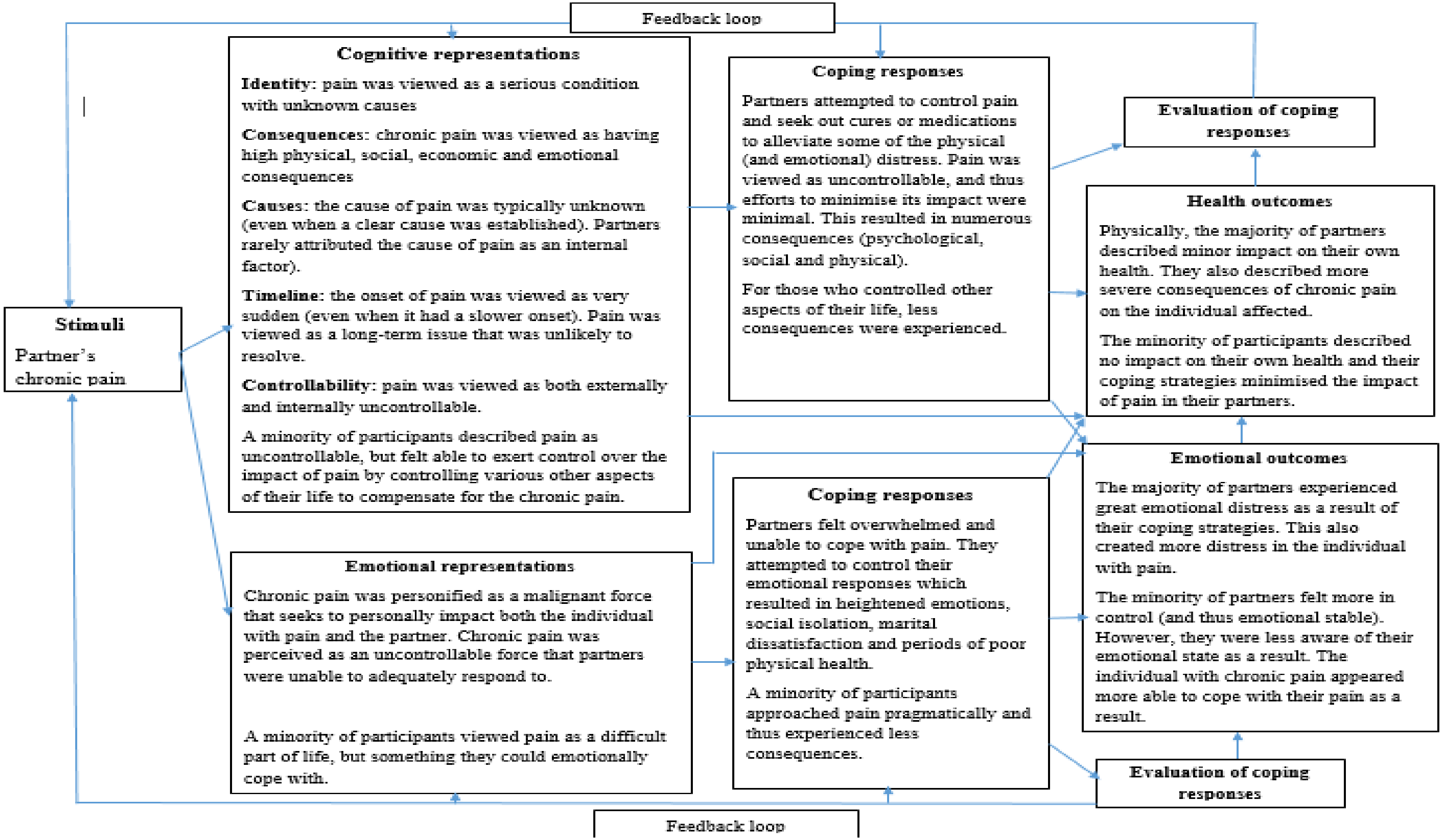
[3] Please not this table is only for the themes not reported in the study.

	Warrior still discussed his experiences as feeling unsupported. Support offered by friends and family was not always useful or beneficial. He experienced a sense of judgement from others, especially due to his wife's unemployment, which resulted in him feeling unsupported by society. Finally, there was a prevalent sense of feeling let down my professionals.	treatments, which proved mostly unsuccessful and developing practical and emotional strategies to cope with the impact of pain. This process occurred after the acceptance that the pain was chronic and unlikely to resolve.
Thomas		*Coming to terms with chronic pain is a seamless process* For Thomas, the process of coming to terms with chronic pain was seemingly easy and seamless. He did experience moving from hope to no hope like other participants; however, for Thomas this was much less difficult and significant.
Sean		*Feeling unable to accept the presence of chronic pain* Sean described his experiences of chronic pain as incredibly challenging. Sean initially described feeling hopeful that her pain would eventually go, or be cured by medications. However, over time he had come to the realisation that the pain was chronic. Despite this, he was unable to accept that his wife's pain may not be curable and continued to search for medical treatments to help her.
Liam	*Feeling alone in coping with the pain* Liam felt totally alone and unsupported in being a partner to someone with chronic pain. He had no family to support him, and limited social relationships due to caring for his partner. Liam felt unable to accept professional support (due to work/caring requirements and due to feeling like he would be taking that help from others who needed it more). He felt unable to turn to his partner for support for fear of making her feel guilty.	

Simon	*Pain filters out those friends who are willing to support me from those who do not understand* Simon experienced differing responses from his friends and family. Some did not understand his circumstances, were perceived as judgemental or unsympathetic. Simon felt this was due to the fact migraines are 'common' and 'non-fatal' and so not worthy of sympathy. On the other hand some friends were incredibly supportive and "stuck around" even when pain impacted on his ability to meet up with them. *Lack of professional support* Simon felt there was not adequate support from the professionals involved in his wife's care. This feeling was heightened during the early days, times when medications were not working, when there were no further medications to be offered or when his wife experienced flare ups.	
Trish	*Feeling let down by the system* There were moments when Trish felt supported by the system, for example by her GP, whom she described as excellent. However, for the most part, Trish felt let down by the system. She felt their basic needs were not being met and that there was nobody able to support her or her husband, especially during times of crisis. She had experienced a decline in the availability of NHS treatments which resulted in her feeling abandoned by those who should help. *The challenge of finding good social support* Trish discussed how difficult, and yet essential, it was to rely	

	on other people. Others being unable to understand their situation, people doubting the severity of her partner's pain and friends being unable to cope with the severity of her partners pain and disability, made it even more difficult to rely on others. She feared their reaction and would hold back from asking for support. For	
Jane	*Feeling supported socially but not professionally* Jane described her experiences in light of having good personal support. She felt surrounded by friends and family who had a good understanding of her husband's pain and the impact it had on both him, and his family. She felt unsupported. Undervalued and forgotten by professionals. She felt their needs were not a priority because pain is not life threatening. Her strong social support balanced these feelings of being professionally unsupported.	*The process of acceptance is something you have to do in order to cope well.* Jane underwent the same process of acceptance and adjustment and going from having hope to no hope as other patients. For Jane this process was a generally easy one, which did not compromise of significant negative feelings. She described adjusting very quickly to her partner's pain. In particular she described making an active choice to accept the pain as she felt that she would cope better that way.
Michael	*A lack of understanding results in a lack of support* Michael experienced an overall sense of lack of support, both professionally and socially. He felt doctors did not understand their situation and did not understand the need to involve partners. This resulted in him feeling under supported. He also experienced a lack of understanding from friends and family. This lack of understanding meant that when support was offered, it was not effective.	*Learning how to live with pain* Michael described coming to terms with chronic pain as a learning process. He placed a lot of his hope in medical cures, however over time learnt practical and emotional strategies to help himself, his wife and his children. This required time and lots of trial and error. *The reciprocal relationship between each partners coping* Michael's coping was directly related to his wife's adjustment to her chronic pain. His wife had an excellent understanding of her pain condition, both medically and how best to cope with it. This minimised the impact pain had on the family and allowed Michael to focus on his adjustment.
Nathan	*See Table 2*	*See Table 2*



Stimuli

Partner's chronic pain

Cognitive representations

Identity: pain was viewed as a serious condition with unknown causes

Consequences: chronic pain was viewed as having high physical, social, economic and emotional consequences

Causes: the cause of pain was typically unknown (even when a clear cause was established). Partners rarely attributed the cause of pain as an internal factor).

Timeline: the onset of pain was viewed as very sudden (even when it had a slower onset). Pain was viewed as a long-term issue that was unlikely to resolve.

Controllability: pain was viewed as both externally and internally uncontrollable.

A minority of participants described pain as uncontrollable, but felt able to exert control over the impact of pain by controlling various other aspects of their life to compensate for the chronic pain.

Emotional representations

Chronic pain was personified as a malignant force that seeks to personally impact both the individual with pain and the partner. Chronic pain was perceived as an uncontrollable force that partners were unable to adequately respond to.

A minority of participants viewed pain as a difficult part of life, but something they could emotionally cope with.

Coping responses

Partners attempted to control pain and seek out cures or medications to alleviate some of the physical (and emotional) distress. Pain was viewed as uncontrollable, and thus efforts to minimise its impact were minimal. This resulted in numerous consequences (psychological, social and physical).

For those who controlled other aspects of their life, less consequences were experienced.

Coping responses

Partners felt overwhelmed and unable to cope with pain. They attempted to control their emotional responses which resulted in heightened emotions, social isolation, marital dissatisfaction and periods of poor physical health.

A minority of participants approached pain pragmatically and thus experienced less consequences.

Evaluation of coping responses

Health outcomes

Physically, the majority of partners described minor impact on their own health. They also described more severe consequences of chronic pain on the individual affected.

The minority of participants described no impact on their own health and their coping strategies minimised the impact of pain in their partners.

Emotional outcomes

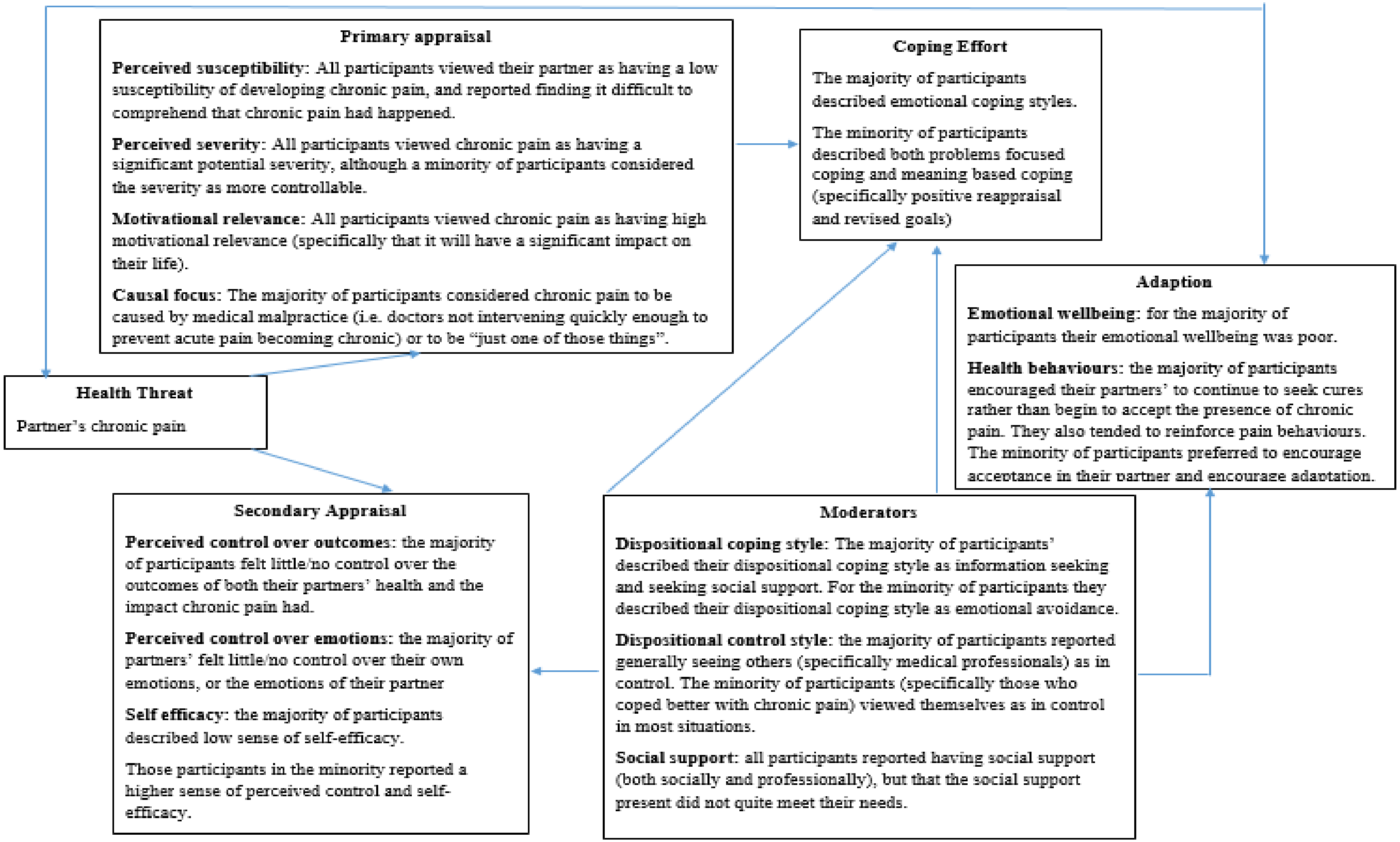
The majority of partners experienced great emotional distress as a result of their coping strategies. This also created more distress in the individual with pain.

The minority of partners felt more in control (and thus emotional stable). However, they were less aware of their emotional state as a result. The individual with chronic pain appeared more able to cope with their pain as a result.

Evaluation of coping responses

Figure 1

Findings applied to the self-regulatory model (Leventhal et al., 1984; 2001)



Primary appraisal

Perceived susceptibility: All participants viewed their partner as having a low susceptibility of developing chronic pain, and reported finding it difficult to comprehend that chronic pain had happened.

Perceived severity: All participants viewed chronic pain as having a significant potential severity, although a minority of participants considered the severity as more controllable.

Motivational relevance: All participants viewed chronic pain as having high motivational relevance (specifically that it will have a significant impact on their life).

Causal focus: The majority of participants considered chronic pain to be caused by medical malpractice (i.e. doctors not intervening quickly enough to prevent acute pain becoming chronic) or to be "just one of those things".

Coping Effort

The majority of participants described emotional coping styles.

The minority of participants described both problems focused coping and meaning based coping (specifically positive reappraisal and revised goals)

Health Threat

Partner's chronic pain

Adaption

Emotional wellbeing: for the majority of participants their emotional wellbeing was poor.

Health behaviours: the majority of participants encouraged their partners' to continue to seek cures rather than begin to accept the presence of chronic pain. They also tended to reinforce pain behaviours. The minority of participants preferred to encourage acceptance in their partner and encourage adaptation.

Secondary Appraisal

Perceived control over outcomes: the majority of participants felt little/no control over the outcomes of both their partners' health and the impact chronic pain had.

Perceived control over emotions: the majority of partners' felt little/no control over their own emotions, or the emotions of their partner

Self efficacy: the majority of participants described low sense of self-efficacy.

Those participants in the minority reported a higher sense of perceived control and self-efficacy.

Moderators

Dispositional coping style: The majority of participants' described their dispositional coping style as information seeking and seeking social support. For the minority of participants they described their dispositional coping style as emotional avoidance.

Dispositional control style: the majority of participants reported generally seeing others (specifically medical professionals) as in control. The minority of participants (specifically those who coped better with chronic pain) viewed themselves as in control in most situations.

Social support: all participants reported having social support (both socially and professionally), but that the social support present did not quite meet their needs.

Figure 2.

Findings applied to the transactional model of stress and appraisal (Lazarus & Folkman, 1984).

Appendix 1-A –

Extract from Reflexive Diary

Interview with Sean

- Sean's experiences were the most negative I had experienced to date. They fit more with what I anticipated, however they were a stark contrast to the three relatively positive interviews thus far.
- During Sean's interview I felt a strong sense of despair and desperation. I almost wanted to end the interview abruptly on several occasions. My feelings seemed to mirror Sean's – wanting to flee from how awful it is but wanting to stay to help and find out more.
- Following Sean's interview I felt a strong urge to cry. I needed an emotional release. Writing in my reflexive journal helped. I then shared my thoughts with my placement supervisor to help make sense of them.
- I was acutely aware at times that Sean's experiences of his wife's chronic pain might mirror some of my family experiences.
- During this interview I found it hard to balance research interview techniques and clinical interview techniques. I felt drawn on several occasions to switch to 'clinical mode' to try and make Sean feel better or to find out more information (that would have been helpful clinically but not for the purposes of my research). I resisted doing this but felt manipulative and uncaring for doing so.
- When Sean's children called him, resulting in the interview being cut short I felt unable to discuss my unease at ending the interview so abruptly. I think this came from my previous feelings of despair, wanting it to end and also knowing his family

were very important to him. I felt I could not keep him from his family for my research purposes.

- The impact on his marriage, especially the rejection and loss of affection and sex seems incredibly important to him.

Interview with Alfonso

- I felt like the interview could have gone better. It felt a little awkward and stilted. I'm not sure if this was because it was my first interview or because of the technological issues at the beginning.
- The interview did not produce the data I was expecting, however it felt ok (and refreshing) to be surprised by Alfonso's responses. His responses did not fit with the literature I have read to date so it will be interesting to see how the other participants respond. I felt eager to interview more people to gain more information and excited that my expectations had been disconfirmed.
- I felt as though Alfonso was wary about discussing the judgement he and Bethan experienced. I got the impression that people perhaps questioned his relationship with her, especially because of the presence of pain. It felt more so that people felt he had an ulterior motive or something to gain from it (perhaps people view him as needy or as someone who likes to look after others) rather than not being able to understand why he would want to start a relationship with someone how was so poorly.
- It seemed that Alfonso was trying to impress me with his ability to care well and this may have led to him downplaying the problems. At times I felt the urge to question or doubt him. I could relate to those people who he says doubt or judge his relationship at times.

Section Three: Critical Appraisal

Reflections on a Research Project Exploring Family Members Experiences of Chronic Illness.

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Word Count: 5726 (including references, tables, figures and appendices)

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This paper will briefly summarise the findings of the research paper and the literature review. It will then explore the limitations and strengths of the research, the importance of the limitations and methods to correct those limitations in future research. Finally, it will identify future avenues of research, explore the importance of gender and reflect on the researcher's role in the project.

The purpose of the review was to synthesise research which had explored mothers' experiences of parenting a child with chronic illness. Thematic synthesis (Thomas & Harden, 2008) revealed four themes. The overarching and pervasive sense of responsibility explored mothers (sometimes reluctant) embracing of responsibility, blaming themselves for their child's illness and feeling solely responsible for their treatment. The altered maternal relationship: the tension between idealised and actual motherhood explored the impact chronic illness has on the maternal relationship. Counting the costs: dismissing one's own feelings to maintain the ability to care detailed the strong emotional reactions mothers experienced as a result of their child's chronic illness and their attempts to cope with those emotions. Finally, becoming the expert describes the process mothers' underwent from uncertainty and incompetence to feeling able to take charge and be the expert.

The purpose of the research paper was to explore partners' experiences of living with someone who has chronic pain. Interpretative phenomenological analysis (IPA, Smith, Flowers & Larkin, 2009) of ten interviews resulted in five themes: (1) the process of acceptance and adjustment; (2) the challenge of accessing effective support; (3) pain as a personal, independent, malignant force; (4) loss and growth in the relationship; and (5) controlling one's awareness as a means of controlling the impact of pain. Due to the previous research exploring the process of acceptance and importance of support in chronic illness (e.g. Fernandez, Reid & Dzuirawiec, 1992; Miller & Timson, 2004; West, Usher, Foster, & Stewart, 2012), themes one and two were not explored beyond their identification. The theme ‘the reciprocity of the spousal relationship and chronic pain’ explored the impact that chronic pain had on the spousal relationship, including physical and emotional intimacy, parenting and communication. It also explored the impact the relationship can have on the experience of living with chronic pain or with a partner with chronic pain. Those participants who identified difficulties in their marriage discussed how those difficulties made surviving pain as a couple more challenging. The theme ‘the personalisation of pain as an independent malignant force’ explored how partners perceived the role of pain in their life and how this affected their ability to cope. Specifically, those partners who personalised pain, and who viewed pain as an independent malignant force discussed struggling more to cope with the role pain has in their life than those partners who did not personalise pain, and who viewed it as an inert part of their life. Finally, the theme ‘the emotional balance between too much and too little information’ explored the way partners controlled the impact of pain by controlling their understanding and awareness of pain. For some partners, information was vital, providing certainty in an uncertain world and providing avenues to seek treatment and strategies to cope and help. For other participants however, being aware of the treatment options, pain trajectory and potential causes was not beneficial. They deliberately avoided developing an awareness of the pain condition as they felt it was unhelpful and hindered their coping. This deliberate lack of awareness extended to their own emotional reactions to being a partner to someone with chronic pain. These partners discussed how in addition to not seeking information out about the pain condition, they also did not dedicate any time or cognitive energy to considering their feelings or reactions to their situation. When this was explored in more depth with participants, their reasons were similar to their reasons for choosing to not seek out information, that being unaware of the ramifications of chronic pain helped them cope.

A comparison of the literature review and research paper

Both the literature review and research paper explore the experiences of similar, vulnerable carers of family members who have a chronic health condition. This raises questions as to the similarities and differences between the two populations and how health psychology models may explain these.

The emotional burden of caring for a family member was evident across both studies. Mothers and partners described this burden as intensely negative and overwhelming. For mothers, there was more concern about the potential for death, although this is likely to be due to the range of illnesses included in the thematic synthesis, compared to chronic pain which is generally not life threatening. Participants across both studies discussed the importance of feeling in control, specifically of the illness, the relationship with healthcare providers and their own emotional responses. For mothers however, this need for control came as an attempt to mitigate, and cope with, the overwhelming sense of responsibility they experienced compared with the male partners of those affected by chronic pain. The importance of information was also discussed across both studies. The emotional burden of being a familial carer, the need for control and the importance of information can be explained by the extensive coping literature, for example, Lazarus and Folkman's (1984) transactional model of stress, appraisal and coping and the self-regulatory model (Leventhal, Nerenz & Steele, 1984; Leventhal, Leventhal & Cameron, 2001).

Despite the similarities between the two populations, there were also some differences. The most significant difference was the personification of pain as a malignant force that desired to personally attack partners of those with chronic pain. This personalisation and personification of chronic pain was strongly evident across the majority of the participants in the research paper. It was however, not evident in any of the papers included in the thematic synthesis. The reasons for this are unclear. It may have been a unique aspect of the sample interviewed. It may also have been due to the method used, the level of depth of analysis, what the researchers chose to focus on during the write up, or the fact that as a researcher exploring original data one understands it in a deeper way than you can during a literature review, where one accesses the data through the researcher's interpretations. This finding was the most novel finding in the research paper and may prove to be an important finding for delivering therapeutic intervention for partners of those with chronic pain. Narrative therapy seeks to help service-users to consider the dominant narratives in their lives, separate the problem from the individual and re-write the narrative in a compassionate and non-blaming approach (Morgan, 2000).

The role of class in partners' participation in the research and adaptation to chronic pain

One interesting observation within the research paper was the role that class played in both recruitment and partners' adaptations to chronic pain. A number of male participants had jobs that could be construed as middle class roles, particularly in business. This allowed them the flexibility to either work from home on the day of our interview, or to manage their schedule to create space to interview during the day. I offered all participants the option to be interviewed via skype or telephone during the evening, but this flexibility in employment certainly contributed to their participation. The only participant I had who expressed and interest and returned consent forms but did not manage to agree an interview time was a woman who worked in a supermarket and who did not wish to be interviewed during the evening but could not manage to be interviewed during her working hours. Additionally, arranging interviews for those participants who did not have flexibility in their employment was much more difficult.

Throughout the interviews, there was a general pattern (although this was not exclusive) that men from more middle class, professional backgrounds reported chronic pain had a greater, more negative, impact on their lives. This appeared partly due to the impact chronic pain had on their traditional gender roles. Specifically, they often had jobs that required travelling for work, evening and weekend social events and working from home. It therefore felt more difficult for these men to take more responsibility for domestic and parenting tasks. Additionally, men reported feelings forced to either cancel social events if their partner was unable to attend with them, or to attend alone, which in turn raised questions from work colleagues. Future research would benefit from exploring the role of class, and its relationship to gender roles, in more detail. Class was not adequately explored in the original literature review articles to be able to thoroughly explore its role in mothers' experiences of parenting a chronically ill child.

Limitations

Gender Imbalance

The empirical study has a number of imbalances in the participant sample. While this is beneficial for IPA, which requires homogeneity (Smith et al., 2009), it does mean the results are limited in terms of recommendations and implications for populations outside of the current study. Further research is required in different populations to produce recommendations appropriate to them. First, the sample of the research paper was comprised of eight men and two women. This reflects the gender imbalance of people enquiring about the research study too, with more men enquiring about participation than women. Of the women who did enquire, but did not participate, time restraints were the most common reason given. Most men who participated worked in jobs which allowed them flexibility in their working day, or were able to work from home and therefore could take part when it suited them. Flexibility around interview times was offered to all potential participants, however the majority of women who enquired about the study either worked shifts or felt they could not make the time to participate outside of their working hours. This reflects the gender difference within the participant group, whereby women were more likely to focus on, and prioritise, the task at hand. It may also be related to the increased prevalence of chronic pain amongst women (van Hecke, Torrance & Smith, 2013).

The experiences for most of the men were very different to those of the two women interviewed. Both of the women interviewed discussed the practical nature of living with somebody with chronic pain but rarely discussed their emotional experiences, even when prompted. The women's attitude towards being a partner to someone with chronic pain was to 'get on with it', with both talking about their seemingly easy acceptance of the chronic pain and its impact. When interviewing the women, I felt there was a sense of acceptance because the alternative, of getting overly upset about it, would cause more problems. With the exception of one of the men (Thomas), the men discussed their experiences very differently. Men explored the emotional impact in much for depth and detail and discussed the challenges, and at times resentment, of having to take on additional household and parenting tasks because of the chronic pain. This is consistent with data suggesting that women with chronic pain are more likely to report family dysfunction compared men (Kyrst & Scherl, 1994).

These differences in gender and why they might have occurred will be discussed in more detail below. However, the gender imbalance within the sample has clearly influenced the results. It was unclear during recruitment that gender would result in such a stark difference, however, the women in the study did share experiences with a minority of men and their experiences were vital for sharing the findings. Future research would benefit from studying men and women separately, and then comparing the findings. This would fulfil the requirement of IPA for homogeneity, while allowing a detailed exploration of gender.

Relationship status variability

All couples recruited identified as heterosexual and married. Great care was taken when developing the recruitment material to ensure diversity in recruitment. For example, *partner* was chosen as it does not have connotations of marriage or sexual orientation. Therefore, it is unclear why the group was homogeneous in respect of the relationships status and sexual orientation of participants. While it is beneficial to the current study that all couples were married, and therefore homogenous, deliberate recruitment of both married and cohabiting partners in separate studies would be beneficial in future research to explore whether experiences differ depending of the type of relationship, will ensuring homogeneity.

No partners currently in a same-sex relationship were recruited into the study, and indeed no homosexual partners approached me for more information about the study or to express an interest. Again, this is beneficial as it ensured homogeneity, but it does mean that results might not be applicable to same-sex couple's experiences. In addition to a lack of homosexual partners participating, no mothers in the articles analysed in the literature review identified themselves as being in a same-sex relationship. It is unclear whether this was due to recruitment strategies or how demographic details were collected. For example, mothers were typically only recorded as married to the biological father, single/divorced/separated from the biological father or in a relationship with another man. It is interesting that no mothers out of 176 identified as lesbian. To my knowledge, articles exploring lesbian or gay partners' experiences of living with someone with chronic pain or homo- or bi-sexual mother's experiences of caring for a chronically ill child have not been conducted. Additionally no articles that I read included any explicitly identified lesbian, gay or bisexual mothers or partners. This may be due to same-sex couples being less likely to have children, however additional research would be beneficial on the experiences of mothers in same-sex relationships.

Recruiting homosexual couples may require purposive sampling and different techniques, such as snowball sampling within the community (McCormack, 2014). It may be that same-sex couples felt that their participation would not be welcomed in the study, or felt uncomfortable approaching me about participating. People who self-identify as lesbian, gay or bisexual experience healthcare provision differently to heterosexual couples (Sabin, Riskind & Nosek, 2015) and that sexual orientation impacts on access to healthcare and risk of chronic disease, mental health and risk of victimization (Conron, Mimiaga & Landers, 2010; Heck, Sell & Sheinfeld Gorin, 2006). This relationship is not simple or well understood but further research exploring their experiences of partnering and parenting is important. Future research could explore, through purposive sampling of people who identify as lesbian or gay and their experiences of chronic illness to build up the evidence base. This in turn would allow for comparisons to heterosexual couples and help healthcare services structure themselves to ensure equitable access.

Social media recruitment

Initially, I had planned to recruit through National Health Services (NHS), online and via face-to-face support groups. Unfortunately, finding a supervisor within an NHS service proved difficult and so Research and Development approval could not be sought within NHS Trusts. Online recruitment was conducted via Twitter, online support groups and forums, and online newsletters or emails distributed by pain charities and support groups. Online recruitment proved incredibly effective, whereas obtaining permission to attend support groups was challenging. It was interesting to me how easy it was to recruit, especially given the difficultly I have had with recruitment of research participants (for a different study completed as part of my Doctorate) in the past, and I spent time reflecting on that throughout the process of completing the study. I believe that the ease of recruitment was perhaps reflective of how under supported partners of those with chronic pain feel. This was corroborated with conversations I had with the participants, and potential participants, in the recruitment process.

While online recruitment proved incredibly successful there are some drawbacks of relying solely on social media and online forums. The vast majority of adults (87.9%) have access to the internet, and use it regularly, within the UK (ONS, 2016b). However, not everybody has access to the internet, and women over 75 and those with a disability are most likely to not access the internet (ONS, 2016b). The current study had a wide age range, although nobody over the age of 63. This may reflect reliance upon online recruitment, however it is difficult to be sure. The use of online recruitment did however, allow me to access participants I would not have been able to meet otherwise due to travelling restrictions. Future research could employ a variety of recruitment methods to ensure those without access to the internet can participate.

Variety of chronic pain conditions and stages

Finally, the participants who took part in the research paper were partners of people with a variety of chronic pain conditions for various lengths of time. In total 10 pain conditions were listed, with one participant's partner being under investigation for either migraines or cluster headaches. The duration of chronic pain ranged from 1.5 to 34 years. The experience of pain is intensely personal and varies from person to person. Additionally, the experience of pain can vary between conditions and at different stages of the diagnosis or pain journey. Given the personal nature of the experience of pain, including the frequency and duration of flare ups and pain experiences, the prognosis and treatments available and the personal impact that has on the individual with chronic pain and their partner, it may be that partners' experiences are heavily influenced by the type of pain condition. While participants shared overall similar experiences, there were differences between participants in the study. For example, Sean's experience of being a partner to somebody with chronic pain was influenced by the fact that doctors had diagnosed his wife with chronic pain, but were unsure of the specific diagnosis. This meant he was consumed at times by trying to find treatments and a diagnosis for her. This is in contrast to Warrior or Trish for example, had chronic pain for much longer, and therefore had achieved a level of acceptance that may be more difficult to achieve when still awaiting a diagnosis (which may bring the potential for a cure or treatment). Additionally, certain pain conditions come with specific challenges or impacts. One treatment for endometriosis for example is a hysterectomy, which raises difficulties for couples wanting to have children. This is a challenge a couple might not face with different pain conditions, suggesting that there may be some unique experiences depending on the pain condition. Future research would benefit from exploring whether partners' experiences of being in a relationship with someone with chronic pain varies between pain conditions and duration of chronic pain.

The importance of gender

As previously mentioned, gender played an important role in both the research paper and the literature review. Within the research paper there was a distinct separation between the experiences of men and women. Additionally, in the literature review, the role of mothers as the primary, and assumed, carer was explored. Mothers felt responsible for their child being ill, no matter what the objective causes were. They felt obliged to take responsibility for caring for their child, even when they did not feel skilled to do so. Additionally, they felt unsupported by health professionals following the acceptance of this responsibility and took complete control over caring for their child. They highlighted fears that nobody knew their child as well as they did and therefore did not trust anyone else with the care of their child. Mothers also discussed the impact the chronic illness had on the maternal relationship, specifically that the lack of physical proximity when the child was hospitalised, especially soon after birth, and the nurses' expertise at caring for their children resulted in women feeling inadequate as mothers.

Gender and roles associated with gender are thus important in both papers. There are multiple theories of how gender roles are formed, and how gender influences our lives. Additionally, it is important to consider that different theories and perspectives are influenced by varying degrees by a multitude of feminist ideologies. Gender is also culturally defined, and many of these theories have been developed within a Western affluent society and therefore will invariably be influenced by that and the definition and importance of gender equality.

The structural functionalist perspective (Parsons, 1951) argues that the labour division based on gender prior to the industrial revolution was functional. However, as women have more opportunity and need to work, this division is less functional, but the perspective of gender based labour division remains. These gender roles are taught through the socialisation process (e.g., Bem, 1981). As a result of these culturally and societally ingrained culture norms, caring is considered ‘women’s business’ (Fisher & Tronto, 1990; Hooyman & Gonyea, 1995). Women are more likely to care than men (Carmichael, & Charles, 2003; Dahlberg, Denmack & Bambra, 2007). For the women interviewed for the research paper, caring for their family members and putting their own needs second is expected of them as women. This therefore may have made the adjustment process easier for the women, resulting in the differing experiences observed. It may also explain why mothers in the literature review felt an obligation to care for their chronically ill child and a need to be responsible and in control of the care provided. However, despite a gender bias in caring, it is important to note that caring is becoming a less gendered activity. For example men are becoming more involved in childcare (Livingston & Parker, 2011), men are more likely to care than they were in the past (Carmichael & Charles 2003), male spousal carers are equally important (Hirst, 2001) and that, at least over the age of 65, there are no gender differences in caring (Ingersoll Dayton, Starrels & Dowler, 1996; Maher & Green, 2002). This must be considered when discussion the role of gender in relation to the adjustment and acceptance of caring in both the literature review and the research paper.

It may be that socialisation and gender roles have conditioned the mothers in the literature review and the wives in the research paper to feel responsible for caring for their loved ones. This sense of obligation may also result in women feeling less able to express dissatisfaction about their caring role. This may explain the practical approach the women took in discussing their experiences as a partner of someone with chronic pain. Additionally, as discussed in Anderson and Elfert (1989), structural sexism exists within society and the healthcare system, that expects women to care for their loved ones and fails to acknowledge the burden of doing so. Anderson and Elfert (1989) go as far as to suggest that the healthcare system relies on these gender roles to financially cover the increasing cost of chronic illness.

Finally, it is important to acknowledge that gender roles also have a negative, or restrictive, influence on men. Pollack (1998 p. 5) coined the term “boy code” and “mask of masculinity” to describe the gender roles American males feel they must follow. Men experience the same restrictions and expectations women experience in terms of what is considered a congruent role for their gender. It is likely that within the research paper, the male participants experienced a sense of incongruence about what their role was as a male. With hindsight, this could have been included in the interview topic guide.

Researcher Reflexivity

The idea for this research project came from reflections within supervision of my experiences on placements during training. Throughout training I have had individual cases which included both physical and mental health, including children and adults. Additionally, I completed a health placement in adult pain management and a paediatric placement (primarily in diabetes and cystic fibrosis). Many family members want to care for their loved ones when they are chronically unwell, despite the impact caring can have. However, throughout my training, one thing which has constantly struck me is how NHS funding streams can create situations whereby family members are encouraged and required to care for their loved ones to relieve pressure on the NHS. Additionally, due to commissioning agreements, the same NHS services that encourage caring cannot always provide support to those carers because they are not the patient and the service is not commissioned to support carers. When support is provided to carers, it has, in my experience at least, always felt like the sole purpose of the support was to provide some benefit to the patient. Caring for a loved one has significant impacts upon multiple facets of a carer's life (Schulz & Sherwood, 2008) and yet for many carers they are unlikely to be able to access support for themselves unless they have significant mental or physical health problems and even then the impact of caring for someone may not be a focus of that support.

Given that family members are not always adequately supported, I wanted to explore the impact of caring from the perspective of multiple family members. The caring literature is a well-developed area of research and yet my experience has been that it does not filter down into NHS services. The idea for the research paper was initially developed while on placement in a pain management service which was considering introducing a 'family day' to its programme. Unfortunately, the service could not support the research project due to staff shortages but the hope is that the research can encourage conversations about how to support partners to care for their loved ones, but also how to support partners to ensure their wellbeing (which will in turn, further increase their ability to care for loved ones). The same applies to the literature review; my aim was to summarise the existing research on mothers experiences to encourage conversations within services about how to best support mothers. The hope is that there will be enough research soon to complete a similar review on fathers' experiences of caring for a chronically ill child and then consider what the similarities and differences are.

The literature review, despite having similar implicit aims to the research paper around guiding services how to support mothers, was not developed with the same level of personal experience, academic interest or emotional investment. Developing a literature review topic was challenging, more so within the time limits required during the thesis. I had attempted to develop several other topic areas first, mostly around chronic pain. I had explored whether a literature review around children's experiences of having a chronic pain condition, children's experiences of having a parent with a chronic pain condition and parents experiences of having a chronic pain condition. I additionally considered exploring women's experiences of pelvic pain. There were however, either published reviews in these areas or not enough qualitative papers in the area of concern. My research interest was always around exploring experiences of chronic health problems and therefore I wanted to conduct a qualitative review. I felt it more important to conduct a review that was robust and of high quality that conduct a review with few research papers that matched my interest. I then began to widen my search to chronic health conditions in general and was initially hoping to complete a review exploring fathers' experiences of having a chronically ill child. I felt this was an important area to explore given that most chronic health research (and indeed clinical practice) is focused around mothers as the main care giver. Unfortunately, there was not enough research to complete a review. I eventually settled on mothers experiences of parenting a child with chronic illness.

Due to my reasons for completing both projects it was difficult at times to prevent myself from over-relating to the participants. In addition to my reasons for completing the research, I had also been through some health concerns both with my child and myself, which made it even more difficult to not over-relate to the participants in both papers. Specifically, during the interviews and analysis for my research paper I often thought about my experience of having post-natal depression and whether my husband's experience was similar to that of my participants. A reflexive journal (see Appendix 2-A) was used to help me monitor this and to process my personal and research based thoughts on the topics. Reflexive journals are recommended within qualitative research to allow the researcher to explore and develop an awareness of how their own life experiences and perspectives may influence their approach to data analysis. While a reflexive journal can help a researcher to develop an awareness of what they bring to the analysis, it can never result in complete detachment from one's beliefs, nor is this recommended (Dahlberg, 2006; Probst, 2015). In addition to my reflexive journal, I also relied on supervision to monitor my involvement with the data and to ensure rigorous, accurate and deep data analysis. My supervisor and I discussed my reflexive journal to identify when I was applying too much of my own opinions to the data. This was incredibly useful and helped further the analysis. A specific example of this is when my supervisor noted that I personified pain within my reflexive journal. Throughout our exploratory discussions it became evident that this was something I had adopted from the participants, but was unaware of. This helped further the theme 'pain as a personal, independent, malignant force'. The dual use of a reflexive journal and supervision helped me ensure that my interpretations were grounded in the data.

Conclusion

In conclusion, this thesis explored specific family member's experiences of chronic health. Specifically, partners of those with chronic pain and mothers of children with chronic health conditions. A key link between both papers was the importance of sex roles for partners and mothers. The conclusions that can be drawn from both papers are restricted by the specific participant sample included. While this can be considered a limitation, it allows for a detailed, in-depth understanding of that specific participant group.

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Section Four: Ethics Section

What are the experiences of caring for a loved one with a chronic condition?

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Word Count: 6900 [1](excluding references, tables, figures and appendices)

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[1] Please note, this word limit has been approved by Dr Suzanne Hodge, Thesis supervisor.

Research Protocol

What are partners’ experiences of living with someone who has a chronic pain?

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Brief Summary

The current study aims to investigate the experiences of partners who live with someone with chronic pain. This project is being completed as part of the Doctorate in Clinical Psychology at Lancaster University.

Background

Pain is defined as an unpleasant sensation associated with either actual or potential tissue damage which often also includes an emotional response. (International Association for the Study of Pain; IASP, 1986). Chronic pain is considered to be pain without a biological cause, which has continued beyond the expected healing period (IASP, 1986). The length of time considered a normal healing period ranges from 3-6 months. Within the UK, it is estimated that 6.4% of the population are currently experiencing chronic pain (Department of Health, 2010). Chronic pain is associated with numerous negative consequences including emotional distress, low mood, anxiety, depression, low self-esteem, fatigue/lack of sleep, quality of relationships, lack of sexual intimacy in relationships, employment prospects and level of daily activity (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006; Kress & Kraft, 2005; Pizzi et al., 2005; Smith, 2003; Thomsen, Sorensen, Sjogren & Eriksen, 2002).

A modest evidence base of qualitative research now exists on the experience of living with chronic pain from a patient's perspective. A meta-synthesis of this research found that the impact of chronic pain could be summarised in four broad themes: the impact on self; relationships with significant others (in the meta-synthesis significant others was used to describe people's relationships with those who provide medical support); relationships with family and friends and coping with chronic pain (Snelgrove & Liossi, 2013). Specifically, the disruption of a normal family life or social life, and their roles within their family and social life were particularly challenging for people with chronic pain. Additionally, participants reported fearing they were burdensome to their loved ones. Participants' reports of social support and social acceptance of their pain varied within the meta-synthesis, with some reporting a sense of mutual spousal support (Mason, 2004) and others reporting that judgemental attitudes were common from loved ones (e.g., Corbett, Foster & Ong, 2007).

Given that the impact of chronic pain on partners is well documented from the perspective of those experiencing chronic pain (e.g. Snelgrove & Liossi, 2013), it is important to understand the impact of chronic pain on the partners from their own perspective. Additionally, it is well documented that significant others can be influential in shaping health related behaviours and pain-related cognitions in their loved ones (e.g. Butterfield & Lewis, 2002; Forgeron, Finley & Arnaout, 2005; Leonard, Cano & Johansen, 2006; Riley-Doucet, 2005). West, Usher, Foster and Stewart (2012) interviewed nine partners of people with a diagnosis of chronic pain and analysed their interviews using thematic analysis. They reported four prevalent themes within the data, including family loss (including for example financial loss and the loss of social activities); life changes (for example role reversals and career prospects); emotional impacts (such as anger and fear) and finally future plans (“surviving” the condition and the expected outcomes of the condition). The authors recommended the inclusion of family members within a chronic pain assessment and rehabilitation/treatment programme, which is supported by other recommendations (e.g. NHS Quality Improvement Scotland, 2006). However, for pain management programmes and other health professionals to support family members and significant others adequately, the impact and experiences of living with someone who experiences chronic pain must be fully understood.

The proposed study aims to expand upon West et al.’s (2012) study by investigating the impact of chronic pain on partners who live with the person with chronic pain. The current study will build upon West et al.’s analysis, which used an interpretative and inductive thematic analysis, by using IPA. This will allow a higher level of analysis to be conducted, therefore furthering the understanding of the experience of partners of those with chronic pain. It will also widen the evidence base by using a UK sample, more specifically those whose chronic pain has required a referral to a pain management programme.

Method

Research Design

The study will use interpretative phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2009) to analyse the data obtained via one to one semi structured interviews.

Participants

Participants will be recruited through chronic pain support groups, the British Pain Society, online pain forums and via social media including twitter and Facebook. The study aims to recruit up to 14 participants using the inclusion/exclusion criteria below.

Inclusion criteria:

- The individual is cohabiting in a romantic relationship with someone with a chronic

- pain condition;
- They are currently aged 18 years old or older;
- They have been in a relationship for a minimum for 12 months;
- They are fluent in written and spoken English.

Exclusion criteria:

- The person with chronic pain must not have pain as a temporary side effect of medical treatment (for example as a result of chemotherapy).

Recruitment Procedure

The study will not use NHS sites to recruit people but will instead recruit people through online recruitment and attending support groups. There were concerns that recruiting through NHS sites might prove difficult and alternative recruitment strategies were more likely to ensure an adequate sample size is reached. Ethical approval will therefore be obtained through Lancaster University. Should a support group/charity have a R&D department then the study will obtain approval from the relevant R&D department, however, it is anticipated that the likely sources of recruitment will not have R&D departments.

Once ethical approval is obtained recruitment will commence. Due to the difficulties in recruiting partners directly, the recruitment strategy will focus primarily on support groups, websites, forums etc. for those who experience chronic pain themselves. Those people will then be encouraged to pass the information on to their partners' to consider. A variety of simultaneous recruitment strategies will also be used due to the difficulties in contacting partners of those experiencing chronic pain. The various recruitment strategies and the steps the researcher will take during each strategy are outlined below.

1. **Social media (twitter).** The rules of the group will be followed. The researcher will set up a twitter account using a Lancaster University email address. The researcher will then search for chronic pain groups and groups/individuals who may have contact

with those with chronic pain. These groups may include but are not limited to support groups and interest groups for example. The study information and recruitment poster will be uploaded to a website and a link to this webpage will be tweeted on a regular basis. Groups and individuals will also be contacted asking if they would be willing to tweet the recruitment information. These groups and individuals will also be asked to distribute the recruitment information in any other way they can. This may include for example newsletters, email lists, tweets, Facebook groups and forums. The researcher will contact people on a regular basis to ask them to distribute the information again. Potential participants will be required to contact the researcher by text/phone call/email/post to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or posted to them.

2. **Online groups**. These groups may include but are not limited to support groups/forums (e.g. www.chronicpainsupportgroup.co.uk) and charity/national organisation websites (e.g. www.thepainrelieffoundation.org.uk). The rules of the group will be followed. If an administrator is easily identifiable then the researcher will send an email enquiring whether it would be ok to advertise my study through various means on their website. These means may include, but are not limited to the online forums, email lists or an advert on the website for example. If they agree then a message will be posted will be uploaded and the recruitment poster if appropriate. A link will also be provided to a website containing all of the relevant recruitment information. Once permission is obtained the information will be posted on a regular basis, unless otherwise requested by the administrator. People will also be asked if they would be willing to distribute the recruitment information and webpage link as widely as possible. This may include distributing it to the mailing list, in a newsletter,

via twitter, Facebook, any other online forums or to physically pass it on to people. If an administrator is not clearly identifiable a message will be posted on the forum on a monthly basis. Potential participants will be required to contact the researcher by text/phone call/email/post to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or posted to them.

3. **Physical support groups.** These may include but are not limited to SMILE for example. The rules of the group will be followed. If an administrator/manager is easily identifiable then the researcher will send an email/telephone the person/write to them enquiring whether it would be ok to advertise my study through various means in their group. These means may include, but are not limited to, attending the group to provide recruitment information, displaying posters, sending information out to email/postal mailing lists and asking members to pass information on to relevant people. Once permission is obtained the information will be posted on a monthly basis, unless otherwise requested by the administrator. The researcher will attempt to attend as many meetings as time allows as guided by the members. Recruitment materials will also be left with the manager/administrator to distribute to their members. People will be asked if they would distribute the information and websites in any ways they feel appropriate. This may include Facebook, twitter, online forums, email lists they may be a part of, to friends or family who may be interested, newsletters etc. Potential participants will be required to contact the researcher by text/phone call/email/ post to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or post to them.

4. The study will also be advertised on the DClinPsy website for people to access. During the various recruitment strategies outlined, the researcher will ask people if they know of any other useful sources of recruitment (for example other websites/support groups etc.). Potential participants can self-refer into the study if they have received the recruitment information from other people, assuming they meet the inclusion criteria. A staged recruitment strategy will be used. Firstly, participants from the north west of England will be recruited. Due to the demands of the DClinPsy course and personal commitments it will be difficult for the researcher to travel long distances for interviews. Prospective participants from the North West will be offered a face to face interview in the first instance. If a potential participant does not wish to take part in a face to face interview they will be offered a telephone or skype interview. If adequate numbers are not achieved the recruitment field will be widened, in the first instance to the rest of the UK, and if necessary worldwide. Participants from outside of the North West will be offered a telephone or skype interview first. If they would prefer to have a face to face interview then the researcher will try and arrange a mutually convenient time around her existing commitments. If participants come forward from outside of the North West initially, a waiting list will be created. It will be explained to participants that the recruitment strategy is primarily focusing on the North West, however if they are keen to be involved their names could be put on a list for the researcher to contact at a later date. Those participants who wish to have a face to face interview, but live outside of the North West, or the UK will be asked if they would consent to being put on a list until a mutually convenient time can be found. Previous research has effectively used skype as a data gathering tool (Hanna, 2012; Svenssona, Samuelssona, Hellstromb & Nolbrisb. 2014), however the use of telephone or skype interviews may pose

technological difficulties and may make it more difficult to elicit quality data from participants. Therefore, the use of a staggered recruitment strategy allows face to face interviews to be prioritised and sought first.

When participants contact the researcher, the researcher will explain the purpose of the study, ensure any questions are adequately answered and arrange a convenient interview appointment. The interviews will take place either at the participant's home or a community venue (library, health centre etc.). Telephone and skype interviews will also be offered to those participants' who would prefer them or who live a substantial distance from the researcher. The lone worker policy will be followed to ensure the researcher's safety. Once at the interview, the study will be explained again, participants will have the opportunity to ask any questions or withdraw from the study. It will be clearly explained that they can withdraw at any point, prior to their interview, and two weeks after their interview, and do not need to give a reason why. They will then be asked to sign the consent form and the interview will commence. At the end of the interview the participant will be given a debrief sheet which contains useful contacts and sources of support. They will have the opportunity to ask any questions. If they wish to be contacted again regarding their interview (e.g. to comment on the transcript, analysis, final report etc.) they can sign a consent for future contact form and provide a preferred means of contact.

The use of skype and telephone interviews.

Previous research has suggested that skype and telephone interviews can be effective methods of data collection (Hanna, 2012; Svenssona et al., 2014). However, the use of these technologies to data collect raises some practical and ethical considerations.

Practically, there are a number of problems that could occur. Phone lines could cut out, internet signal could be lost and the recording device could fail. To overcome these difficulties the researcher will ensure that she has adequate telephone/internet signal. During the communication to arrange an interview time the researcher will also explain to the participant the importance to selecting a comfortable, private and quiet place that has adequate telephone/internet signal. At the beginning of the interview the researcher will explain the procedure should the signal fail or the technology crash. The researcher will explain that it will be her responsibly to reconnect with the participant (whether that be making another phone call or resending a skype communication). If the researcher cannot get back in contact with the participant then they will try again within a few minutes. If after half an hour communication cannot be re-established the researcher will contact the participant using their communication method of choice (for example, email or phone call) and rearrange another date.

The use of technology to conduct long distance interviews also raises some ethical considerations, specifically around safe guarding and responding to distress. Should a participant become distressed during a telephone or skype interview, the researcher will respond empathically. The researcher will stay with the participant, as they would in a face to face interview. If the participant becomes distressed and ends the interview, the researcher will follow the protocol described above for practical issues. If communication cannot be re-established an email or phone call will be made the next day to ensure the participant is ok. The limits of confidentiality will be explained for all participants, however, managing risk and potential disclosures during a long distance interview raises some specific challenges. For those participants interviewed over telephone or skype, it will be explained that for the purposes of safeguarding it would be beneficial for the researcher to have their address. This will then allow the researcher to inform the relevant authorities should it be necessary. If the participant is not willing to disclose their address then the researcher will explain that the interview cannot be completed. As with face to face interviews, the researcher will endeavour to disclose any planned confidentiality breaches, although, as with face to face interviews this may not always be possible. Additionally, should the participant end the phone call or skype conversation the researcher will attempt to reinitiate communication by following the protocol for technical difficulties.

Interview Schedule

Please see the interview schedule for more details. The interview schedule, and the researcher's technique, will be reviewed following the initial interview to ensure the data collected is appropriate and relevant.

Demographics

Please see the demographic details sheet enclosed within this section for more information.

Analysis

After the interviews are completed they will be transcribed verbatim by the researcher. They will be anonymised and a pseudonym chosen by the participant will be used. The interviews will be listened to several times and read several times to allow the researcher to become familiar with the data. As the aim of the research is to explore partner's experiences of living with somebody with chronic pain, IPA has been identified as the most appropriate methodology to use (Smith & Osborn, 2008). IPA will allow the researcher to explore how individuals make sense of, and experience, a specific phenomenon (in this case chronic pain). IPA will be used to analysis the transcripts, specifically using the steps outline by Smith et al. (2009). The transcripts will be read and re-read to ensure the researcher is familiar with the data. This stage also allows the researcher to enter the world of the participant (Smith et al., 2009). Following this stage the data will be explored with a sense of curiosity, particularly focusing on the language used to make sense of their experiences (Smith et al., 2009). This produces emerging themes, which help the researcher to reduce the volume of data now in existence, while maintaining the complexity of the data (Smith et al., 2009). Once themes are developed, the researcher will then explore how the themes are connected. Following this the researcher will then move onto the next case and repeat the previous steps. Finally patterns that occur across the themes producing a final set of themes that encompass the entire data set.

Practical Issues

A mobile phone provided by Lancaster University will be used for potential participants to contact the lead researcher. The researcher's Lancaster University email address will also be used. A twitter account will be set up for the duration of the research project using the researchers Lancaster University email address. Some online forums may require the researcher to set up a profile, in which case the researchers Lancaster University email address will be used. Predicted costs include the researcher's travel (according to LCFT guidance), the production of information packs, potential phone calls to participants' and the participants' travel. Participants will be reimbursed for their travel up to a maximum of £10. The British Pain Society and other organisations may charge for advertisement of the study. For those participants who opt to be interviewed by telephone there will also be the additional cost of the phone call. These costs will be negotiated with the course over the duration of recruitment. The Doctorate in Clinical Psychology course at Lancaster University has agreed to cover appropriate costs.

Data Storage

Lancaster University's policy on data storage will be followed. This can be found at http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinnpsy/new/onlinehandbook/ethics_and_data_storage_advice/

All data collected will be stored on the university server which is password protected. This data includes consent forms, audio recordings of interviews, typed transcripts, future contact forms, demographic forms, etc. Data will also be encrypted. Any paper copies of data (for example consent forms) will be scanned and stored electronically on the university server. The paper copies will be securely disposed. The data will be stored for ten years following the submission of the thesis and then destroyed. The data will be stored by the DClinPsy administrator who will be responsible for both storing and deleting the data. Data which contains personal information which could identify a participant (the list of names and addresses who have consented for future contact) will be destroyed by the researcher once all relevant correspondence has been completed following the submission of the project. Data containing identifiable information will be stored separately on the university server to prevent participants being identified. Any data which contains identifiable information within it will be stored in individual password protected documents.

Ethical issues

The project was peer reviewed as part of the doctoral programme research requirements, which was supervised by members of the research team. Ethical approval will be sought from Lancaster University Research Ethics Committee. Participants will be informed at each stage of recruitment that they can withdraw at any time. It will be explained that they can withdraw at any point during the interview and two weeks after the interview. After seven days the data will have been transcribed and analysed and therefore cannot be removed from the project.

If a participant became upset or distressed they will be offered a short break, or to stop the interview. The researcher can support any distress during the interview and signpost the participant to relevant support agencies including their GP, national helplines, their social network or pain support groups. These will be provided on the debrief sheet. The researcher will be clear that then can offer comfort but they cannot offer clinical advice or support. Should this issue arise they will be directed to the relevant support agencies mentioned above. If a safeguarding concern should arise then the researcher will make a clinically relevant decision as to whether authorities need to be informed or not. If the researcher is unsure about what is the most appropriate decision they will talk to Dr Jane Simpson or Dr Fiona Eccles as supervisors. If they cannot be reached a member of the clinical team on the course will be contacted. If the situation is considered urgent then the researcher will contact the local police/social services/the participants GP if necessary. The limits of confidentiality are explained on the information sheet and will be referred to throughout the interview.

Dissemination

The project will be written up and submitted as a thesis for the Doctorate in Clinical Psychology at Lancaster University. A report will also be prepared for publication in a peer reviewed journal.

Proposed Timescale

January 2015 – August 2015: Prepare and submit a proposal to ethics

September 2015: Receive ethical approval and amendments if necessary

September - December 2015: Data collection and draft writing

January - March 2016: Analyse data and draft writing.

March - April 2016: Finalise drafts and submit to supervisors twice and make amendments

May 2016: Submit thesis

June 2016: Viva

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research involving direct contact with human participants

Instructions [*for additional advice on completing this form, hover PC mouse over 'guidance']*

1. Apply to the committee by submitting:
   a. The University's **Stage 1 Self Assessment (part A only)** and the **Project Questionnaire**. These are available on the Research Support Office website: LU Ethics
   b. The completed application **FHMREC form**
   c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)
   d. All accompanying research materials such as, but not limited to,
      1) Advertising materials (posters, e-mails)
      2) Letters/emails of invitation to participate
      3) Participant information sheets
      4) Consent forms
      5) Questionnaires, surveys, demographic sheets
      6) Interview schedules, interview question guides, focus group scripts
      7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submit all the materials electronically as a **SINGLE email attachment in PDF format** by the deadline date. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.***
3. Submit one collated and signed paper copy of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the FHMREC website. Applications must be submitted by the deadline date, to:

   Dr Diane Hopkins
   B14, Furness College
   Lancaster University,
   LA1 4YG
   d.hopkins@lancaster.ac.uk

5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.
6. Attend the committee meeting on the day that the application is considered, if required to do so.

1. **Title of Project**: What are partners' experiences of living with someone who has a chronic pain condition?

2. **Name of applicant/researcher**: Laura Smith

3. **Type of study**

☒ Includes *direct* involvement by human subjects.

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: LU Ethics. Submit this, along with all project documentation, to Diane Hopkins.

4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters dissertation ☐ DClinPsy SRP ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy Thesis ☒

Applicant Information

5. **Appointment/position held by applicant and Division within FHM** Trainee Clinical Psychologist, DClinPsy

6. **Contact information for applicant**:

E-mail: smithl4@lancaster.ac.uk **Telephone**: 07772075004 (please give a number on which you can be contacted at short notice)

Address: 64 Wingate Road, Kirkby, Merseyside, L33 6UQ

7. **Project supervisor(s), if different from applicant**: Dr Jane Simpson and Dr Fiona Eccles

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**: Dr Jane Simpson – Research Director, DClinPsy, Lancaster University.

Dr Fiona Eccles – Research Lecturer, DClinPsy, Lancaster University.

9. **Names and appointments of all members of the research team (including degree where applicable)**

N/A

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. **Summary of research protocol in lay terms (indicative maximum length 150 words**):

The research aims to explore the experiences of partners of people with chronic pain conditions. Previous research has investigated the experiences of partners of people with a number of other chronic health conditions but not chronic pain. Research suggests that partners influence on a person's ability to adjust to, and accept, their chronic pain condition. It is therefore important to understand the experience of being a partner to a person with a chronic pain condition. The research aims to recruit between 10-15 partners. Participants will be interviewed for approximately 60-90 minutes using a semi structured interview schedule. Their interviews will be analysed using Interpretative Phenomenological Analysis (IPA), which is a type of data analysis which specifically focuses on how people experience phenomenon.

11. **Anticipated project dates (month and year only**)

Start date: June 2015 End date June 2016

12. **Please describe the sample of participants to be studied (including maximum & minimum number, age, gender**):

The study aims to recruit between 10-15 participants. Participants must be living with their partner, in a romantic relationship. They must be over 18 years old; however there is no maximum age limit. They must be fluent in English (although English does not have to be their first language). Participants must have been in a relationship with their partner for over 12 months. Partners of those people whose chronic pain is a temporary result of medical treatment (for example chemotherapy) will not be included in the study. IPA requires participants to be homogenous and therefore it was felt that the experiences of living with someone with a chronic pain condition would be different from the experience of being in a non-cohabitating relationship. Participants will primarily be recruited from the North West of England. Face to face interviews will be offered first, however, if a participant prefers to be interviewed via telephone or skype it will be provided. If recruiting adequate numbers proves difficult, the recruitment field will widened to the UK, and if necessary outside of the UK. Telephone and skype interviews will be offered firstly to those outside of the North West and the UK. If a mutually convenient time can be arranged face to face interviews will be offered throughout the UK. This is to ensure that face to face interviews are prioritised, as the use of telephone interviews or skype interviews can pose technological and ethical difficulties and also may make it difficult to elicit quality data.

13. **How will participants be recruited and from where? Be as specific as possible**.

Due to the difficulties in coming into contact with partners directly, the recruitment strategy will focus primarily on support groups, websites, forums etc. for those who experience chronic pain themselves. Those people will then be encouraged to pass the information on to their partners. Alternatively, they could also pass the information on to others whom they think might be interested in the study. This may be through Facebook, twitter, online forums, newsletters, email bulletins, physical notice boards, word of mouth etc. A variety of simultaneous recruitment strategies will also be used due to the difficulties in contacting partners of those experiencing chronic pain. The various recruitment strategies and the steps the researcher will take during each strategy are outlined below.

1) Social media (twitter). The researcher will search for chronic pain groups within the UK. These groups may include but are not limited to, support groups and interest groups for example. The rules of the group will be followed. If an administrator is easily identifiable then the researcher will send an email/private message on that social media site enquiring whether it would be acceptable to advertise my study. If they agree then a message will be posted (see appendices for social media recruitment information). Once permission is obtained, the information will be posted on a regular basis, unless otherwise requested by the administrator. If an administrator is not clearly identifiable,

a message will be posted on a regular basis, without permission from an administrator. Potential participants will be required to contact the researcher using their preferred method of contact (text/phone call/email/post) to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or posted to them.

2) Online groups. These groups may include but are not limited to, support groups/forums (e.g. www.chronicpainsupportgroup.co.uk) and charity/national organisation websites (e.g. www.thepainrelieffoundation.org.uk). The rules of the group will be followed. If an administrator is easily identifiable then the researcher will send an email enquiring whether it would be acceptable to advertise the study through various means on their website. These means may include, but are not limited to, the online forums, email lists or an advert on the website for example. If they agree then a message will be posted (see appendices for online recruitment information). Once permission is obtained, the information will be posted on a regular basis, unless otherwise requested by the administrator. If an administrator is not clearly identifiable, a message will be posted on the forum on a monthly basis without seeking permission from an administrator. Potential participants will be required to contact the researcher using their preferred method of contact (text/phone call/email/post) to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or posted to them.

3) Physical support groups. These may include but are not limited to, SMILE for example. The rules of the group will be followed. If an administrator/manager is easily identifiable then the researcher will send an email/telephone the person/write to them enquiring whether it would be acceptable to advertise the study through various means in their group. These means may include, but are not limited to, attending the group to provide recruitment information, displaying posters, sending information out to email/postal mailing lists and asking members to pass information on to relevant people (see appendices for physical support group recruitment information). Once permission is obtained, the information will be posted on a monthly basis, unless otherwise requested by the administrator. The researcher will attempt to attend as many meetings as time allows, as guided by the members. Recruitment materials will also be left with the manager/administrator to distribute to their members. Potential participants will be required to contact the researcher using their preferred method of contact (text/phone call/email/Facebook private message/post) to discuss the project in more detail and arrange an interview date. A copy of the information sheet will be provided either via email, website or posted to them. During the various recruitment strategies outlined above the researcher will ask people if they know of any other useful sources of recruitment (for example other websites/support groups etc.). The researcher will also ask if people could pass the information on, for example to any Facebook groups they belong to, via twitter, email lists, online forums, newsletters etc. Potential participants can self-refer into the study if they have received the recruitment information from other people, assuming they meet the inclusion criteria. Once participants contact the researcher, the researcher will explain the purpose of the study, ensure any questions are adequately answered and arrange a convenient interview appointment. The interviews will take place either at the participant’s home or a community venue (which are currently to be arranged). The lone worker policy (see appendices) will be followed to ensure the researcher’s safety.

14. **What procedure is proposed for obtaining consent**?

Participants are likely to be recruited through their partner who has a chronic pain condition. Information about the study will be disseminated as outlined in question 13. People will then be asked to pass that information on to their partners, or people whom they think may be interested in the study. If the participant would like to participate they will be asked to contact the lead researcher, Laura Smith, using the contact details provided. The lead researcher will explain the purpose of the study, provide additional information if necessary and then explain the process of consent. It will be explained to participants that they do not have to consent to take part and that they may withdraw at any time prior to their interview, and two weeks after their interview without giving a reason. An appointment will be arranged to interview the participant and at that appointment the lead researcher will explain the project again, ensure any questions are adequately answered and then ask the participant to sign and date the consent form.

15. **What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.**

There are no anticipated risks associated with the study. The interview is expected to take between 60-90 minutes, which may place a burden or inconvenience upon participants' time. However, it is hoped that as participants will opt to take part, they will only do so if they feel they have the time to commit to the research project. The topic of the research is a sensitive and potentially emotionally laden topic. The interview schedule (see appendices) has been designed to ask open ended questions around several broad areas of interest to the researcher. The open ended and non-specific nature of the questions allows participants to provide as much or as little information as they feel comfortable doing so. It will be made clear to all participants that they do not have to answer the questions asked and that if they do not wish to answer a question the researcher will not pursue a reason for that decision. The lead researcher is training to be a clinical psychologist and therefore has been trained to deal with emotionally sensitive situations in a professional and compassionate manner. Time will be provided at the end of the interview to discuss anything the participant may have found distressing. There will be time to answer any questions and a thorough debrief will take place. For participants who are being interviewed via telephone or skype there is the potential inconvenience of having to download skype (if they do not already have it) and be able to access a telephone or computer with internet access during the interview. The researcher will phone the participant so that the participant does not incur financial costs due to the interview. Additionally, participants will be advised to find a quiet and private place to be interviewed which may be an inconvenience.

In the event of a disclosure from participants that requires follow up, the university guidance will be followed and support will be provided from Dr Jane Simpson or Dr Fiona Eccles. In all cases of disclosure, the lead researcher will consult initially with Dr Jane Simpson or Dr Fiona Eccles to discuss the next step in dealing with the disclosure. If they are not available a member of the Doctorate in

Clinical Psychology clinical team will be consulted. The limits of confidentially are fully explained in the participant information sheet and will also be discussed when obtaining consent at the beginning of the interview. If possible, it will be made clear to the participant that the lead researcher will have to discuss the disclosure with another person, however, researcher discretion will be used to determine the urgency of the disclosure. Support for the lead researcher in the event of a disclosure will be provided through supervision from Dr Jane Simpson and Dr Fiona Eccles. A protocol is in place to manage any disclosure difficulties that occur due to the potential communication difficulties of dealing with disclosures during interview over skype or telephone. The participant will be required to provide their home address prior to the interview. This is to ensure that the researcher has adequate details to pass on to the relevant authorities should it be necessary. If the participant hangs up or disconnects from skype when discussing a disclosure the researcher will try to contact them again. If the researcher cannot get back in contact with the participant then they will try again within a few minutes. If after half an hour communication cannot be re-established the researcher will contact the participant using their communication method of choice (for example, email or phone call) and re-arrange another date.

16. **What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take**).

Participants will be offered the opportunity to be interviewed in the community or in their own home. This therefore poses some risk to the researcher due to lone working considerations. A lone worker policy has been developed, which draws upon Lancashire Care Foundation Trust's lone working policy (the Trust is the employer of Laura Smith) and the Lancaster University lone working policy. Once an interview has been scheduled, Laura Smith will email Dr Jane Simpson and Dr Fiona Eccles explaining the location and the time of the interview. These emails will ascertain whether Dr Jane Simpson or Dr Fiona Eccles will be available to act as a "buddy" and to provide safeguarding guidance should it be required. If Dr Jane Simpson or Dr Fiona Eccles are unavailable, Laura Smith will contact a member of the clinical team or a fellow trainee on the course to act as a buddy and to provide safeguarding guidance should it arise. The LCFT and Lancaster University lone working policies are included for further information.

17. **Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study**.

Participants may find their participation interesting and they may benefit from contributing to research and service development, however there are no anticipated benefits to participants for this study.

18. **Details of any incentives/payments (including out-of-pocket expenses) made to participants**:

There will be no payment available for taking part in the research. Participants will be reimbursed for their travel up to a maximum of £10.

19. **Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality**.

Data will be collected via approximately 60-90 minute interviews using open ended questions (see appendices). These interviews will take place by face to face interview, telephone calls or skype calls. A staggered recruitment strategy will be used to try and prioritise face to face interviews. The lead researcher, Laura Smith, will then transcribe the interviews and analyse them using IPA. IPA was selected as it specifically looks at peoples experiences of a phenomenon (in this case, living with someone with chronic pain) and how people make sense of that experience. This made IPA the most appropriate method of analysis for the research question.

Participants will be asked to choose a pseudonym to ensure their anonymity in transcripts.

Protecting confidentiality

Face to face interviews: Participants will be given the choice of whether the interview takes place in their own home or in a community venue. It will be explained to participants that their personal details (including their name, address etc.) will be confidential. However, it will also be explained that confidentiality cannot be kept if the researcher is worried that they, or others, are at risk of harm (either by self or others). It will be explained that the researcher will do everything possible to ensure they are aware of the breach of confidentiality and included in all stages, however this may not be possible. Participants will be informed that in the first instance the researchers academic supervisors will be informed (Dr Jane Simpson and Dr Fiona Eccles) and if they are not available a member of the clinical team at university. It will be explained that members of staff are bound by the same limits of confidentiality as the lead researcher.

Telephone/skype interviews: the same process as detailed above will be followed. However, due to the long distance nature of the interviews some amendments will be made. It will be explained to participants that for safeguarding reasons they will be required to provide their address to the researcher in case a safeguarding disclosure needs to be made. As participants have the opportunity to stop the interview by disconnecting the telephone or skype, there is a protocol in place to try and re-establish communication. The lead researcher will try and contact the participant for half an hour. If contact is not made, advice will be sought from the supervisors or a member of the clinical team. An email or phone call will also be made the next day to try and make contact. If possible a message will be left requesting they contact the researcher immediately.

20. **If relevant, describe the involvement of your target participant group in the *design and conduct* of your research**.

Although service users have not been consulted, several professionals who specialise in chronic pain have been consulted on multiple occasions throughout the process of developing this research.

21. **What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998**.

Interviews will be audio recorded to allow for accurate transcription. Lancaster University's data storage policy will be followed (http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinnpsy/new/onlinehandbook/ethics_and_data_storage_advice/) All data collected will be stored on the university server which is password protected. This data includes consent forms, audio recordings of interviews, typed transcripts, future contact forms, demographic forms, etc. Data will also be encrypted. Any paper copies of data (for example consent forms) will be scanned and stored electronically on the university server. The paper copies will be securely disposed of. The data will be stored for ten years following the submission of the thesis and then destroyed. The data will be stored by the DClinPsy administrators who will be responsible for both storing and deleting the data. Data which contains personal information which could identify a participant (the list of names and addresses who have consented for future contact) will be destroyed by the researcher once all relevant correspondence has been completed following the submission and completed assessment of the project. Data containing identifiable information will be stored separately on the university server to prevent participants being identified

22. Will audio or video recording take place? ☐ No ☒ audio ☐ video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews will be audio recorded to allow for accurate transcription. Lancaster University's data storage policy will be followed (http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinnpsy/new/onlinehandbook/ethics_and_data_storage_advice/). The data will be stored for ten years following the submission of the thesis and then destroyed. The data will be stored by the DClinPsy administrator who will be responsible for both storing and deleting the data. As the audio recorder cannot be encrypted any audio recordings will be transferred to a password protected computer and stored on the university server as soon as possible. The audio recorder will be stored securely until the recordings can be transferred.

23. **What are the plans for dissemination of findings from the research? If you are a student, include here your thesis**.

The research will be submitted as a thesis for the Doctorate in Clinical Psychology. It will also be submitted for publication. The researcher will also seek out opportunity to present the findings in other forums (e.g. Special Interest Groups and conferences as applicable).

24. **What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC**?

As previously stated, the researcher will ensure that the participants understand what they are taking part in and that they can withdraw at any time. Should a participant become upset the researcher will offer the participant a break and clarify whether they wish to continue with the interview. Should they become distressed this can be discussed during the interview. A list of appropriate support will be provided on the debrief sheet. Should the participant request clinical advise they will be directed to the debrief sheet. As previously stated should a safeguarding concern be raised, the researcher will seek support from Dr Jane Simpson or Dr Fiona Eccles. If they cannot be reached the researcher will seek support from a member of the clinical team at university. Should the concern be urgent the researcher will ring the police or local social services if necessary. The limits of confidentiality are clearly explained on the participant information

Signatures: Applicant: ……………………………………………………………………………………..

Date: ………………………………………………………………………………………………

*Project Supervisor (if applicable): ………………………………………………….....

Date: ………………………………………………………………………………………………

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

References

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Appendix 4-A

Information to be posted on forums/online support group

Hi,

My name is Laura Smith and I am a trainee clinical psychologist. I'm conducting some research as part of my doctorate in clinical psychology and was hoping you could help. I'm looking at the experiences of partners of somebody with chronic pain.

So why do the research? We know that partners play a hugely influential role in supporting somebody with chronic pain and that partners can influence how well somebody with chronic pain copes. It would be beneficial therefore to understand partner's experiences of chronic pain so that services can help support partners and help partners support the person with chronic pain so that professionals can better understand the impact of chronic pain upon partners.

I'm interested – what next?

- **If you are a partner of somebody with chronic pain** and you live together, you can click on the link below for more information. If you're happy to take part then contact me on the details below and we can arrange to meet up for an interview. It will last approximately an hour although we can take as little or as much time as you like.
- **If you are somebody who experiences chronic pain** but you think you know someone who would be interested in taking part, then please do pass this information on to them and they can contact me on the details provided.

You can follow me on twitter (xxx)

Link to participant information sheet.

Laura Smith

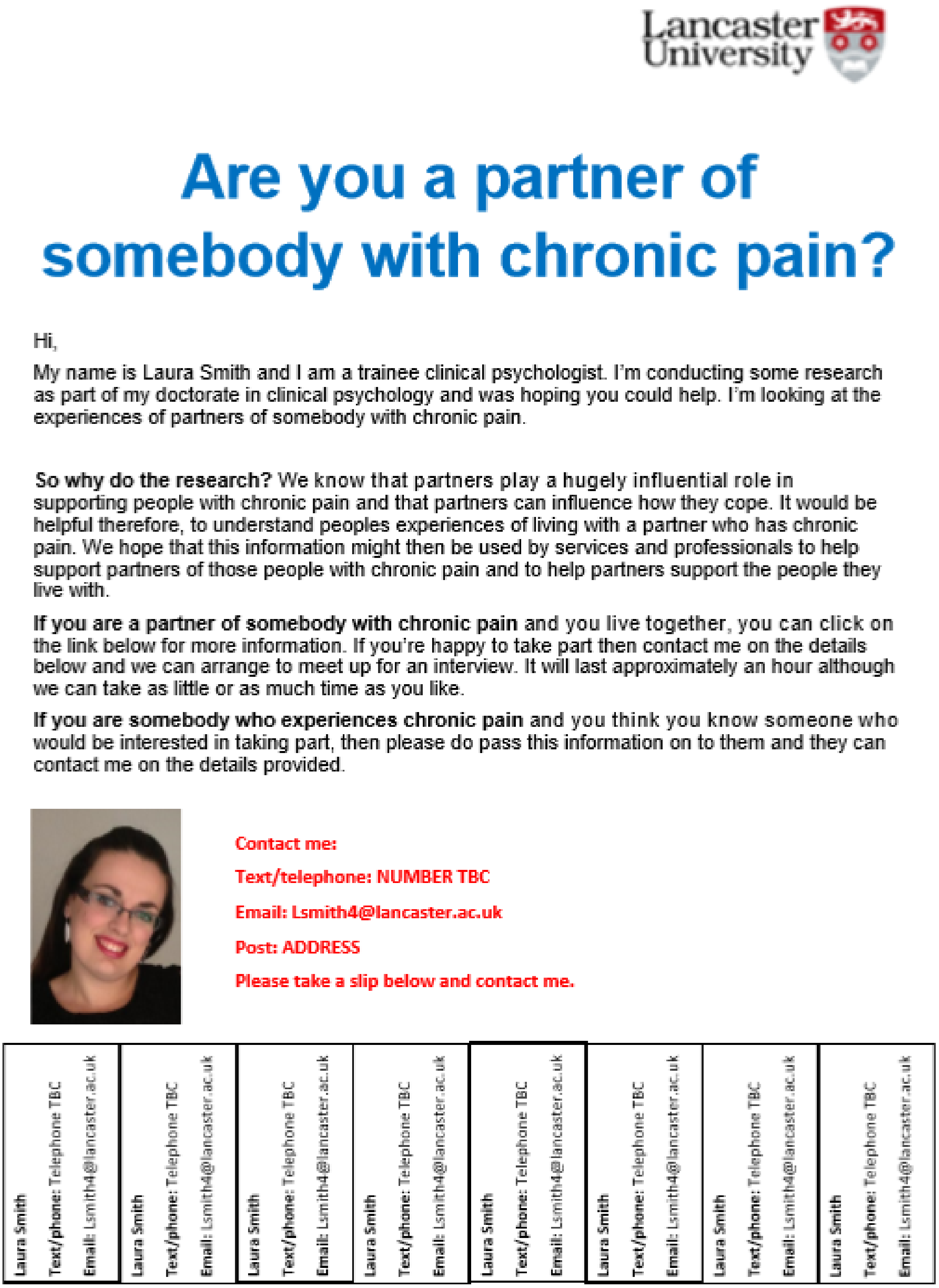
Telephone/Text: Number TBC

Email: Lsmith4@lancaster.ac.uk

Postal address: INSERT ADDRESS

Appendix 4-B

Recruitment Poster



Lancaster University

Are you a partner of somebody with chronic pain?

Hi,

My name is Laura Smith and I am a trainee clinical psychologist. I'm conducting some research as part of my doctorate in clinical psychology and was hoping you could help. I'm looking at the experiences of partners of somebody with chronic pain.

So why do the research? We know that partners play a hugely influential role in supporting people with chronic pain and that partners can influence how they cope. It would be helpful therefore, to understand peoples experiences of living with a partner who has chronic pain. We hope that this information might then be used by services and professionals to help support partners of those people with chronic pain and to help partners support the people they live with.

If you are a partner of somebody with chronic pain and you live together, you can click on the link below for more information. If you're happy to take part then contact me on the details below and we can arrange to meet up for an interview. It will last approximately an hour although we can take as little or as much time as you like.

If you are somebody who experiences chronic pain and you think you know someone who would be interested in taking part, then please do pass this information on to them and they can contact me on the details provided.

Contact me:

Text/telephone: NUMBER TBC

Email: Lsmith4@lancaster.ac.uk

Post: ADDRESS

Please take a slip below and contact me.

Laura Smith
Text/phone: Telephone TBC
Email: Lsmith4@lancaster.ac.uk

Laura Smith
Text/phone: Telephone TBC
Email: Lsmith4@lancaster.ac.uk

Laura Smith
Text/phone: Telephone TBC
Email: Lsmith4@lancaster.ac.uk

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Laura Smith
Text/phone: Telephone TBC
Email: Lsmith4@lancaster.ac.uk

Laura Smith
Text/phone: Telephone TBC
Email: Lsmith4@lancaster.ac.uk

Appendix 4-C

Participant information sheet

Particpant Information Sheet

Study Title: What are partners' experiences of living with someone who has a chronic pain condiiton?

Hi. My name is Laura Smith. I'm training to become a clinical psychologist and I'm doing this study as part of my training course at Lancaster University.

Please read this leaflet before deciding whether you want to take part. If there is anything you are unsure about, you can contact me.

What is the study about?

The study is looking at the experiences of partners of people with a chronic pain condition. I would like to hear about your experiences. This research can then be distributed within the academic and professional field and can be used to help increase the understanding and awareness of partners' experiences. This research may be used to help services to help support you and your partner Please be assured, this study is not connected to any NHS services provided to those with chronic pain and so will in no way affect the services offered to you or your partner.

Do I have to take part?

No. If you don't want to that is ok and it won't affect your ability to get help from NHS services or support groups.

I’m happy to take part. What happens next?

How to contact the researcher?: you can contact me either by phone/text, email or by post on the details provided. I will then contact you and arrange an appointment to interview you.

Where/how will I be interviewed? Interviews can be conducted in person (either at your home or a local community venue near your home), via telephone or via skype. It is up to you to decide which method of interview you would prefer. If you live too far for me to travel to you at a mutually convenient time, telephone or skype interviews will be required.

How long will it last? The interview will last approximately 60-90minutes. Some interviews may take more or less time and that is ok.

What will happen before the interview? Before the interview starts I will go through this information sheet with you again and you will be able to ask any questions you may have. I will then go through a consent form with you, which asks several questions to ensure you fully understand what you are consenting to. You do not have to provide consent to take part, however, without consent the interview cannot occur.

What questions will the interview ask? The interview will explore your experience of living with a partner who has chronic pain. Some of the broad areas we may discuss are the impact of pain on you, the impact pain has on various relationships and how your experiences have changed over time.

Recording the interview: The interview will be audio recorded. If we meet face to face, or via skype a Dictaphone will be used. If we have a telephone interview there is a device which is used to record our phone conversation. This is to ensure I can accurately transcribe your interview afterwards.

Confidentiality of the interview: During transcription your personal details (for example your name and where you live) will be anonymised. You will be asked to choose a pseudonym. This is to ensure that people cannot identify you by name. **After the interview:** I will transcribe our conversation and then analyse your data, along with the other interviews I will have collected. This analysis will then be written up into a research report which will be part of my doctoral thesis. It will also hopefully be published and distributed in various forums (for example conferences and pain related special interest groups).

What if I change my mind after saying I want to take part?

You can change your mind about taking part whenever you want and you don’t have to give a reason why you changed your mind. If you change your mind, it won’t stop you obtaining any medical treatment or support from NHS services or support

groups. You can change your mind after we have completed the interview however, if you change your mind more than two weeks after our interview, your data will still be included in the study. This is because it will have already been pooled with the other interviews I will have collected and analysed, making it difficult to separate your interview data from other people's.

Will my data be confidential?

The information you provide is confidential and anonymous. Your information will be kept safe on a password protected computer. When the study is finished, my University will keep copies of the typed interviews and the audio recordings on an encrypted and password protected computer network. After ten years these will be destroyed. Should you disclose information that causes me concern that you, or another person are at risk of harm I will have to break your confidentiality. I will always try and discuss this with you first and to come to a mutual agreement as to the best course of action. I may also seek support from my research supervisors or a member of the clinical team at Lancaster University as to the best course of action.

What if I say something to you that suggests that there is a danger to myself or somebody else? Is that kept confidential?

If you say something which causes me to be concerned about yours or another’s safety I will have to tell somebody about this. I will always try to make sure I tell you beforehand so that you know what is happening. However, sometimes, if I feel that the risk is urgent then I may not be able to do this.

What will happen to the results? I will type up all of the interviews and then analyse the transcripts and write a report. The report may be published in a journal.

Who has reviewed the study?

This study has been reviewed by Lancaster University Faculty of Health and Medicine Research Ethics Committee and approved by Lancaster University Research Ethics Committee.

Are there any risks to me taking part?

As stated above the Lancaster University Faculty of Health and Medicine Research Ethics Committee and Lancaster University Research Ethics Committee deem this study safe for you to participate in. The topic we will be discussing may be distressing or upsetting for some people. If anything upsets you please do let me know and we can discuss it during the interview. We can stop the interview if you feel it is too upsetting.

Are there any rewards to taking part?

You may find taking part interesting however, there will not be any rewards for you taking part in my study.

Where can I get more information about the study if I need it?

If you have any questions please contact me on the contact details below.

Laura Smith, Trainee Clinical Psychologist,

Telephone Number: TBC

Email address: Lsmith4@lancaster.ac.uk

Postal Address: Laura Smith, c/o DClinPsy programme, Furness Building, Lancaster University, LA1 4YG.

Who are the research supervisors of this project?

Dr Jane Simpson.

Email: J.simpson2@lancaster.ac.uk

Address: DClinPsy, Furness Building, Lancaster University, LA1 4YG.

Dr Fiona Eccles

Email: f.eccles@lancaster.ac.uk

Address: DClinPsy, Furness Building, Lancaster University, LA1 4YG.

Complaints.

If you wish to make a complaint or you are worried about it and you don't want to talk to me, you can talk to:

Prof. Bruce Hollingsworth

Head of the Division of Health Research
594154

Email: b.hollingsworth@lancaster.ac.uk
Furness Building

Lancaster University

Bailrigg

Lancaster

LA1 4YG

Prof. Roger Pickup

Chair of the ethics committee Tel: (01524)
Tel: (01524) 593746

Email: r.pickup@lancaster.ac.uk
Furness Building

Lancaster University

Bailrigg

Lancaster

LA1 4YG

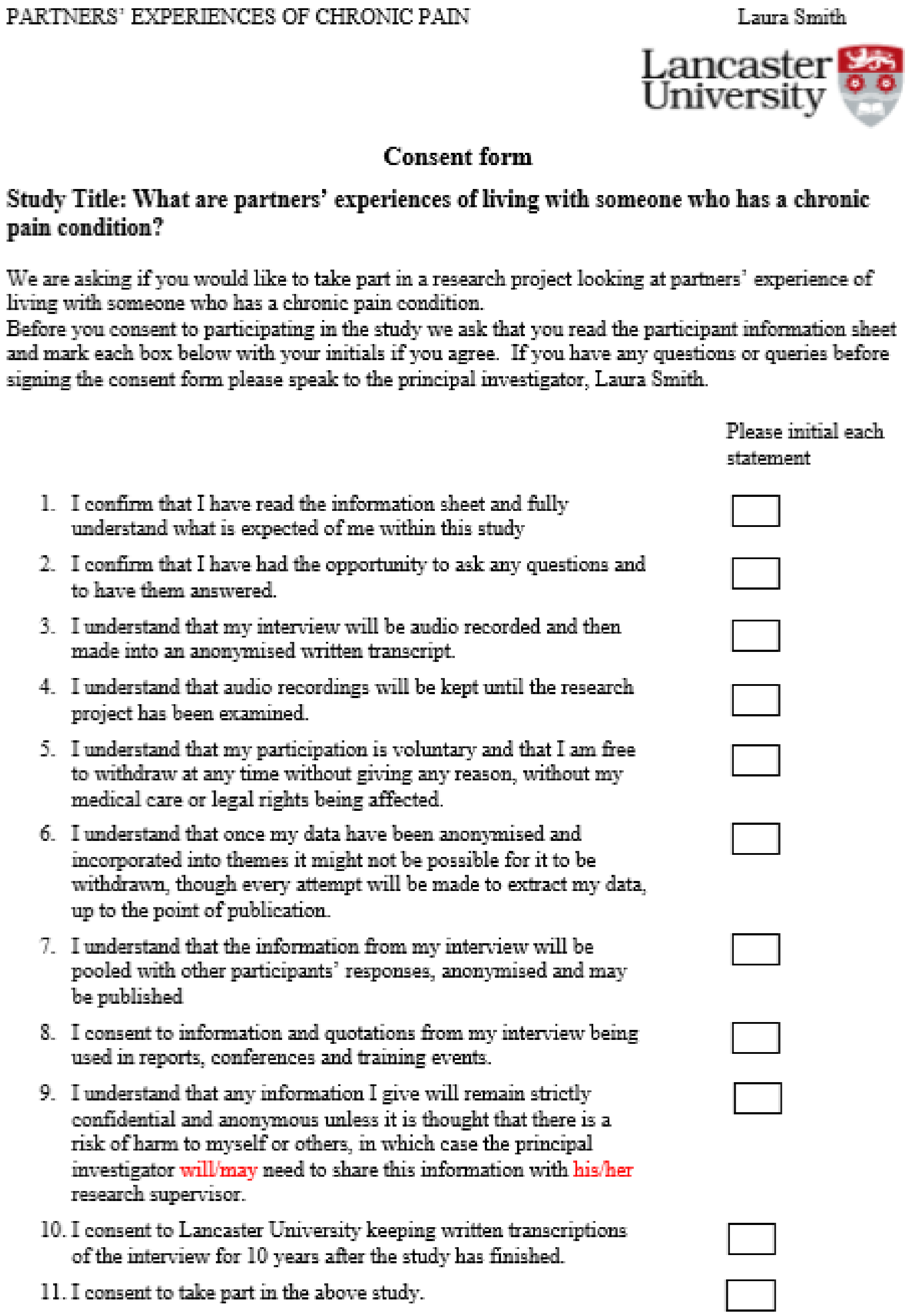
What other help can you get if you feel upset by this study?

Should you feel upset as a result of taking part, please inform me. I will not be able to provide ongoing counselling or support, however we can stop the interview for a short break, rearrange an alternative time or cease your involvement in the study. Alternatively, if you feel you cannot do this, please contact your GP, the Samaritans (08457 90 90 90) or Pain Concern (0300 123 0789).

Thank you for taking the time to read this sheet!

Appendix 4-D

Consent Form



PARTNERS' EXPERIENCES OF CHRONIC PAIN

Laura Smith

Lancaster University

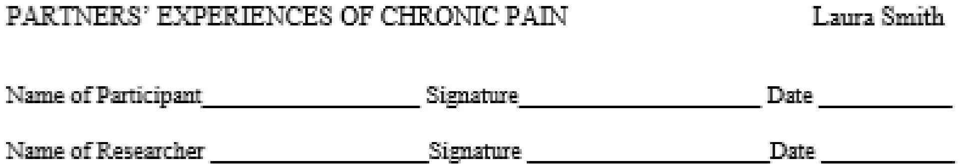
Consent form

Study Title: What are partners' experiences of living with someone who has a chronic pain condition?

We are asking if you would like to take part in a research project looking at partners' experience of living with someone who has a chronic pain condition.
Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Laura Smith.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
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 understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will/may need to share this information with his/her research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I consent to take part in the above study. ☐



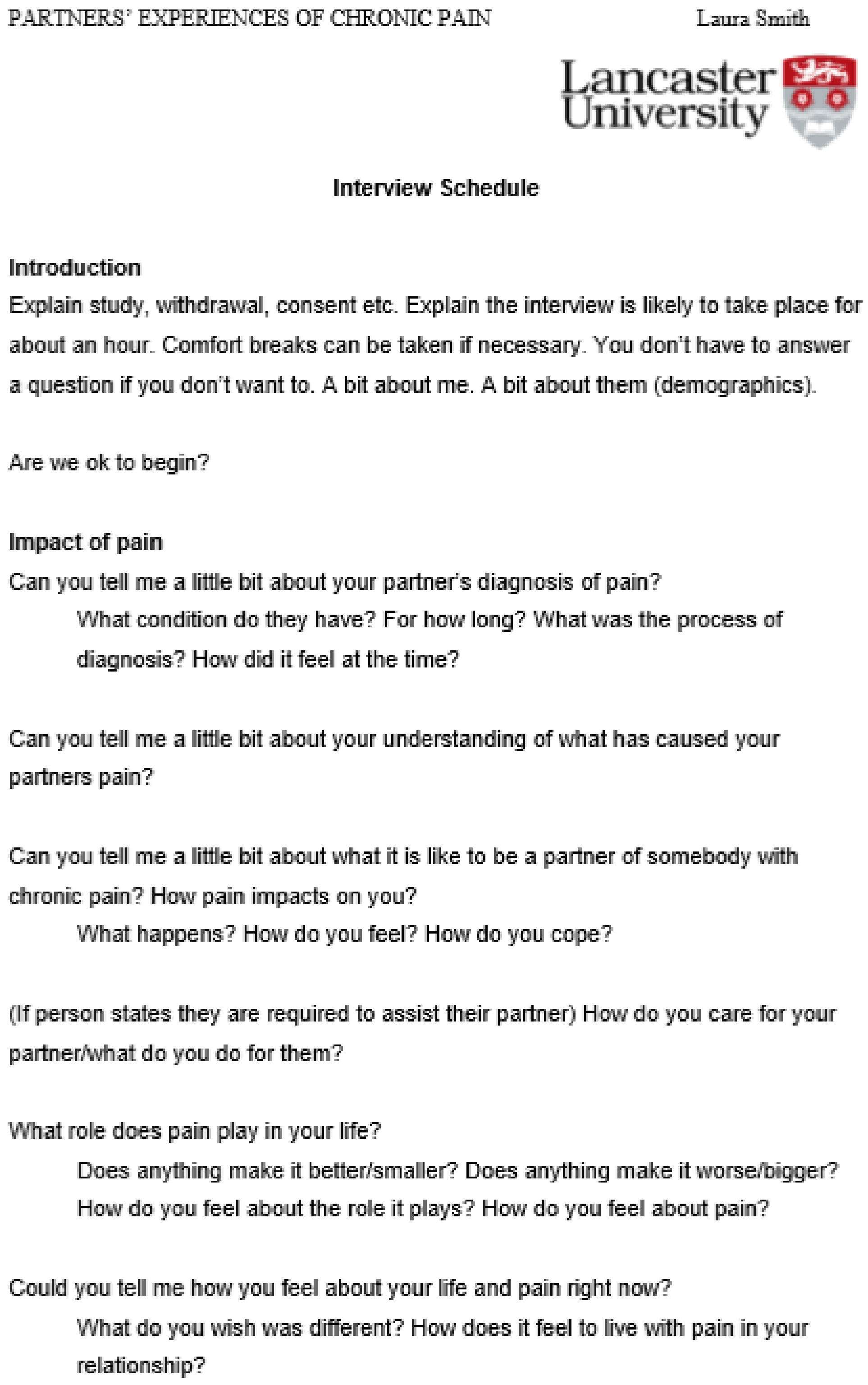
PARTNERS' EXPERIENCES OF CHRONIC PAIN Laura Smith

Name of Participant____________________ Signature______________________ Date ____________

Name of Researcher ____________________Signature ______________________Date ____________

Appendix 4-E

Interview Schedule



PARTNERS' EXPERIENCES OF CHRONIC PAIN Laura Smith

Lancaster University

Interview Schedule

Introduction

Explain study, withdrawal, consent etc. Explain the interview is likely to take place for about an hour. Comfort breaks can be taken if necessary. You don't have to answer a question if you don't want to. A bit about me. A bit about them (demographics).

Are we ok to begin?

Impact of pain

Can you tell me a little bit about your partner's diagnosis of pain?

What condition do they have? For how long? What was the process of diagnosis? How did it feel at the time?

Can you tell me a little bit about your understanding of what has caused your partners pain?

Can you tell me a little bit about what it is like to be a partner of somebody with chronic pain? How pain impacts on you?

What happens? How do you feel? How do you cope?

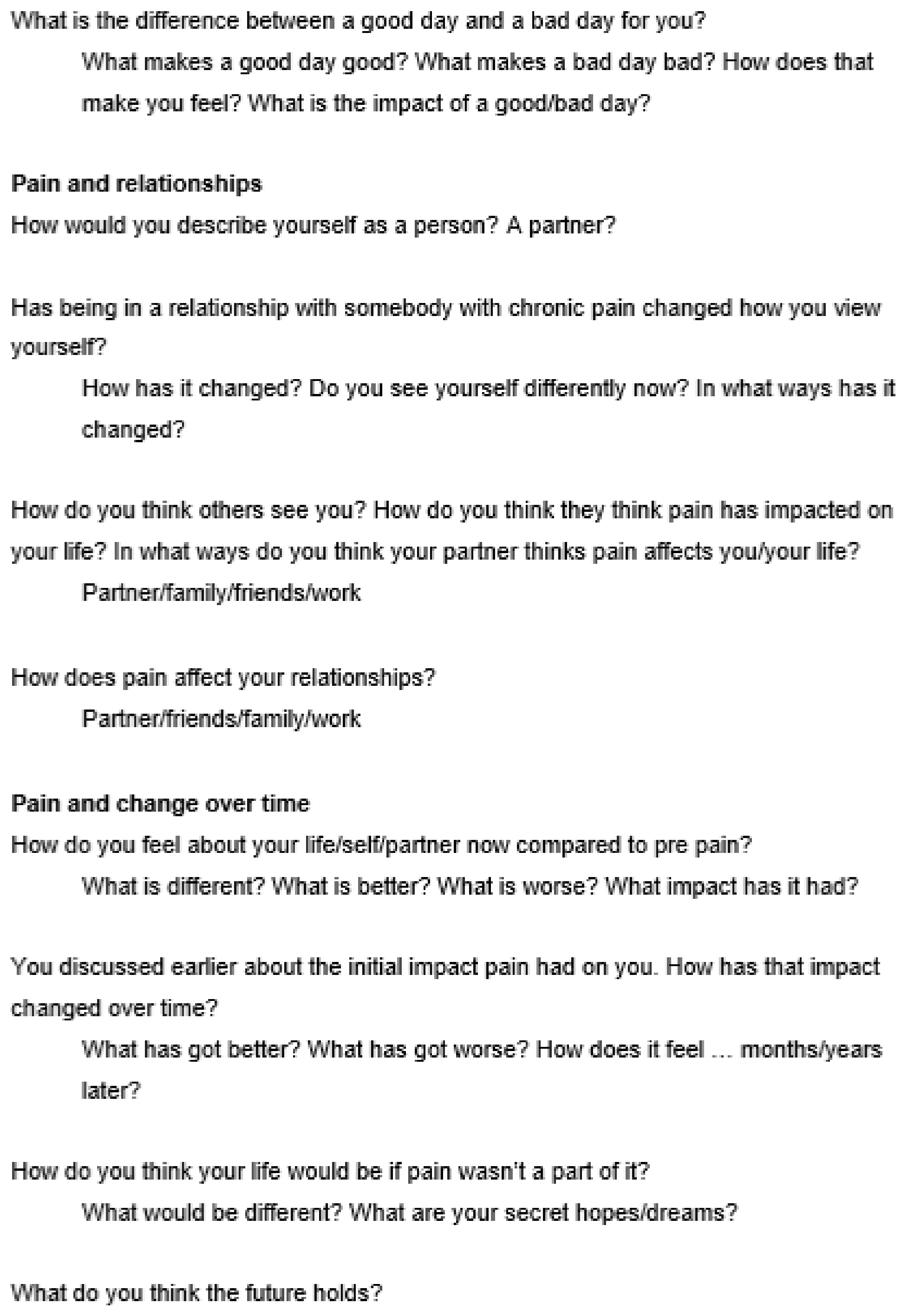
(If person states they are required to assist their partner) How do you care for your partner/what do you do for them?

What role does pain play in your life?

Does anything make it better/smaller? Does anything make it worse/bigger? How do you feel about the role it plays? How do you feel about pain?

Could you tell me how you feel about your life and pain right now?

What do you wish was different? How does it feel to live with pain in your relationship?



What is the difference between a good day and a bad day for you?

What makes a good day good? What makes a bad day bad? How does that make you feel? What is the impact of a good/bad day?

Pain and relationships

How would you describe yourself as a person? A partner?

Has being in a relationship with somebody with chronic pain changed how you view yourself?

How has it changed? Do you see yourself differently now? In what ways has it changed?

How do you think others see you? How do you think they think pain has impacted on your life? In what ways do you think your partner thinks pain affects you/your life?

Partner/family/friends/work

How does pain affect your relationships?

Partner/friends/family/work

Pain and change over time

How do you feel about your life/self/partner now compared to pre pain?

What is different? What is better? What is worse? What impact has it had?

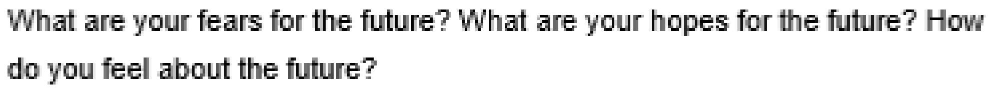
You discussed earlier about the initial impact pain had on you. How has that impact changed over time?

What has got better? What has got worse? How does it feel … months/years later?

How do you think your life would be if pain wasn't a part of it?

What would be different? What are your secret hopes/dreams?

What do you think the future holds?



What are your fears for the future? What are your hopes for the future? How do you feel about the future?

Appendix 4-F

Demographic Details

Please complete the form below. The information provided will help the researcher during the analysis of the data.

Pseudonym:

Participant number:

Age:

Relationship status: *(delete as appropriate)* Married / Cohabiting /

Length of current relationship:

How long have you and your partner been living together?:

What is your partners' chronic pain condition?:

How long has your partner had chronic pain?:

Do you consider yourself to have a chronic pain condition?:

If so, what is your diagnosis?:

Do you have any children with your partner?

If so, how many?

If so, do they live at home?

Thank you for answering these questions.

Appendix 4-G

Debrief Sheet

What are partner's experiences of living with someone who has a chronic pain condition?

This study was investigating the experiences of partners who live with somebody with chronic pain. Research has examined the experiences of people with chronic pain and partner's experiences of various other long term health conditions. Yet there is currently very little known about partner's experiences of chronic pain. Research shows that partners, family members and friends are hugely influential in terms of how people with chronic pain view their pain and respond to pain related interventions. Research also shows that the impact of chronic pain goes beyond the person with chronic pain. I hope to develop an understanding of what it is like for partners of those who experience chronic pain. By interviewing partners of those who experience chronic pain and then analysing all of the interviews together to look for common themes, a comprehensive understanding of what the experiences are of partners can be developed. This project will hopefully provide a foundation for future research to build upon.

This analysis can take a while to complete and require all of the interviews to be included. This means I won't be able to share the results with you now. However, if you would like to see a copy of your transcript, a copy of the provision analysis and/or a copy of the final report I can send them to you for you to comment on.

If you have any further questions you can contact me on:

Lsmith4@lancaster.ac.uk

NUMBER TBC

Laura Smith, Doctorate in Clinical Psychology, Furness College, Lancaster University, Lancaster, LA1 4YG

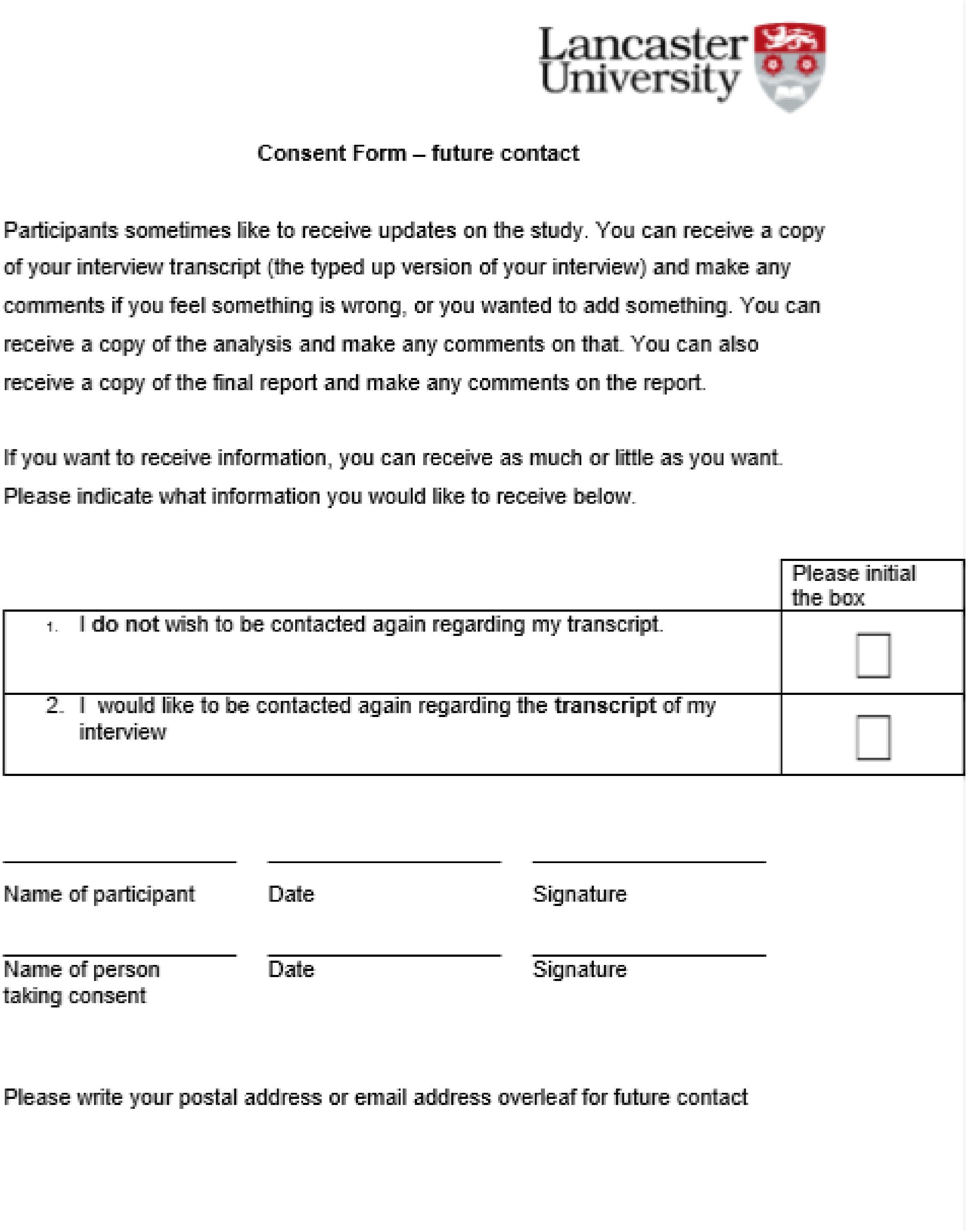
If you feel distressed following this interview, I would recommend talking to friends or family first. If you still feel distressed then you can contact your GP, the Samaritans (08457 90 90 90) or Pain Concern (0300 123 0789).

Thank you very much for your participation in this research.

Laura

Appendix 4-H

Consent for Future Contact Form



Lancaster University

Consent Form – future contact

Participants sometimes like to receive updates on the study. You can receive a copy of your interview transcript (the typed up version of your interview) and make any comments if you feel something is wrong, or you wanted to add something. You can receive a copy of the analysis and make any comments on that. You can also receive a copy of the final report and make any comments on the report.

If you want to receive information, you can receive as much or little as you want. Please indicate what information you would like to receive below.

	Please initial the box
1. I **do not** wish to be contacted again regarding my transcript.	☐
2. I would like to be contacted again regarding the **transcript** of my interview	☐

Name of participant ____________ Date ____________ Signature ____________

Name of person taking consent ____________ Date ____________ Signature ____________

Please write your postal address or email address overleaf for future contact

Appendix 4-I

Correspondence regarding Ethics

Email correspondence between Laura Smith (principle investigator), Suzanne Hodge (ethics committee reviewer) and Diane Hopkins (admin, ethics committee) regarding obtaining consent from a participant who is blind. 3rd – 7th September 2015.

1. Email from Laura Smith to Suzanne Hodge and Jane Simpson

Hi Jane and Suzanne,

I've copied Suzanne in as she was the one who looked at my ethics application and I wasn't sure who was the right person to contact.

I've got a potential participant come forward however we have run into a slight hiccup. She is registered blind and therefore cannot read the information. She has software that reads stuff out for her, but my consent form is causing some problems because of the lay out of it (the tick boxes in particular). She cannot write due to her blindness. She has been able to read some of the documentation (the PIS and demographics form) but the consent form and consent for future contact is the problem. She would really like to take part but we're trying to work out a way for the consent forms to be signed.

The two ideas I've come up with so far is to post the documents and provide an electronic version of just the text for her to use her software to read out. However, he husband would have to sign the documents on her behalf.

Alternatively, I thought I could provide her with electronic copies of just the text in the consent forms and get her to provide an email of written consent (she can type as she uses the same talk-type software I use).

I didn't think about this in my ethics as it hadn't crossed my mind. I did say those requiring interpreters would not be eligible. It seems a little discriminatory of me to exclude her, but I just wanted to check I would be going about getting consent appropriately.

2. Email From Suzanne Hodge to Laura Smith

Hi Laura,

I would definitely get your participant's consent, rather than proxy consent from her husband. The method usually used when people are unable to give written consent is to record their verbal consent on a separate audio file at the start of the interview. Just read through the consent form with them (and state the participant's name at the start) and ask them to confirm that they agree to each of the clauses and to take part. Your suggestion of emailing the consent form beforehand also sounds sensible - maybe do both so she has chance to read it before the interview, then record consent on the day. If you save the file as a separate file you can then store it separately from the interview transcript, as it won't be anonymous.

In terms of the ethics approval process, I would email Di Hopkins to let her know what you intend to do. If necessary she might ask you to submit an amendment, but I think an email should be sufficient.

Email from Diane Hopkins to Laura Smith

Hello Laura – what Suzanne suggests is correct. They key is that you get consent directly from all participants. Simply send me a new email, outlining the situation and detailing what you intend to do (as advised by Suzanne). I will then forward this to UREC for their records.

3. **Email from Laura Smith to Diane Hopkins**

Hi Diane,

As per our previous emails I am sending you an email to detail some changes to my protocol for my thesis project. I have a participant who is legally blind and uses software which reads aloud documents. Due to the layout of the consent form with the boxes for initialling her software cannot read it aloud. I have sought advice from Suzanne Hodge. I have copied the text for the consent form and consent for future contact form into an email for her. This has allowed her to "read" the documentation before she actually has the interview. Because she cannot sign the form I have agreed with her to read each statement of the consent form aloud and if she agrees to it she will say "I agree". This will be audio recorded separately from the actual interview and kept as a record of her consent.

Appendix 4-J

Confirmation of Ethical Approval.

Research and Enterprise
Services Division

Lancaster University

Applicant: Laura Smith
Supervisor: Dr Jane Simpson and Dr Fiona Eccles
Department: DHR
UREC Ref: RS2014/132

17 August 2015

Dear Laura, Jane and Fiona,

Re: What are partners experiences of living with someone who has a chronic pain condition?

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C. Tay

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).

Section Five: Appendices

What are the experiences of caring for a loved one with a chronic condition?

Laura Smith*

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Contributors for selected journal notes

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

- Papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- Theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- We particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- Methodological papers dealing with methodological issues of particular relevance to health psychology.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes but excluding the abstract, tables, figures and references). The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- The content of the paper falls within the scope of the Journal
- The methods and/or sample size are appropriate for the questions being addressed
- Research with student populations is appropriately justified
- The word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help your prepare your paper.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found here.

- Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.

- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.

- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book.* City, Country: Publisher.
Author, A. (2013). Title of journal article. *Name of journal, 1,* 1-16. doi: 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.

- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.

- Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.

- Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

If you need more information about submitting your manuscript for publication, please email Hannah Wakley, Managing Editor (bjhp@wiley.com) or phone +44 (0) 116 252 9504.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of terms and conditions is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form.

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