

Title: Partners' experiences of chronic pain: A qualitative evidence synthesis

Abstract

Objectives: This systematic review of qualitative studies synthesised evidence on the experience chronic pain from the perspective of romantic partners.

Methods: Medline via Ovid, Embase via Ovid, CINAHL via EBSCO, APA PsycInfo via Ovid, Scopus, and Web of Science databases were searched. Studies exploring the impact of chronic pain from partners' perspectives using qualitative data collection methods were eligible for inclusion. Thematic synthesis was conducted, and confidence in the review findings was assessed using GRADE CERQual criteria.

Results: A total of 198 participants were represented from 15 primary studies. Four interconnected analytical themes were developed: 'life is different', 'internal conflict between two worlds', 'togetherness vs separateness' and 'coping in the longer term'. Out of 27 review findings, 9 were assessed as high confidence, 12 as moderate confidence, 4 as low confidence, and 2 as very low confidence.

Discussion: Socially isolated partners, those in strained relationships, and partners who continually sacrificed their own needs were more likely to experience distressing emotions. Greater recognition of partners' needs is needed within pain management services.

Keywords: chronic pain, persistent pain, partners, qualitative, qualitative evidence synthesis.

Introduction

Chronic pain is defined as pain that persists for longer than three months. Approximately 20% of the population are affected (International Association for the Study of Pain [IASP], 2019). Chronic pain can have a significant, negative impact on physical, emotional and social functioning (Driscoll et al., 2021). Pain and associated symptoms such as fatigue can be barriers to engaging in valued activities and social roles. Loss of social roles and shrinking social networks are recognised as predictors of psychosocial distress and depression among people with chronic pain (Bailly et al., 2015; Toye et al., 2017). This can create a vicious cycle, as the presence of depression and unhelpful thought patterns such as catastrophising are associated with greater pain intensity and disability (Bair et al., 2003; Katon & Ciechanowski, 2002; Driscoll et al., 2021). Due to the interconnected processes between biological and psychosocial factors, the biopsychosocial model proposed by Engel (1977) is the dominant conceptual model in chronic pain research and practice (Gatchel et al., 2007). Adoption of the biopsychosocial model has led to an increase in treatments, including psychological interventions (Driscoll et al., 2021). Some researchers have identified that within clinical settings, application of the biopsychosocial model has led to greater emphasis on medical and psychological aspects of the model rather than the social context (Blyth et al., 2007; Riva et al., 2014).

Relational processes and chronic pain

This review was primarily concerned with the social component of the biopsychosocial model, specifically the idea that chronic pain can be understood relationally as well as individually. Pain occurs within an interpersonal context and responses from others can form feedback loops, reinforcing or punishing pain behaviour (Knight et al., 1997;

Mason, 2003). Supportive relationships have generally been associated with greater pain acceptance, adaptive coping, reduced pain and improved adjustment and functioning (López-Martínez et al., 2008; Che et al., 2018). Solicitous responses (where others are overly concerned and eager to help) and punishing responses, (where pain is ignored or met with anger) have been associated with increased pain and disability (McCracken, 2005). There can be stigma associated with chronic pain, particularly in the absence of visible symptoms or a clear disease pathology (De Ruddere & Craig, 2016). People with chronic pain may experience discrediting and devaluing responses at a variety of levels; including from society, health professionals and within personal networks of friends and family (Snelgrove & Lioffi, 2013). Such stigmatising reactions to chronic pain have been associated with reduced self-esteem and loss of dignity (De Ruddere & Craig, 2016).

Impact for partners

Chronic pain has been associated with depression, irritability and sleep problems which can affect not only the person with pain, but also the system around them (Mason, 2003). Partners sharing their lives with the person with chronic pain are likely to be significantly affected, perhaps more so than other family members (MacAdams, 2021). People with chronic pain often see a reduction in recreational and social activities, and this can also extend to partners. Partners may see a change in their social, sexual, and working lives, including increased financial stress (McPhee & Robinson, 2020). They may provide emotional and practical support, including taking on additional household responsibilities or a formal caregiving role (Cooper & Gilbert, 2017; Fallatah & Edge, 2015). Roles may need to be renegotiated and there may be a shift in the dynamic of the couple's relationship (Lewandowski et al., 2007; Snelgrove & Lioffi, 2013). When couples struggle to adjust to

pain-related changes in their relationship, this can lead to reduced marital and sexual satisfaction (Flor et al., 1987 as cited in MacAdams, 2021).

Literature investigating the impact of chronic pain for partners has identified increased burden and psychological distress (Cano et al., 2018; Tankha et al., 2020). Partners may experience a sense of helplessness through watching their loved one in pain, or loneliness if their relationship deteriorates and there is a lack of social support (Rokach et al., 2016). If partners are concerned that stressful interactions could exacerbate pain, they may suppress rather than communicate their needs, ultimately leading to increased relational strain affecting both partners (Acitelli & Badr, 2005). Although evidence suggests that chronic pain adversely impacts partners, this is not always the case. Some studies have reported that families can adapt and even flourish in response to pain (Becvar, 2007; West et al., 2012). The emotional toll for partners is likely related to the wider context, including the severity of pain, dependency level, closeness of the relationship before chronic pain, and the availability of social support (Schulz et al., 1997; Rokach et al., 2016).

Recognising the importance of the social context, National Institute of Clinical Excellence (NICE) guidelines for managing chronic pain advise that assessments should include questions about how family members influence pain and how chronic pain impacts family members (NICE, 2021). It is also recommended that family members receive appropriate information about chronic pain (NICE, 2021). Partners may be actively engaged in treatment, for example attending sessions as part of pain management programmes or involved in couple-based interventions (Elphick, 2004; Lewandowski et al., 2007). The rationale for involving partners in therapeutic interventions has primarily been to improve

pain-related and psychological outcomes for the person with pain (Keefe et al., 1996; Martire et al., 2003). Interventions have rarely addressed relationship dynamics or the partner's wellbeing, with partners put in a coaching rather than co-participant position (Tankha et al., 2020). Thus, the needs of partners as individuals have tended to be overlooked within services, particularly if they are not a formal caregiver (MacAdams 2021; West et al., 2012).

Review questions

This review set out to synthesise the experiences and needs of partners of people with chronic pain. The findings were intended to inform the development, evaluation and implementation of interventions for partners, which may in turn benefit the person with chronic pain. The review questions were:

- How are romantic partners impacted by chronic pain?
- Why are some partners able to adjust to life with chronic pain while others seem to struggle?

Qualitative research typically addresses exploratory 'how' and 'why' questions such as those posed in this review. A qualitative evidence synthesis was therefore undertaken, bringing together evidence from primary qualitative studies which explored partners' lived experiences of chronic pain.

Evidence from qualitative studies was selected above mixed-methods or quantitative data as methods of synthesising qualitative data are more developed, meaning that findings can be used to inform intervention recommendations with greater confidence (Flemming & Noyes, 2021). Qualitative evidence synthesis also requires in-depth engagement with the text

(Cochrane Effective Practice and Organisation of Care, 2019); therefore, having fewer studies with rich textual data is helpful for the quality of the review

Method

A review protocol was developed and pre-registered on PROSPERO (reference: blinded). Registration was completed after full-text sources had been identified, but prior to data extraction.

Information sources

A comprehensive search strategy was used, aiming to identify all relevant primary studies (Tong et al., 2012). Medline via Ovid (1946- 2021), Embase via Ovid (1974 – 2021), CINAHL via EBSCO (1958- 2021), APA PsycInfo via Ovid (1967-2021), Scopus (1960-2021) and Web of Science (1970-2021) databases were searched on 13 December 2021. These databases were selected as they included journals from medical and psychosocial fields, both of which may include literature on chronic pain. Publication dates differed across databases according to their availability. The first 300 results on Google scholar (Haddaway et al., 2015), and reference lists of selected full-text articles were searched for additional relevant studies.

Search strategy

Search terms were organised into three categories; the health topic ‘chronic pain’; the perspective of interest ‘partners’, and study design ‘qualitative’. Chronic pain conditions were identified using classifications from International Classification of Diseases 11th

revision (ICD-11, World Health Organisation [WHO], 2020; Treede et al., 2019), the NHS website (NHS, 2021), and terms from a systematic review carried out before the implementation of ICD-11 (Busse et al., 2018). ‘Partner*’, ‘spouse*’ and ‘caregiver’ were examples of some of the terms used to identify studies that focussed on the perspective of romantic partners. Study design search terms included ‘qualitative’ and ‘focus group*’ as well as other terms informed by Braun and Clarke’s book on qualitative research (2013). A full list of terms included in the search can be found in supplementary file 1 to aid replication.

Selection of studies

Primary studies were eligible if they used qualitative methods to collect data on the impact of chronic pain or a recognised chronic pain condition (e.g., fibromyalgia or osteoarthritis). Studies that focussed on acute pain or did not specify the chronicity of pain were excluded.

The focus of the review was on the impact of chronic pain from the perspective of partners. ‘Partner’ was defined as anyone in a romantic relationship of any duration with someone with chronic pain. Studies that addressed other aims could be included if data about partners’ experiences of pain were reported separately and could be extracted. Studies that looked at dyads (e.g., individuals with pain and their partner) or multiple perspectives (e.g. mixed groups of relatives) were eligible only if partners were interviewed separately. This allowed quotes from partners and the authors’ interpretations to be extracted.

Empirical qualitative studies where methods of obtaining textual data had been used (e.g., open-question surveys, interviews and focus groups) were included. Mixed methods

studies could be included if qualitative data were reported separately. Quantitative studies, books, conference presentations, protocol papers and reviews were excluded. Studies could be published from any date until 13th December 2021; however, only studies in English were included.

Sources were screened by title, abstract and full text by the primary reviewer according to inclusion and exclusion criteria. A colleague screened 10% of papers at full-text level to increase reliability. A minimum 80% agreement rate was agreed a priori, and if this was not met, they would review all papers. Any disagreements were resolved by discussion until a final decision could be reached.

Data extraction

A data collection tool was developed on word processing software. The following data were extracted by the primary reviewer: title, authors, publication year, country, chronic pain condition, participant characteristics (N, gender, age, ethnicity, socioeconomic grouping and relationship to the person with pain), data collection method, analysis methods, main themes, conclusions, strengths, and limitations.

Critical appraisal

There is divided opinion about the appropriateness of assessing the methodological quality of qualitative evidence, therefore it was decided *a priori* that no studies would be excluded due to poor quality (Noyes et al., 2018). The Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative studies was used to assess rigour through consideration of methodological strengths and limitations. The CASP (2018) checklist was selected as it allowed primary studies using different qualitative methodologies to be assessed

using the same tool (Noyes et al., 2018). Quality appraisal was completed independently by the primary reviewer.

Synthesis of results

Once the final selection of studies had been identified, the Review question- Epistemology- Time/Timescale-Resources-Expertise-Audience and purpose-Type of data (RETREAT) framework was used to select the synthesis method (Booth et al., 2018). This review was underpinned by a critical realist ontology and contextualist epistemology. These positions assume knowledge is reproducible in similar contexts, so some shared reality is assumed (Braun & Clarke, 2013). The aim of the synthesis was to aggregate findings across studies rather than to develop a new theory, and there was variation in terms of data richness across the primary studies. This indicated thematic synthesis as the preferred methodology for the analysis (Flemming & Noyes, 2021; Booth et al., 2018).

A thematic synthesis was carried out using the three-stage process outlined by Thomas and Harden (2008), and reported according to guidelines for enhancing transparency in reporting the synthesis of qualitative research (ENTREQ; Tong et al., 2012). Primary studies were imported as PDF files on to NVivo for Windows. The first step involved line-by-line coding of text in the results/findings, discussion and conclusions. Any data relevant to partner's experiences of chronic pain were coded. Each sentence was allocated at least one code, and some were categorised using multiple codes (Thomas & Harden, 2008). The rationale for coding text beyond participant quotations was to ensure that researchers' interpretations were also included in the synthesis (Khanom et al., 2020; Thomas & Harden, 2008). Codes were initially assigned on a free form basis (not mapped to higher order

themes). The first and second authors independently coded a sample (20%) of the primary studies, selected based on highest quality appraisal ratings. The reviewers met to discuss their respective codes, collaboratively agreeing on a combined bank of codes. The primary reviewer then completed coding for the remainder of the studies, adding new codes where appropriate.

The second phase of the analysis involved grouping similar concepts together in a hierarchical tree structure, forming descriptive themes. The third stage involved further interpretation of descriptive themes to form analytical themes. Analytical themes identify patterns and relationships across studies, thus going beyond describing the content of the original studies (Khanom et al., 2020; Thomas & Harden, 2008). Recognising that data analysis is more susceptible to bias when completed independently, the second author reviewed codes and contributed to process of grouping these together into descriptive and analytical themes.

Confidence in review findings

The GRADE-CERQual approach was used to assess how much confidence to place in the findings from the review (Lewin, Booth & Glenton et al., 2018). This offers a systematic and transparent framework for assessing confidence in a finding based on methodological limitations, coherence, adequacy of data, and relevance of primary studies to the review question (Lewin, Bohren & Rashidian et al., 2018). The primary reviewer independently assessed confidence in the review findings.

Findings

Screening of eligible studies

The search and selection process for this review is reported in a PRISMA flowchart (Moher et al., 2009; see supplementary file 2). A total of 7582 papers were identified through database searches. This was reduced to 4990 after the removal of duplicates. No additional records were found through searching Google Scholar or the reference lists of included studies. The primary reviewer excluded 4700 studies based on title and abstract. There were 290 articles to assess at full-text level, 17 of which met all inclusion criteria. Two of these were dissertations that could not be accessed after attempting to contact the authors (Brown, 2007; Cohn, 2020). They were therefore excluded, bringing the total number of studies included in the qualitative evidence synthesis to 15. There were no disagreements in the 10% of full-text papers that were screened by two reviewers. In four of the included studies, only part of the data were relevant to the review objectives. MacKay (1996) used a concept mapping design, collecting qualitative data but analysing this statistically. Similarly, Fernandez et al. (2006) employed a mixed-methods design, using a closed-choice survey followed by an interview. In both cases, only the qualitative data were extracted. McPhee and Robinson (2020) conducted interviews with partners followed by interviews with couples. Two themes were based on partners' perspectives and a third theme presented couples' accounts. Only the first two themes were extracted. Finally, Sadownik et al. (2017) reported partners' experiences of provoked vestibulodynia and the impact of a treatment intervention. Partners' experiences of interventions were outside the scope of this review, so this data was not extracted.

Study and participant characteristics

Descriptive information about the primary studies is summarised in Table 1. The studies were conducted in the United Kingdom (33.3%), Canada (20%), United States of America (13.3%), Sweden (13.3%), Australia (13.3%) and Spain (6.67%). A total of 198 participants were represented across the studies. Two studies analysed data from the same sample of participants (Culley et al., 2017; Hudson et al., 2020). Demographic data for these participants was only counted once. There were 111 (56.1%) male partners, 69 (34.8%) female partners and one person (0.5%) who identified as gender-neutral. Gender was not reported for the remaining 17 (8.6%) participants. Only five studies (33.3%) reported the ethnicity of participants. Within these studies, either all or the majority of participants were White. The age of participants was reported in ten (66.7%) studies, ranging between 22-70 years (mean = 42.9 years). Relationship duration was reported in ten (66.7%) studies. This ranged between 9 months to 46 years (mean = 15.68 years). Seven of the primary studies (46.67%) had outlined inclusion criteria specific to the relationship, such as a minimum relationship length or partners that were cohabiting or married to the person with pain. It was possible to determine marital status of 101 participants (51.0%); 33 (16.7%) were married; 62 (31.3%) were cohabiting (and may also be married); and 6 (3.0%) were dating. The following pain conditions were represented: fibromyalgia (20%), endometriosis (20%), unspecified chronic pain (20%), rheumatoid arthritis (13.3%), chronic low-back pain (13.3%), chronic migraines (6.67%) and provoked vestibulodynia (6.67%). The duration of partner's pain was measured in five studies (33.3%), ranging between 8 months to 20 years. The following qualitative methods were used to analyse data in the primary studies: thematic analysis (40%), grounded theory (13.3%), interpretative phenomenological analysis (6.67%), thematic content analysis (6.67%), phenomenological hermeneutic analysis (6.67%), transcendental

phenomenological reduction (6.67%), crystallised/immersion method (6.67%), and Gadamerian hermeneutical approach (6.67%).

INSERT TABLE 1 APPROXIMATELY HERE

Quality appraisal

Appraisal ratings from the CASP (2018) checklist were used to systematically identify methodological strengths and weaknesses across studies. Methodological limitations were considered when assessing confidence in the findings of the review using a GRADE CERQual approach (Lewin, Booth & Glenton et al., 2018).

Two studies showed no or very minor concerns based on CASP criteria (MacAdams, 2021; Romero-Alcalá et al., 2019). Since these studies obtained the highest quality appraisal ratings, they were coded first. New codes were generated in response to each new paper; however, studies coded at the beginning of the process may contribute more to the coding framework and overall analysis. It was therefore deemed appropriate to begin the analysis with the studies with the fewest methodological concerns.

Six studies showed minor methodological concerns (MacKay, 1996; Miller & Timson, 2004; Matheson et al., 2010; Sadownik et al., 2017; Garg et al., 2021; McPhee & Robinson, 2020). Across studies, there were concerns regarding researcher reflexivity. Most studies (73.3%) did not report who conducted the interviews or discuss how the researcher's role or personal characteristics might have shaped the interpretation of findings. The majority

of studies (66.7%) also failed to discuss data triangulation or contradictory data, affecting credibility.

Three studies showed moderate concerns (Paulson et al., 2003; Söderberg et al., 2003 & West et al., 2012), and four studies showed serious concerns (Elphick, 2004; Fernandez et al., 2006; Culley et al., 2017 & Hudson et al., 2020). Two of these studies included data from the same sample of male participants, although the research questions and participant quotations were different (Culley et al., 2017; Hudson et al., 2020). In addition to not discussing the role of the researcher and credibility of findings, these studies did not adequately consider ethical issues, rigor of the analysis and whether the recruitment strategy was appropriate to the research aims.

One study that showed serious methodological concerns appeared to be a summary report of a doctoral thesis (Elphick, 2004). An email was sent to the author requesting access to the full dissertation, but no response was received. The summary report was included; however, there was a lack of information reported to allow for thorough consideration of the methodological strengths and weaknesses.

Reviewer reflexivity

It was important to consider and be transparent about professional and personal factors that may have shaped the reviewer's approach to the analysis (Flemming & Noyes, 2021). The qualitative evidence synthesis was primarily undertaken by a [profession blinded], with a particular interest in relationships and relational approaches to care. Such interests led them to pose the review question in the first instance, but it also likely meant that they

interpreted the findings through this professional lens. In particular, they may have been unconsciously primed towards identifying emotional responses, mental health or adjustment difficulties within the accounts of participants in the primary studies. This was not necessarily problematic, as it aligned with the review objectives; however an important step for improving confidence in the QES involved looking through the primary studies for cases that contradicted the analytic themes (Flemming & Noyes, 2021; Lewin, Bohren & Rashidian et al., 2018). In terms of personal characteristics, the primary reviewer identified as a woman, and they recognised that they see the world through a feminist lens. In particular, they found themselves struggling to be balanced in their interpretation of a study focussing on how men's sexuality was affected by their female partner having fibromyalgia. They identified feelings of frustration when reading some of the quotes, which were important to acknowledge and reflect on to ensure that the rigour of the analysis was not threatened.

Confidence in synthesis findings

The findings of this review including GRADE CERQual confidence assessments and illustrative quotes are presented in Table 2 (Lewin, Bohren & Rashidian et al., 2018). A Summary of Evidence table is available in supplementary materials (file 3) to illustrate how each confidence rating was arrived at. Out of 27 review findings, 9 were rated as high confidence, 12 as moderate confidence, 4 as low confidence and 2 as very low confidence. Confidence in each review finding was taken into consideration when discussing the clinical and research recommendations following this review.

Analytical themes and review findings

A total of 106 unique codes were generated and these were mapped on to 12 descriptive themes. These were: ‘additional responsibilities’, ‘emotional responses’, ‘loss or change’, ‘unpredictable nature of pain’, ‘impact on family life’, ‘impact on sex and intimacy’, ‘partners needs go unrecognised’, ‘oscillation between two roles’, ‘togetherness and team-working’, ‘separateness within the relationship’, ‘acceptance and self-care’ and ‘suppressing needs and self-sacrificing’. The descriptive themes were developed into four interconnected analytical themes: ‘life is different’, ‘internal conflict between two worlds’, ‘togetherness vs separateness’ and ‘coping in the longer term’. These analytical themes and associated sub-themes are depicted in Figure 1. Each analytical theme pointed to the challenges that chronic pain brings in terms of everyday life and within the romantic relationship. There were also occasionally opportunities for growth and acceptance. Although the experience of pain is not a linear process, there was a sense of the themes progressing from partners’ experiences at the onset of pain to their coping in the longer term. Analytical themes, with associated sub-themes and review findings are presented in Table 3 and described narratively below.

Theme 1: Life is Different

The first analytic theme related to how life is different when you are the partner of someone with chronic pain. Many of the participants in the primary studies were with their partner before the onset of pain, therefore they talked about how life had changed. There were five interconnected subthemes including: ‘additional responsibilities’, ‘emotional responses’, ‘loss or change’, ‘endless uncertainty’ and ‘impact on family life’. These subthemes represent findings 1-11 in Table 3.

Over time, partners who took on additional responsibilities such as household tasks, parenting, and providing support, could become overwhelmed and exhausted (finding 1, high confidence). In four studies, there were partners who took on an over-protective role, taking on more tasks than necessary to shield the person with pain from stress or exacerbated pain. Greater pain severity was linked with additional burden for partners (finding 2), however, confidence in this finding was low due to a lack of adequate data. The financial impact of pain fell under the subtheme ‘additional responsibilities’ as partners could feel responsible for contributing more to the family’s finances (finding 3, moderate confidence). Financial stress was primarily attributed to reduced household income, but in countries with privatised healthcare systems, pain treatments also had to be paid for.

Gender was relevant to several of the review findings. The redistribution of tasks due to pain could either reinforce traditional gender roles or reverse them (finding 4, low confidence). There were mixed views among partners as to whether they identified as caregivers. Women seemed to more readily accept this role, while male partners saw themselves as ‘lending a helping hand’ (finding 5, moderate confidence). The impact of pain on the entire family unit was raised (finding 10, moderate confidence). Although this finding was coded for both male and female partners, all of the direct quotes (as opposed to the author’s interpretations) were from women, indicating potential gender differences. The subtheme ‘impact on family life’ included the impact that chronic pain can have on fertility and family planning (finding 11, very low confidence). This finding was specific to endometriosis, where the condition can affect fertility, and Rheumatoid Arthritis, where medical treatments can cause risks in pregnancy. This finding was only relevant to male partners in three primary studies so there were serious concerns about data adequacy. No studies included data from female partners about how pain affected family planning.

Partners experienced helplessness from witnessing the pain and feeling powerless to change it (finding 6, high confidence). They highlighted change or losses that pain was responsible for, which brought a sense of grief (finding 8, moderate confidence). Frustration and anger were common responses to the restrictions imposed by pain (finding 7, high confidence). Anger could be directed at the situation, the pain, health professionals and occasionally towards the person with pain. Frustration that partners felt towards health professionals was often related to the perception that they had not received satisfactory information or answers, which exacerbated uncertainty (finding 9, high confidence). Two studies conducted in the context of Rheumatoid Arthritis were an exception to this, with some partners in these studies receiving adequate information, although this did not necessarily alleviate uncertainty. Compared to some other pain conditions, Rheumatoid Arthritis has a clear disease trajectory and treatments. Patients are routinely reviewed which may provide more opportunities for information-sharing.

Theme 2: Internal Conflict between Two Worlds

Within this theme, partners described a motivational conflict between prioritising the relationship or external factors. Sub-themes were ‘life at home with the person with pain’, ‘outside life’ and ‘partners go unrecognised’. Review findings 12-17 in Table 3 relate to this analytical theme.

There were times when partners had to choose between providing support to the person with pain or fulfilling their work commitments (finding 12, moderate confidence). Some partners sought out employment closer to home or with greater flexibility so they could

be more available. Some partners explicitly chose to be at home more often. This could be driven by a desire to spend meaningful time with the person with pain, or by a sense of guilt for carrying on with normal life. Some partners more readily carried on with life independently, framing this as an act of self-care.

The uncertainty of pain and difficulties committing to social plans meant that partners often felt disconnected from friends and family (finding 13, moderate confidence). Many partners had experienced invalidating responses such as having the legitimacy of pain questioned, receiving unsolicited advice, or being encouraged to end the relationship (finding 14, moderate confidence). A few partners had played a role in helping the person with pain to minimise or mask their pain in social situations, highlighting the anticipated stigma (finding 15, low confidence). When the person with pain was not physically and emotionally available, partners could feel unseen, unheard and lonely.

Feeling unseen often extended to interactions with the healthcare system, with partners highlighting a lack of recognition, support, and involvement in treatment (finding 16, moderate confidence). In five studies, partners of people with CLBP, fibromyalgia and unspecific chronic pain described stigma in healthcare settings. This impacted the support offered to partners and also led to them playing an advocacy role. There was some initial evidence to suggest that peer support, including online forums, could be helpful for partners (finding 17, very low confidence). Confidence in this finding was very low confidence due to a lack of adequate data.

Theme 3: Togetherness vs Separateness

Partners described their romantic relationships in such a way that they could be conceptualised on a continuum of ‘togetherness’ to ‘separateness’. Separateness was depicted as the larger sub-theme in figure 1 because more of the data spoke to the strain that pain caused in the relationship. Only a minority of the findings related to the positive impact of pain on the relationship. The way that partners responded to changes in their sex lives and re-evaluated their commitment to the relationship either enhanced closeness or exacerbated strain. Sub-themes of this analytic theme included: ‘togetherness’, ‘separateness’, ‘responding to reduced sex & intimacy’ and ‘re-evaluating the relationship’. Findings 18-24 in Table 3 relate to this analytical theme.

Adjusting to chronic pain, some couples had drawn closer together (finding 18, high confidence). Features of good communication, spending time together, team-working and compassion were evident in close romantic relationships. For some couples, chronic pain had caused or exacerbated relationship strain (finding 19, high confidence). Some partners reflected on how the temperament of the person with pain had changed, leading to a sense of ‘walking on eggshells’. Over time, partners’ in strained relationships experienced more unpleasant emotions such as resentment, sadness, loneliness or frustration (finding 20, moderate confidence).

Many partners reported reduced sex (finding 21, high confidence). This was particularly relevant when the health condition studied was endometriosis, provoked vestibulodynia, or where sexuality was the topic of the research. Partners commonly described reduced sexual satisfaction which they attributed to physical changes affecting the

person with pain, reduced sexual desire, and sex that was less spontaneous. Partners were often hesitant to initiate sex for fear of exacerbating pain. A minority of partners also described how the shift in relationship dynamics led them to feel less attracted to the person with pain. The extent to which less frequent sex affected the relationship depended on the meaning attached to sex and how the couple were able to negotiate different sex drives (finding 22, moderate confidence). When there was a lack of trust or partners felt their needs were not being met, then a lack of sex exacerbated relationship strain (finding 23, moderate confidence). This finding was relevant to five studies with mostly male participants. This may reflect cultural norms or be due to the composition of primary studies included in the review.

References to the competing ideas of leaving the relationship and commitment were made by partners across nine studies, suggesting that chronic pain prompts partners to re-evaluate the relationship (finding 24, high confidence). When there was a high degree of separateness and partner's felt their needs were not being met, they actively weighed up whether they wanted to remain in the relationship. A minority of married participants in two studies felt that their wedding vows kept them committed to the relationship even if they were unhappy. On the contrary, when there was a strong bond, intimacy (not necessarily sex), and a sense of togetherness, partners made an active choice to remain with the person in pain.

Theme 4: Coping in the Longer Term

The sample of partners represented in this review was skewed towards those in long-term relationships or marriages where pain had been present for a long time. As such, there was a journey described in terms of adjustment to chronic pain in the longer term. This theme

could be conceptualised as two continuums; the first ranging from prioritising self-care to sacrificing personal needs, and the second ranging from acceptance to being controlled by pain. Sub-themes were ‘acceptance’, ‘controlled by pain’, ‘prioritising self-care’ and ‘self-sacrificing’. Partners who found ways to live a meaningful life alongside pain and looked after their own wellbeing were less distressed by it. Those who sacrificed their own needs and felt controlled by pain were more likely to struggle emotionally. Review findings 25-27 presented in Table 3 relate to this theme.

Across all of the included studies, there were partners who had reached a place of acceptance and found ways to live well alongside pain (finding 25, moderate confidence). Letting go of expectations of what life *should* be like and finding meaning in the experience facilitated acceptance. There was a sense of couples growing together and of participants becoming more appreciative, compassionate, or resilient, ultimately making them a better partner to the person with pain. Partners used words such as ‘we’ and ‘us’ to describe how the couple had evolved together, emphasising the importance of dealing with the challenges of chronic pain as a team. Such growth allowed partners to look to the future with a preserved sense of hope.

An intermediate point on the continuum of acceptance to controlled by pain was ‘resigned to live with it’. This was relevant to 14 studies. Being able to live with pain without feeling constantly controlled by it allowed partners some freedom to carry on with life and look to the future, but with a lingering sense of frustration. Partners in 8 studies felt that their lives were completely controlled by pain. Partners who continually sacrificed their own needs (e.g., by portraying unshakeable strength or showing constant consideration to the person

with pain) were more likely to feel distressed and controlled by pain (finding 27, high confidence). Those who prioritised self-care were more equipped to deal with the challenges of chronic pain (finding 26, moderate confidence). Creating distance (physically or emotionally) was described by partners across 8 studies; however, the line between taking time for oneself as self-care and shutting down or escaping during difficult times was often blurred.

INSERT TABLE 2 APPROXIMATELY HERE

INSERT FIGURE 1 APPROXIMATELY HERE

Discussion

This qualitative evidence synthesis aimed to understand how romantic partners are impacted by chronic pain. It sought to understand what helps and hinders partners' adjustment to chronic pain to inform recommendations for research and clinical practice. The experiences of 198 partners were represented in the review from 15 primary studies. Four analytical themes were developed which loosely described partners' experiences of chronic pain over time.

The first theme captured how life is different when you are the partner of someone with chronic pain. Partners described shifts in the distribution of tasks, financial stress, uncertainty, loss and change, often accompanied by feelings of anxiety, sadness or anger. This was consistent with quantitative studies (Rokach et al., 2016), and literature exploring the impact of chronic pain from the perspective of the person with pain (Dueñas et al., 2016; Wallis et al., 2019; Toye et al., 2017). Qualitative evidence syntheses exploring patients' experiences have demonstrated that chronic pain leads to shifts in relationship roles and a

reduced social network (Nichols et al., 2017; Toye et al., 2013; Snelgrove & Liossi, 2013). The current review found that this experience is mirrored for partners. There were mixed responses to the term ‘caregiver’ in this review, with male partners being more likely to reject this identity. This has important clinical implications, as services should ensure that the language used in services does not unintentionally exclude people who do not identify as caregivers.

Previous literature has demonstrated that individuals with pain often struggle to prove pain is real (De Ruddere & Craig, 2016). They can experience a dilemma between showing and hiding pain due to stigma (Toye et al., 2013). Partners in this review described invalidating or dismissive responses, and a minority had played a role in helping their partner to mask their pain in social settings. Some partners also described experiences of stigma in healthcare settings. This finding was relevant to health conditions with poorly understood physiological aetiology such as fibromyalgia, chronic low-back pain and unspecific chronic pain. Rich data relating to experiences of stigma were lacking, so confidence in this review finding was low. The impact of stigma, discrimination and shame on chronic pain patients and their families warrants further investigation so this can be better understood and addressed, particularly within healthcare systems.

Partners were often unsatisfied with healthcare services and providers. They reported feeling excluded by services that provide care to the person with pain. In line with previous findings, partners generally felt that they had not received sufficient information on chronic pain, nor been adequately involved in pain management decisions (Tankha et al., 2020; Elphick, 2004; Mason 2003). There were exceptions to this in some primary studies; with a

minority of partners attending consultations or receiving adequate information. Partners appeared to be more involved in the context of rheumatoid arthritis, although the topic of one of these studies was reproductive decision making, where focus on the couple might be expected.

For patients with chronic pain, supportive relationships have been associated with greater acceptance, adaptive coping and improved adjustment and functioning (López-Martínez et al., 2008; Che et al., 2018). Therefore, greater acknowledgement of the social system should be a priority within pain management services (Mason, 2003; Lewandowski et al., 2007). A step towards involving partners more readily in pain management that concurrently respects confidentiality and patient preferences would be to ensure that the interpersonal context of pain is adequately considered in pain management assessments. Exploring the reciprocal influence of pain on relationships and relationships on pain is important (NICE, 2021). If patients consent to the involvement of their partner in pain management, then this should be facilitated and couple-focussed therapeutic interventions should be available for those reporting high levels of strain or separateness. The implementation of this would likely differ across geographical contexts. Some services may have the resources and skill-mix to be able to offer such interventions; whereas others may need to signpost to relationship-focussed services.

Partners could face an internal conflict between two worlds: a more insular life at home with the person with pain, or their regular ‘outside life’ including employment, hobbies and other relationships. Evidence from a quantitative study underpinned by Self-Determination Theory showed that when partners’ motivation to care for their partner was

intrinsic (autonomous) as opposed to coming from external pressures, there was a positive association with partners' wellbeing and relationship quality (Kindt et al., 2015). A similar finding was identified in this qualitative evidence synthesis whereby partners that sacrificed their own needs and felt controlled by pain were likely to have poorer wellbeing. In line with previous research, this review also found that partners in close relationships experienced less burden and distress than those in strained relationships (Schulz et al., 1997; Rokach et al., 2016). Features of open communication, care, compassion, team-working and valuing time together were apparent in close relationships. Finding alternative ways of being intimate, even if sex was reduced or absent was important for preserving the couple's bond. When partners felt shut out, or on the receiving end of anger and fluctuating moods, this caused relationship strain. A lack of sex could exacerbate relationship difficulties if partners felt their needs were not being met or if added to problems with trust. It is important for sex to be discussed in pain services so information and support can be provided to couples who have struggled to find alternative ways of being intimate (Romero-Alcalá et al., 2019).

The final theme captured partners' experiences of coping with chronic pain in the longer term. Like individuals with chronic pain, many partners were able to adjust to chronic pain (Toye et al., 2013); however, others struggled with diagnostic and treatment uncertainty, which may reflect difficulties with pain acceptance. Partners who prioritised their own wellbeing and who grew personally and as a couple were more likely to live well alongside pain. This is in line with literature on post-traumatic growth, which refers to the ability to rebuild core beliefs and improve functioning following a traumatic event (Tedeschi & Calhoun, 2004). Previous research identified that post-traumatic growth is most likely to occur when pain has been distressing enough to alter core assumptions about the world, but not so distressing that the person is overwhelmed (Ayache & Goutaudier, 2022). Partners

who neglected their own needs were likely to feel controlled by pain and distressed, thus less likely to experience post-traumatic growth.

Clinical & research implications

All studies were conducted in developed countries where healthcare systems predominantly focus on the patient or individual receiving care. This was reflected in partners accounts, where they felt inadequately recognised and supported by healthcare providers. Involving partners more readily in pain management and providing support for them as individuals was recommended as an outcome from all of the included studies. This review adds specificity to this recommendation by identifying that partners in strained relationships, and partners who feel socially isolated are particularly vulnerable to distress and in greatest need of support. Services treating people with chronic pain are in a good position to also support partners, either by offering couple-based interventions or through signposting to relevant services. It is possible that supporting partners could also benefit the person with pain through the increased availability of support, perhaps reducing the level of input required from pain services. It would be beneficial for future research to look at the economic costs and benefits of supporting partners to inform decisions about how this support should be funded.

Recognising that more support is needed for partners, it is recommended that a further review is conducted to investigate the experiences and outcomes for partners who have received support or been involved in pain management interventions. This would allow for a greater understanding of interventions that are acceptable and helpful to partners, including the potential value of peer support.

This review was concerned with the experiences of partners in current romantic relationships with a person with chronic pain. The sample was skewed towards partners in long-term relationships where chronic pain had been present for a long time. The findings are consequently more applicable to partners in this position. In terms of expanding the evidence base, it would be useful for future studies to consider the perspectives of former partners, particularly if pain was a factor in the relationship breakdown. Gaining this perspective may offer further insights into pain-related factors that contribute to relationship strain.

Strengths and limitations of the primary studies

A limitation of this qualitative evidence synthesis was that the findings were relevant primarily to heterosexual, White partners in developed countries. This was a reflection of the available evidence from primary studies. Therefore, a recommendation for future research is to explore the experiences of partners from minoritised groups. Another issue was inadequate reporting of sample characteristics. This was often rationalised by researchers as a means of protecting participant anonymity, but it had the effect of limiting the transferability of findings.

There was an over-reliance on snowball sampling (recruiting partners from patients involved in pain management programmes or research), with 80% of primary studies using this approach. This likely biased the sample towards couples with more open communication as patients in strained relationships may be less likely to pass study information on to their partners. A recommendation for future research would be to adopt alternative recruitment strategies where partners are sought out directly.

Strengths and limitations of this QES

This review contributed to the evidence based by synthesising partners' experiences of living with someone with chronic pain. There are a number of strengths and limitations to consider which impact the trustworthiness of the review findings.

A range of medical and social sciences databases were searched to identify primary studies for the qualitative evidence synthesis. Grey literature including dissertations were included which was a strength as qualitative evidence is commonly found in the grey literature (Flemming & Noyes, 2021). However, a lack of diversity in the participants included in the primary studies limited the transferability of findings. Eight studies were excluded based on Language. It would have been beneficial to include studies published in non-English languages; however, there were no resources available for translation to support this.

In terms of the search strategy, terms were informed by clinical guidelines and published reviews wherever possible. Support from a librarian was also sought to ensure that searches could be operationalised effectively within the selected databases. No additional studies were discovered through searching Google Scholar or the reference lists of included studies, indicating that the initial search strategy was sufficiently comprehensive. A proportion of papers (10%) were double-screened at full-text level for quality control. This enhanced the reliability of the study selection process, although it did not overcome the limitation of using a single screener (Nevis et al., 2015). A proportion of data coding (20%) was also undertaken by the second reviewer, which enhanced the credibility and

dependability of the data synthesis. Credibility and dependability were also enhanced by consideration of reviewer reflectivity, use of direct participant quotes from primary studies and transparency in reporting the methodology. The implementation of guidance from the Cochrane Qualitative & Implementation Methods Group was a further strength. The synthesis method, assessment of confidence, and overall reporting were informed by published guidelines (Thomas & Harden, 2008; Lewin, Booth & Glenton et al., 2018 and Tong et al., 2012, respectively), which enhanced transparency and rigour.

Due to the context in which this qualitative evidence synthesis was conducted, it was not possible to have a second reviewer for all tasks. Quality appraisal using the CASP checklist and assessment of confidence using GRADE CERQual were carried out independently by the primary reviewer. This was a limitation as it is contrary to best practice guidelines and reduced dependability (Lewin, Bohren & Rashidian et al., 2018).

Conclusions

This qualitative evidence synthesis explored partners' experiences of chronic pain. Four inter-connected analytical themes were identified reflecting the consequences and emotional impact of pain over time. Many partners were able to accept pain and live a meaningful life in its presence. Partners who were in strained relationships, felt socially isolated or consistently sacrificed their own needs were more vulnerable to distress. Greater involvement of partners is needed within pain management services, with support available for those reporting high levels of distress. Conducting research within more diverse samples is also a priority to improve the transferability of findings.

Supplemental online material

Review search terms and the GRADE CERQual evidence profile are included as supplementary materials.

References

- Acitelli, L. K., & Badr, H. J. (2005). My illness or our illness? Attending to the relationship when one partner is ill. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping* (pp.121–136). American Psychological Association. <https://doi.org/10.1037/11031-006>
- Ayache, R. A., & Goutaudier, N. (2022). Posttraumatic growth and pain acceptance: A profile analysis of chronic pain experience. *Canadian Journal of Behavioural Science*, 54(3), 163–172. <https://doi.org/10.1037/cbs0000289>
- Bailly, F., Foltz, V., Rozenberg, S., Fautrel, B., & Gossec, L. (2015). The impact of chronic low back pain is partly related to loss of social role: A qualitative study. *Joint Bone Spine*, 82(6), 437–441. <https://doi.org/10.1016/j.jbspin.2015.02.019>
- Bair, M. J., Robinson, R. L., Katon, W., & Kroenke, K. (2003). Depression and pain comorbidity: a literature review. *Archives of Internal Medicine*, 163(20), 2433–2445. <https://doi.org/10.1001/archinte.163.20.2433>
- Becvar, D. S. (2007). *Families That Flourish: Facilitating Resilience in Clinical Practice*. WW Norton & Company.
- Blyth, F. M., MacFarlane, G. J., & Nicholas, M. K. (2007). The contribution of psychosocial factors to the development of chronic pain: the key to better outcomes for patients? *Pain*, 129(1-2), 8–11. <https://doi.org/10.1016/j.pain.2007.03.009>
- Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., Mozygemba, K., Refolo, P., Sacchini, D., Tummers, M., & Rehfuss, E. (2018). Structured methodology review identified seven (RETREAT) criteria for selecting

- qualitative evidence synthesis approaches. *Journal of Clinical Epidemiology*, 99, 41–52. <https://doi.org/10.1016/j.jclinepi.2018.03.003>
- Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. Sage.
- Brown, K. S. (2007) *Dyspareunia due to endometriosis: A qualitative study of its effect on the couple relationship*. [Doctoral dissertation, Syracuse University]. ProQuest Dissertations Publishing.
- Busse, J. W., Wang, L., Kamaleldin, M., Craigie, S., Riva, J. J., Montoya, L., Mulla, S. M., Lopes, L. C., Vogel, N., Chen, E., Kirmayr, K., De Oliveira, K., Olivieri, L., Kaushal, A., Chaparro, L. E., Oyberman, I., Agarwal, A., Couban, R., Tsoi, L., Lam, T., ... Guyatt, G. H. (2018). Opioids for chronic noncancer pain: A systematic review and meta-analysis. *JAMA*, 320(23), 2448–2460. <https://doi.org/10.1001/jama.2018.18472>
- Cano, A., Corley, A. M., Clark, S. M., & Martinez, S. C. (2018). A couple-based psychological treatment for chronic pain and relationship distress. *Cognitive and Behavioral Practice*, 25(1), 119-134. <https://doi.org/10.1016/j.cbpra.2017.02.003>
- Che, X., Cash, R., Ng, S. K., Fitzgerald, P., & Fitzgibbon, B. M. (2018). A systematic review of the processes underlying the main and the buffering effect of social support on the experience of pain. *The Clinical Journal of Pain*, 34(11), 1061–1076. <https://doi.org/10.1097/AJP.0000000000000624>
- Cochrane Effective Practice and Organisation of Care (EPOC). (2019, October 03). *EPOC Qualitative Evidence Syntheses guidance on when to sample and how to develop a purposive sampling frame*.

https://epoc.cochrane.org/sites/epoc.cochrane.org/files/public/uploads/Resources-for-authors2017/qes_guidance_on_sampling.pdf

Cohn, M. W. (2020). *The caregiver's experience of chronic headache: A qualitative study*. [Doctoral Dissertation, The Alder University]. ProQuest Dissertations Publishing.

Cooper, S., & Gilbert, L. (2017). An exploratory study of the experience of fibromyalgia diagnosis in South Africa. *Health, 21*(3), 337–353.

<https://doi.org/10.1177/1363459316677623>

Critical Appraisal Skills Programme (2018). *CASP Qualitative Checklist*. <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>

Culley, L., Law, C., Hudson, N., Mitchell, H., Denny, E., & Raine-Fenning, N. (2017). A qualitative study of the impact of endometriosis on male partners. *Human Reproduction, 32*(8), 1667–1673. <https://doi.org/10.1093/humrep/dex221>

De Ruddere, L., & Craig, K. D. (2016). Understanding stigma and chronic pain: A-state-of-the-art review. *Pain, 157*(8), 1607–1610.

<https://doi.org/10.1097/j.pain.0000000000000512>

Driscoll, M. A., Edwards, R. R., Becker, W. C., Kaptchuk, T. J., & Kerns, R. D. (2021). Psychological interventions for the treatment of chronic pain in adults. *Psychological Science in The Public Interest: A Journal of The American Psychological Society, 22*(2), 52–95. <https://doi.org/10.1177/15291006211008157>

Dueñas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A review of chronic pain impact on patients, their social environment and the health care system. *Journal of Pain Research, 9*, 457–467. <https://doi.org/10.2147/JPR.S105892>

- Elphick, C (2004). Involving partners in pain management programmes. *Clinical Psychology Forum*, 39, 23-36.
- Engel G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>
- Fallatah, F., & Edge, D. S. (2015). Social support needs of families: the context of rheumatoid arthritis. *Applied Nursing Research*, 28(2), 180–185. <https://doi.org/10.1016/j.apnr.2014.10.004>
- Fernandez, I., Reid, C., & Dziurawiec, S. (2006). Living with endometriosis: the perspective of male partners. *Journal of Psychosomatic Research*, 61(4), 433–438. <https://doi.org/10.1016/j.jpsychores.2006.06.003>
- Flemming, K., & Noyes, J. (2021). Qualitative evidence synthesis: Where are we at? *International Journal of Qualitative Methods*, 20, 1-13. <https://doi.org/10.1177/1609406921993276>
- Flor, H., Turk, D. C., & Scholz, O. B. (1987). Impact of chronic pain on the spouse: Marital, emotional and physical consequences. *Journal of Psychosomatic Research*, 31(1), 63–71. [https://doi.org/10.1016/0022-3999\(87\)90099-7](https://doi.org/10.1016/0022-3999(87)90099-7)
- Garg, R., Rebić, N., Amiri, N., Hazlewood, G., Baldwin, C., Ensworth, S., Proulx, L., & De Vera, M. A. (2021). Partners of female patients with rheumatoid arthritis and reproductive decision-making: a constructivist grounded theory study. *Rheumatology Advances in Practice*, 5(3), 1-9. <https://doi.org/10.1093/rap/rkab040>
- Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The biopsychosocial approach to chronic pain: Scientific advances and future

directions. *Psychological Bulletin*, 133(4), 581–624. <https://doi.org/10.1037/0033-2909.133.4.581>

Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The Role of Google Scholar in Evidence Reviews and its Applicability to Grey Literature Searching. *PloS one*, 10(9), e0138237. <https://doi.org/10.1371/journal.pone.0138237>

Hudson, N., Law, C., Culley, L., Mitchell, H., Denny, E., Norton, W., & Raine-Fenning, N. (2020). Men, chronic illness and healthwork: Accounts from male partners of women with endometriosis. *Sociology of Health & Illness*, 42(7), 1532–1547. <https://doi.org/10.1111/1467-9566.13144>

International Association for the Study of Pain. (2019). *Chronic pain has arrived in the ICD-11*. <https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=8340>

Katon, W., & Ciechanowski, P. (2002). Impact of major depression on chronic medical illness. *Journal of Psychosomatic Research*, 53(4), 859–863. [https://doi.org/10.1016/s0022-3999\(02\)00313-6](https://doi.org/10.1016/s0022-3999(02)00313-6)

Keefe, F. J., Caldwell, D. S., Baucom, D., Salley, A., Robinson, E., Timmons, K., Beaupre, P., Weisberg, J., & Helms, M. (1996). Spouse-assisted coping skills training in the management of osteoarthritic knee pain. *Arthritis Care & Research*, 9(4), 279–291. [https://doi.org/10.1002/1529-0131\(199608\)9:4<279::AID-ANR1790090413>3.0.CO;2-6](https://doi.org/10.1002/1529-0131(199608)9:4<279::AID-ANR1790090413>3.0.CO;2-6)

Khanom, S., McDonagh, J. E., Briggs, M., Bakir, E., & McBeth, J. (2020). Adolescents' experiences of fluctuating pain in musculoskeletal disorders: a qualitative systematic

review and thematic synthesis. *BMC Musculoskeletal Disorders*, 21(1), 645.

<https://doi.org/10.1186/s12891-020-03627-1>

Kindt, S., Vansteenkiste, M., Loeys, T., Cano, A., Lauwerier, E., Verhofstadt, L. L., & Goubert, L. (2015). When Is Helping your Partner with Chronic Pain a Burden? The Relation Between Helping Motivation and Personal and Relational Functioning. *Pain medicine (Malden, Mass.)*, 16(9), 1732–1744. <https://doi.org/10.1111/pme.12766>

Knight, J. A., Green, S., & Hinson, W. (1997). Chronic pelvic pain: A systemic approach to assessment and treatment. *Families, Systems, & Health*, 15(2), 135–146. <https://doi.org/10.1037/h0089796>

Lewandowski, W., Morris, R., Draucker, C. B., & Risko, J. (2007). Chronic pain and the family: Theory-driven treatment approaches. *Issues in Mental Health Nursing*, 28(9), 1019–1044. <https://doi.org/10.1080/01612840701522200>

Lewin, S., Booth, A., Glenton, C., Munthe-Kaas, H., Rashidian, A., Wainwright, M., Bohren, M. A., Tunçalp, Ö., Colvin, C. J., Garside, R., Carlsen, B., Langlois, E. V., & Noyes, J. (2018). Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implementation Science*, 13(1), 1-10. <https://doi.org/10.1186/s13012-017-0688-3>

Lewin, S., Bohren, M., Rashidian, A., Munthe-Kaas, H., Glenton, C., Colvin, C. J., Garside, R., Noyes, J., Booth, A., Tunçalp, Ö., Wainwright, M., Flottorp, S., Tucker, J. D., & Carlsen, B. (2018). Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 2: how to make an overall CERQual assessment of confidence and create a Summary of Qualitative Findings table. *Implementation Science*, 13(1), 11-23. <https://doi.org/10.1186/s13012-017-0689-2>

- López-Martínez, A. E., Esteve-Zarazaga, R., & Ramírez-Maestre, C. (2008). Perceived social support and coping responses are independent variables explaining pain adjustment among chronic pain patients. *The Journal of Pain*, 9(4), 373–379.
<https://doi.org/10.1016/j.jpain.2007.12.002>
- MacAdams, E. I. (2021). *Silent sufferers and unseen warriors: The significant other's experience of chronic pain* [Doctoral Dissertation, Michigan School of Psychology] ProQuest Dissertations Publishing.
- MacKay, A. (1996). *The experience of female spouses of chronic low back pain sufferers*. [Doctoral dissertation, The University of Alberta]. ProQuest Dissertations Publishing
- McCracken L. M. (2005). Social context and acceptance of chronic pain: the role of solicitous and punishing responses. *Pain*, 113(1-2), 155–159.
<https://doi.org/10.1016/j.pain.2004.10.004>
- McPhee, D. P., & Robinson, W. D. (2020). Couples living with chronic migraines: A phenomenological study. *Contemporary Family Therapy*, 42(3), 271-283.
<https://doi.org/10.1007/s10591-019-09513-w>
- Martire, L. M., Schulz, R., Keefe, F. J., Starz, T. W., Osial, T. A., Jr, Dew, M. A., & Reynolds, C. F. (2003). Feasibility of a dyadic intervention for management of osteoarthritis: a pilot study with older patients and their spousal caregivers. *Aging & Mental Health*, 7(1), 53–60. <https://doi.org/10.1080/1360786021000007045>
- Mason, B. (2003). *The development of a relational approach to the understanding, treatment and management of chronic pain* [Doctoral dissertation, University of East London]. EThOS e-theses online service.

- Matheson, L., Harcourt, D., & Hewlett, S. (2010). 'Your whole life, your whole world, it changes': Partners' experiences of living with rheumatoid arthritis. *Musculoskeletal Care*, 8(1), 46–54. <https://doi.org/10.1002/msc.165>
- Miller, J., & Timson, D. (2004). Exploring the experiences of partners who live with a chronic low back pain sufferer. *Health & Social Care in The Community*, 12(1), 34–42. <https://doi.org/10.1111/j.1365-2524.2004.00466.x>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
- National Institute of Clinical Excellence. (2021, April 07). *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain*. <https://www.nice.org.uk/guidance/ng193>.
- Nevis, I. F., Sikich, N., Ye, C., & Kabali, C. (2015). Quality control tool for screening titles and abstracts by second reviewer: QCTSTAR. *Journal of Biometrics & Biostatistics* 6(2), 230-235. <https://doi.org/10.4172/2155-6180.1000230>
- NHS Inform (2021, June 16) *Chronic Pain*. <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain>
- Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series-paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative

findings. *Journal of Clinical Epidemiology*, 97, 49–58.

<https://doi.org/10.1016/j.jclinepi.2017.06.020>

Nichols, V. P., Ellard, D. R., Griffiths, F. E., Kamal, A., Underwood, M., Taylor, S., & CHES team (2017). The lived experience of chronic headache: A systematic review and synthesis of the qualitative literature. *BMJ Open*, 7(12), e019929.

<https://doi.org/10.1136/bmjopen-2017-019929>

Paulson, M., Norberg, A., & Söderberg, S. (2003). Living in the shadow of fibromyalgic pain: The meaning of female partners' experiences. *Journal of Clinical Nursing*, 12(2), 235–243. <https://doi.org/10.1046/j.1365-2702.2003.00733.x>

Riva, P., Wesselmann, E. D., Wirth, J. H., Carter-Sowell, A. R., & Williams, K. D. (2014). When pain does not heal: The common antecedents and consequences of chronic social and physical pain. *Basic and Applied Social Psychology*, 36(4), 329-346.

<http://doi.org/10.1080/01973533.2014.917975>

Rokach, A., Rosenstreich, E., Brill, S., & Goor Aryeh, I. (2016). Caregivers of chronic pain patients: Their loneliness and burden. *Nursing and Palliative Care* 1(5) 111-117.

<http://doi.org/10.15761/NPC.1000128>

Romero-Alcalá, P., Hernández-Padilla, J. M., Fernández-Sola, C., Coín-Pérez-Carrasco, M., Ramos-Rodríguez, C., Ruiz-Fernández, M. D., & Granero-Molina, J. (2019). Sexuality in male partners of women with fibromyalgia syndrome: A qualitative study. *PloS One*, 14(11), e0224990. <https://doi.org/10.1371/journal.pone.0224990>

Sadownik, L. A., Smith, K. B., Hui, A., & Brotto, L. A. (2017). The impact of a woman's dyspareunia and its treatment on her intimate partner: A qualitative analysis. *Journal*

of Sex & Marital Therapy, 43(6), 529–542.

<https://doi.org/10.1080/0092623X.2016.1208697>

Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine: A Publication of The Society of Behavioral Medicine*, 19(2), 110–116. <https://doi.org/10.1007/BF02883327>

Snelgrove, S., & Lioffi, C. (2013). Living with chronic low back pain: A meta synthesis of qualitative research. *Chronic Illness*, 9(4), 283–301.

<https://doi.org/10.1177/1742395313476901>

Söderberg, S., Strand, M., Haapala, M., & Lundman, B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing*, 42(2), 143–150. <https://doi.org/10.1046/j.1365-2648.2003.02597.x>

Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. *Current Diabetes Reports*, 12(6), 769–781. <https://doi.org/10.1007/s11892-012-0317-0>

Tedeschi, R. G., & Calhoun, L. G. (2004). Target Article: "Posttraumatic growth: Conceptual foundations and empirical evidence". *Psychological Inquiry*, 15(1), 1–18. https://doi.org/10.1207/s15327965pli1501_01

Tankha, H., Caño, A., Corley, A., Dillaway, H., Lumley, M. A., & Clark, S. (2020). A novel couple-based intervention for chronic pain and relationship distress: A pilot study. *Couple & Family Psychology*, 9(1), 13–32. <https://doi.org/10.1037/cfp0000131>

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45) 1-10.
<https://doi.org/10.1186/1471-2288-8-45>
- Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1), 1-8. <https://doi.org/10.1186/1471-2288-12-181>
- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). *A meta-ethnography of patients' experience of chronic non-malignant musculoskeletal pain*. NIHR Journals Library.
- Toye, F., Seers, K., Hannink, E., & Barker, K. (2017). A mega-ethnography of eleven qualitative evidence syntheses exploring the experience of living with chronic non-malignant pain. *BMC Medical Research Methodology*, 17(1), 1-11
<https://doi.org/10.1186/s12874-017-0392-7>
- Treede, R. D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Cohen, M., Evers, S., Finnerup, N. B., First, M. B., Giamberardino, M. A., Kaasa, S., Korwisi, B., Kosek, E., Lav and'homme, P., Nicholas, M., Perrot, S., Scholz, J., Schug, S., Smith, B. H., ... Wang, S. J. (2019). Chronic pain as a symptom or a disease: The IASP classification of chronic pain for the International Classification of Diseases (ICD-11). *Pain*, 160(1), 19–27. <https://doi.org/10.1097/j.pain.0000000000001384>
- Wallis, J. A., Taylor, N. F., Bunzli, S., & Shields, N. (2019). Experience of living with knee osteoarthritis: a systematic review of qualitative studies. *BMJ Open*, 9(9), e030060.
<https://doi.org/10.1136/bmjopen-2019-030060>

West, C., Usher, K., Foster, K., & Stewart, L. (2012). Chronic pain and the family: the experience of the partners of people living with chronic pain. *Journal of Clinical Nursing*, 21(23-24), 3352–3360. <https://doi.org/10.1111/j.1365-2702.2012.04215.x>

World Health Organization. (2020, February). *International Classification of Diseases for mortality and morbidity statistics 11th Revision (ICD-11)*. <https://icd.who.int/browse11/1-m/en>