Chronic Pain Self-Management and The Impact of Self-Reported Cognitive Symptoms

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Thesis Portfolio Abstract

Background: Chronic pain is a long-term condition with a considerable impact on health, emotional and cognitive functioning. Cognitive Behavioural therapy (CBT) is the most commonly applied psychological approach to chronic pain, often delivered as part of a pain management programme to support individuals to self-manage pain. Little is known about who might benefit most from CBT for chronic pain, or to what extent cognitive complaints impact on self-management of pain. **Methods:** A systematic review examined the predictors of outcomes in CBT for chronic pain. A cross-sectional survey then investigated the extent to which subjective cognitive symptoms predict chronic pain self-management after controlling for sociodemographic, pain and mood variables. The survey was completed by 286 people experiencing chronic pain who were recruited from NHS services and social media. **Results:** The systematic review identified 18 randomised control or cohort studies. A narrative synthesis identified baseline sociodemographic, physical and emotional factors that influence the outcomes of CBT for pain. The most commonly reported predictors of outcome were anxiety, depression and negative cognitions about pain. The survey found mood accounted for the most variance in self-management and that, whilst it accounted for only a small amount of variance, subjective executive functioning was a significant predictor of self-management. **Conclusions:** Future research is needed to identify the predictive factors which influence treatment outcomes in chronic pain. Significant associations were found between sociodemographic, mood variables and subjective executive functioning with pain self-management, suggesting potential benefits for the screening of subjective cognitive complaints in clinical practice.

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Chapter One

Introduction

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Chapter 1: Introduction

The Impact and Prevalence of Chronic Pain

The personal and financial impact of chronic pain is vast. In the United Kingdom (UK), it is estimated to affect 35-51.3% of the population (Fayaz et al, 2015). People with chronic pain who attend pain clinics report high levels of distress, disability and loss of social role (Froud, 2014). When severe, chronic pain is associated with increased risk of mortality independently of socio-demographic factors (Torrance et al, 2010). It accounts for 4.6 million general practice consultations each year (Department of Health, 2009) and the economic cost of chronic pain has been estimated at between £1475 and £8360 per patient, per year, making it one of the most expensive long-term health conditions worldwide (Azevedo, 2016).

The Definition and Classification of Chronic Pain

The International Classification of Diseases (ICD) of the World Health Organization (WHO) classifies chronic pain as pain that has persisted for three months or more (Treede et al., 2019). It is described as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020). The most common forms of adult chronic pain are chronic back pain, fibromyalgia, headache and neuropathic pain (WHO, 2019).

Chronic pain is classified as primary, or secondary chronic pain. Primary chronic pain is pain that persists for three months or more, associated with emotional distress and /or disability and the symptoms are not better accounted for by another diagnosis (Nicholas et al., 2019). The ICD-11 (ICD 11; WHO, 2019) developed a general structure of the classification of chronic primary pain subtypes, consisting of chronic widespread pain (fibromyalgia), complex regional pain syndrome, chronic primary headache or orofacial pain, chronic primary visceral pain and chronic primary musculoskeletal pain. In contrast, secondary chronic pain is pain that is better accounted for as a consequence of another health diagnosis, such as sickle cell disease, or cancer pain. It understood that perception of pain, in the presence of painful stimuli, is highly variable between individuals. In

individuals with increased pain processing in the presence of a stimuli, pain is described as pronociceptive, whereas individuals with reduced pain processing capacity are characterised as anti-nociceptive (Cheng et al., 2015).

Symptoms of Chronic Pain

Chronic pain is a complex sensory and emotional experience. The symptoms of which are multifaceted and can be broken down into three main areas: physical, emotional and cognitive. Chronic pain is associated with clusters of somatic symptoms, such as fatigue, poor sleep, weakness, nausea, dizziness and gastrointestinal symptoms (Barksy & Borus, 1991).

The emotional symptoms of chronic pain include depression, anxiety and irritability. The estimated prevalence of depression varies between 30-60% (Goesling et al., 2013). Depressed mood has also been identified as a barrier to self-managing chronic pain (Bair et al., 2009), the SCAMP randomised clinical trial (Damush et al., 2008) found that baseline depression severity substantially decreased the use of exercise as a pain management strategy, and that a pain management program and antidepressant medication increased self-management behaviours at 12 months.

The Cognitive Behavioural Therapy Fear Avoidance Model of pain (CBT; Lethem et al., 1983) identifies depression and pain catastrophising as key maintenance factors in pain experience. Pain catastrophising can be conceptualised as a negative cognitive affective response to pain (Quartana et al., 2009). Catastrophising involves dwelling on the worst possible outcome of any situation in which there is a possibility of an unpleasant outcome (Beck and Emery, 1985). The Pain Catastrophising Scale breaks it down into three core elements: magnification, helplessness and rumination (Sullivan et al., 1995). Pain catastrophising is associated with negative pain-related outcomes (Craner et al., 2016) and predicts depression in chronic pain (Hanley et al., 2008).

Chronic pain is also associated with a range of impaired cognitive functions, with the most evident being executive functioning, attention, processing speed and memory (Baker et al, 2016; Berryman et al, 2013; Pulles & Oosterman, 2011). Cognitive impairments pose challenges to daily life and the effectiveness of treatment for chronic pain (Moriarty et al., 2011). Moriarty and

colleagues hypothesised that reduced attention in chronic pain is due to limited cognitive resources, caused by the experience of having pain, which can have consequences for memory and executive functions. These impairments are likely to hinder self-management of pain and impact on comprehension, memory and attention in the pain management programme. Severity of pain has been linked with the level of cognitive decline (Montoro et al., 2015). Medications for pain relief can also impact on cognitive functioning, with patients receiving analgesic opioids being found to have significantly worse attentional abilities as those not receiving medication. However, no differences were found between the two groups, either taking opioids daily or not taking them, on tests of memory or executive function (Richards et al, 2018).

It is likely that the affective symptoms of chronic pain are also associated with cognitive deficits (Snyder, 2013). McCracken and Iverson (2001) found that 54% of chronic pain participants reported at least one area of significant cognitive deficit, such as forgetfulness, minor accidents, difficulty with finishing tasks or attention. The number of self-reported cognitive complaints were correlated with depression, antidepressant use, pain severity and pain-related anxiety. In addition to depression, self-reported cognitive complaints have also been found to be associated with pain catastrophising (Roth et al., 2004).

Associations of Chronic Pain with Sociodemographic Variables

The prevalence of chronic pain varies according to sociodemographic features, such as age, gender and ethnicity. There is a pattern of increasing chronic primary pain prevalence with age. A systematic review reported that pain increases with age from 14.4% in 18-25 years olds to as high as 62% in the over 75 age group (Fayaz et al., 2016). Ageing is associated with declines in hearing and vision and as pain includes a peripheral sensory component it is possible that it too changes with age (Gadkaree et al., 2016). It could also be explained by an increase in overall tissue injury with age (Dahlhamer et al., 2018).

The prevalence of chronic pain is higher in women than men. The health survey for England (2017) reported that women have a higher prevalence of chronic pain (37%) compared to men

(30%). A systematic review of chronic pain and gender disparities found that women also experience higher pain intensity than men (LeResche, 2011). These gender disparities may be explained by biopsychosocial factors such as hormones playing a role in increased pain sensitivity in women (Craft, 2007). Oestradiol and progesterone effects on pain sensitivity are complex as they have pro-nociceptive and anti-nociceptive effects. Testosterone has only anti-nociceptive effects which could explain why men have lower pain sensitivity than women. However most of the research in this area is focused on pain sensitivity in the menstrual cycle and effects are small at best (Sherman & LeResche, 2006). Psychosocial processes such as pain coping and exposure to stress in early life may explain gender related differences in pain. While it has been found that men tend to use behavioural distraction to manage pain, women tend to use social support, emotion-focused techniques and are more attentionally focused on pain (Fillingham et al., 2016). Research has also found that pain catastrophising is associated with increased pain-related disability, and that women engage more with pain catastrophising than men (Keefe et al., 1989). It is likely that sociocultural beliefs about gender play a role in gender disparities in pain. Pain expression is generally more acceptable among women, which may contribute to higher reports of pain and increased engagement in pain services (Robinson et al., 2001). With respect to early life stressors, Fillingim and colleagues (2005) observed that a history of childhood abuse was associated with decreased pain sensitivity, but only in women.

There are also substantial variations in the prevalence and impact of chronic pain across ethnicities and cultural backgrounds. Those who identify as White have been found to experience less self-reported pain and less pain-related disability than those who identify as Black (Campbell et al., 2012). A recent survey in the UK found that those who identify as Black, Asian or mixed ethnicity were more likely to report chronic pain than their White counterparts (Macfarlane et al., 2015). However, once adjusted for income, employment and adverse life events, the association between ethnicity and chronic pain was significantly attenuated. These results further highlight the link between socio-economic background and the prevalence of chronic pain. Macfarlane et al

(2015) found that those who earn under £18,000 a year reported a 52.5% prevalence of chronic pain, whilst those earning over £100,000 a year reported a lower prevalence of 33.5%. They also reported a chronic pain prevalence of 78.9% in those who were unemployed, compared to 39.8% in those in paid employment.

Psychological Interventions for Chronic Pain

The National Institute for Health and Care Excellence (NICE) guidelines (2021) recommend that treatments for chronic pain include antidepressant medication, exercise therapy and psychological therapies. In terms of psychological therapies, NICE recommends Cognitive Behavioural Therapy (CBT; Beck et al., 1983) or Acceptance and Commitment Therapy (ACT; Hayes et al, 2012) as effective psychological approaches for the self-management of chronic pain. ACT and CBT have both been found to be clinical and cost effective treatments for chronic pain (Hann & McCracken, 2014; Ehde et al, 2014).

A Cochrane review evaluated the efficacy of CBT for chronic pain and concluded that compared with treatment as usual or waitlist control conditions, it has statistically significant but small effects on pain and disability, and moderate effects on low mood and catastrophising (Williams et al., 2012). CBT for chronic pain is based on the CBT Fear Avoidance Model of Pain (Lethem et al., 1983). This was originally developed to explain the transition from acute to chronic lower back pain (Vlaeylen & Linton, 2000). The model posits that pain-related fear leads to the avoidance of movement and activity. This avoidance is likely adaptive in the context of acute pain and injury as it allows the body to rest and repair, however in the context of chronic pain, reduced functioning can lead to increased disability, through deconditioning, and increased depression. The model suggests that fear of pain may also be negatively reinforced by avoidance behaviours over time. The model has been supported by a systematic review of randomised controlled trials (RCTs) of treatments for people suffering from chronic pain (Wertli et al., 2014). Wertli and colleagues found that greater fear avoidance beliefs at baseline were associated with greater levels of self-reported disability and reduced likelihood of returning to work at follow-up assessments.

ACT for chronic pain (Mckracken., 2005) focuses on helping patients to acquire effective behaviour patterns guided by what they hold as important such as goals and values in life. The primary treatment processes in ACT include acceptance, cognitive defusion, committed action, contact with the present moment, self-as context and values. Systematic reviews of ACT for chronic pain have found ACT to be equally as effective as CBT for chronic pain (Veehof et al., 2016; Hughes et al., 2017).

The NICE guidelines for chronic pain in over 16s (2021) recommend the use of multi-disciplinary pain management programmes (PMPs) for the treatment of chronic pain. These deliver supported self-management, which has been defined in the NHS Long Term Plan as "the ways that health and care services encourage, support and empower people to manage their ongoing physical and mental health conditions themselves" (Alderwick and Dixon, 2019). PMPs are a multidisciplinary treatment package grounded in CBT or ACT. The British Pain Society have produced guidelines from PMPs for adults (British Pain Society, 2013). These state that PMPs are designed to improve function by supporting changes in behaviours which maintain or worsen pain. Research has found that PMPs are effective for improving pain experience, emotional distress, disability, pain behaviour and coping (McCracken et al., 2002, Williams et al., 2012). Despite the effectiveness of PMPs, many people find optimal self-management difficult to achieve, with difficulties adhering to daily self-management activities, identifying lack of motivation and lack of support as barriers to adherence (Matthias et al, 2020).

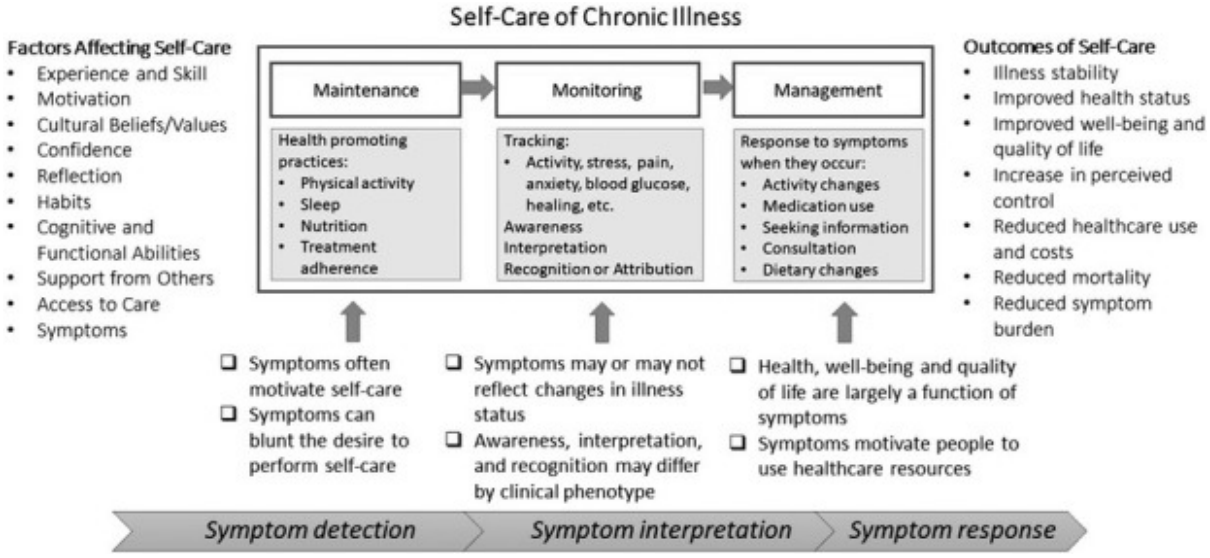
Theories of Self-Management of Chronic Illness

Self-management of chronic illness has been defined as a process of maintaining health through health promoting practices and managing illness (Riegel et al., 2012, Figure 1). A key underlying process in self-management, outlined in the theory of self-care by Riegel and colleagues (2012) is that symptoms interact directly with self-care monitoring and self-care management. Active monitoring and interpretation of symptoms is needed to guide helpful self-care behaviours. There is also a need for decision-making and reflection concerning intended and unintended

outcomes of behaviours. The model stipulates that cognitive and functional abilities affect self-care as decision-making about self-care and reflection on symptoms require cognitive resources, and can be developed through self-management education.

Figure 1.

Theory of self-care (Rigel et al., 2012)



Adapting to chronic illness is condition-specific and therefore the desired outcomes of self-management may vary. For example, for a condition associated with chronic pain such as arthritis, the key task may be coping with pain and potential progressive disability, so the desired outcome may be to maintain quality of life in the face of illness. Low distress may not always be obtainable. Whereas with a condition such as Sickle Cell Disease the goal may be to prevent infections and learn health behaviours to reduce the likelihood of Sickle Cell crisis. This may include having an awareness of the early signs of a Sickle Cell crisis and learning to self-manage with bed rest, hydration and the use of analgesic medication.

Adjustment to chronic illness can also be understood using the stress and coping model of Lazarus and Folkman (1984). This suggests that adjustment to situations such as illness is

influenced by the individual's appraisal of the situation, the coping strategies they use to manage stressors, and their appraisal of the efficacy of their coping strategies.

Self-management is multifaceted and therefore increasing self-efficacy needs to take into account background factors which influence how people respond and adapt to chronic illness, their personality traits, their physical and psychological functioning and their social and environmental influences.

Self-Management in Chronic Pain

The NHS Long Term Plan (2019) has placed increasing focus on the management of long-term conditions, such as chronic pain. The plan outlines the move towards more personalised care to enable professionals to tailor treatment approaches to patient needs. This approach takes into account any individual barriers to ensure that approaches such as health coaching, peer support and self-management education are systematically offered to enhance confidence and skills in self-managing a long-term condition. The NHS Long Term Plan identifies patient activation as an important marker of supported self-management.

Patient activation refers to the knowledge, skills and confidence people have to manage their own health. Patient activation can be measured using the Patient Activation Measure (PAM; Hibbard et al., 2005) which is a 13-item survey that assesses an individual's knowledge, skills and confidence in managing one's own health and healthcare. The measure has been found to be stable across differing levels of health status. The reliability of the PAM is also stable across gender, age groups, education level and differing chronic illnesses. This suggests the measure can be used to assess activation across a variety of subgroups in the population (Hibbard et al, 2004).

Research has shown that increased scores in patient activation are correlated with improved health behaviours (Hibbard et al, 2007). Numerous studies in chronic disease have found that compared to those with higher scores on the PAM measure, those with lower scores are less likely to manage their condition effectively, have less adherence to medication, poorer diets and exercise regimes, and are less likely to ask a question in a medical appointment (Hibbard et al., 2005, Mosen

et al., 2007, Greene et al., 2013). This suggests that people with lower scores on the PAM measure may benefit more from tailored support to help them to better manage their health.

Existing research has identified some predictors of self-management in chronic pain. Gender differences have been identified, with increased chronic pain prevalence and pain perception in women (Unruh, 1996). Women have also been found to have better clinical outcomes from PMP's (Pieh et al., 2012). Research has also found age, level of education and occupational status to be predictors of self-management in chronic lower back pain (Kawi, 2014). Unsurprisingly, pain intensity has also been shown to predict self-management in pain. McCracken and Yang (2006) found pain intensity accounted for significant variance in health care use, disability and distress in chronic pain.

Mood disorders such as depression and anxiety have been associated with poorer adherence to self-management strategies of long-term health conditions, including chronic pain (Nicholas et al, 2012). In comparison, pain self-efficacy moderates the relationship between pain intensity and depression, so that when self-efficacy is high, there is a decrease in association between pain intensity and depression (Cheng et al, 2018).

The NICE (2021) guidelines for chronic pain identified that barriers to self-management in chronic pain are an important area in need of further research. NICE (2021) made a research recommendation in this area to investigate the factors that may be barriers to successfully managing chronic pain. The NICE committee reviewed the evidence concerning a large number of biopsychosocial factors that may act as barriers to successful pain self-management. Little research evidence was identified, however, on the association between cognitive symptoms and pain self-management.

Cognitive impairment has been found to affect self-management in other chronic health conditions. For instance, executive functioning was identified as a predictor of poorer inhaler technique in COPD and found to be associated with the need for assistance in daily living and treatment adherence (Baird et al., 2017). A systematic review of self-management in heart failure

found people with lower cognitive scores were less likely to seek support and less likely to adhere to diet and exercise recommendations (Lovell et al., 2019). The relationship between cognitive impairment and self-management in chronic pain has not yet been investigated.

In addition to needing more research on barriers to successful self-management of pain in general, little is known, specifically, about the extent to which cognitive impairments in chronic pain are associated with pain self-management, separately to the impact of depression or pain catastrophising. This is an important question in the field of clinical psychology, as understanding this link may help psychologists to better tailor pain management programmes to individual needs, therefore increasing the effectiveness of interventions and ensuring scarce NHS resources are systematically offered in the most clinical and cost effective way.

The following chapters present new investigations of the factors that influence self-management of pain. First, a systematic review is presented of research identifying factors that predict outcomes of CBT for chronic pain management. Second, a large cross-sectional survey of people with chronic pain is presented, which was used to investigate the extent to which subjective cognitive complaints are associated with pain self-management, separately to the impact of pain intensity, depression or pain catastrophising.

Chapter Two

Systematic Review

Word Count: 6488

Chapter 2: Systematic Review

Predictors of Treatment Outcome in Cognitive Behavioural Therapy for Chronic Pain: A Systematic Review

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Abstract

Purpose: The aim of this systematic review was to synthesise the research identifying possible influences on CBT outcomes in chronic pain. Variations in the effectiveness of psychological therapies, such as CBT, in chronic pain have led to research investigating predictors of improved treatment outcomes. **Materials and methods:** We identified randomised controlled and cohort studies of CBT for chronic pain, published between 1974 to 2022, which identified predictors of CBT outcomes. **Results:** Eighteen studies were included in the review. Baseline sociodemographic, physical and emotional factors that influence the outcomes of CBT for chronic pain were identified. The most commonly reported predictors of CBT outcome, with medium to large effect sizes, were anxiety, depression and negative cognitions about pain and coping. Sociodemographic predictors of outcomes demonstrated small effects and lacked replicability. **Discussion:** There was variability across study designs, CBT delivery and outcomes measures. Future research is needed in chronic pain to identify the predictive factors which influence treatment outcomes, and consistency across study designs and outcome variables is needed to reduce heterogeneity.

Keywords': Chronic pain, self-management, pain management, cognitive deficits, cognitive impairment, cognitive symptoms

Introduction

Chronic pain, classified as pain that persists for three months or more (Treede et al., 2019) is associated with significant emotional distress and interference with daily functioning (Nicholas et al., 2019). Non-pharmacological management approaches include Cognitive Behavioural therapy (CBT), an effective psychological treatment for chronic pain, reported to improve quality of life and pain-related distress and disability in people living with chronic pain (Morey et al., 1999; Butlet et al., 2006; Wetherell et al., 2011). Alongside Acceptance Commitment Therapy (ACT), CBT is a first line recommended treatment for chronic pain (NICE, 2021). Its use was supported by a recent Cochrane review of psychological therapies for chronic pain, which found that CBT had the largest evidence base (59 studies). However, when compared to an active control, or treatment as usual, it showed only small beneficial effects for pain and distress post-treatment (Williams et al., 2020).

The latest version of the United Kingdom (UK) National Institute for Health and Care Excellence guidelines on chronic pain made a research recommendation for studies to identify barriers to successful management of chronic pain to enable stratification of treatment (NICE, 2021). The evidence reviewed suggested that CBT for pain improves quality of life for people with chronic primary pain, but consistent benefits were not found for other outcomes. To date, there is insufficient evidence to indicate if specific psychological, biological or social factors predict successful outcomes for pain management (NICE, 2021). Previous systematic reviews attempted to identify predictors of CBT and ACT outcomes in chronic pain. McCracken and Turk (2002) found that differences in sample characteristics, treatment features and assessment methods produced large variability in CBT outcomes, and that patients who are highly distressed and view their pain as an uncontrollable and as a highly negative life event, derive less benefit than other patients. Decreased negative emotional responses to pain, decreased perceptions of disability and increased orientation toward self-management predicted favourable treatment outcomes. Gilpin and colleagues (2017) conducted a systematic review of the predictors of ACT outcome in chronic pain. They reported there was some evidence that baseline emotional functioning predicted treatment

response but that the direction of this association varied across studies, and that overall, there was heterogeneity in the treatment delivery.

There is increasing consensus in the literature that improvements in CBT for chronic pain may derive from a better understanding of the patient characteristics which predict, moderate and mediate key outcomes in chronic pain. It is likely that understanding these factors will help refine and individualise psychological treatments for chronic pain (DeRubeis et al., 2014; Gilpin et al., 2017; Kraemer et al., 2002; Turner et al., 2007; Williams et al., 2012).

In line with the CBT model for chronic pain, research has attempted to identify factors which not only maintain pain-related distress and disability but also predict outcomes following psychological treatment for pain. Pain-related cognitions such as catastrophising and sense of helplessness have been linked to CBT treatment outcomes (Turner et al., 2007; Jensen et al., 2001). Emotional factors such as depression and fear of movement (or fear avoidance) have been associated with greater pain intensity and disability (Ang et al., 2010).

Within health research "prognostic study designs" aim to identify variables, or predictors, associated with health outcomes of interest to help inform clinical decisions and identify targets for new interventions with the aim of modifying the course of a disease or health condition (Riley et al., 2013). In the present study the terms predictive variable and prognostic factor have been used interchangeably.

Despite advances in the understanding of pain mechanisms and psychological treatments for chronic pain, the effectiveness of treatment for pain and distress is low (Williams et al., 2020). This systematic review therefore aimed to identify predictors of outcome in CBT for chronic pain to help guide the use of treatment resources and support more targeted interventions for those unlikely to benefit from CBT for chronic pain.

Method

Protocol Registration

This systematic review was preregistered on the PROSPERO International Prospective Register of Systematic Reviews (PROSPERO-ID CRD42016038795) and conducted in accordance with the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2015).

Search Strategy

The search strategy was developed with input from clinical psychologists working in chronic pain and a specialist librarian. A systematic literature search was conducted on 14/03/2022 to identify eligible studies published between January 1974 to 14th March 2022 in four relevant electronic databases (Medline, EMBASE, PsychINFO and CINAHL). The search included (1) terms relating to Cognitive Behavioural therapy (2) terms related to chronic pain and (3) free text terms related to various pain conditions. The search strategy covered all types of chronic pain, and had English language limits, human limits and clinical trial limits. In EMBASE and MEDLINE a limit was added for adults aged 18-65. Reference lists for all included studies were scanned for relevant articles. The search was conducted by one reviewer (G.F). For further details see the search strategy section (Appendix B).

Eligibility Criteria

Studies were assessed for their eligibility according to the following inclusion criteria: 1) participants were aged 18 or older and had chronic pain, defined as pain that has persisted for three months or more (Treede et al., 2019); 2) the study designs were cohort studies or randomised controlled trials (RCT) comparing CBT to a waitlist control, treatment as usual or active/comparison condition; 3) outcome measurement included one of the following: pain intensity, pain interference, physical function, emotional functioning, quality of life, social functioning, ability to work, sleep and healthcare utilisation; 4) CBT was delivered one-to-one, as a group, part of a multidisciplinary programme or online; and 5) the studies identified predictors of CBT outcomes in chronic pain.

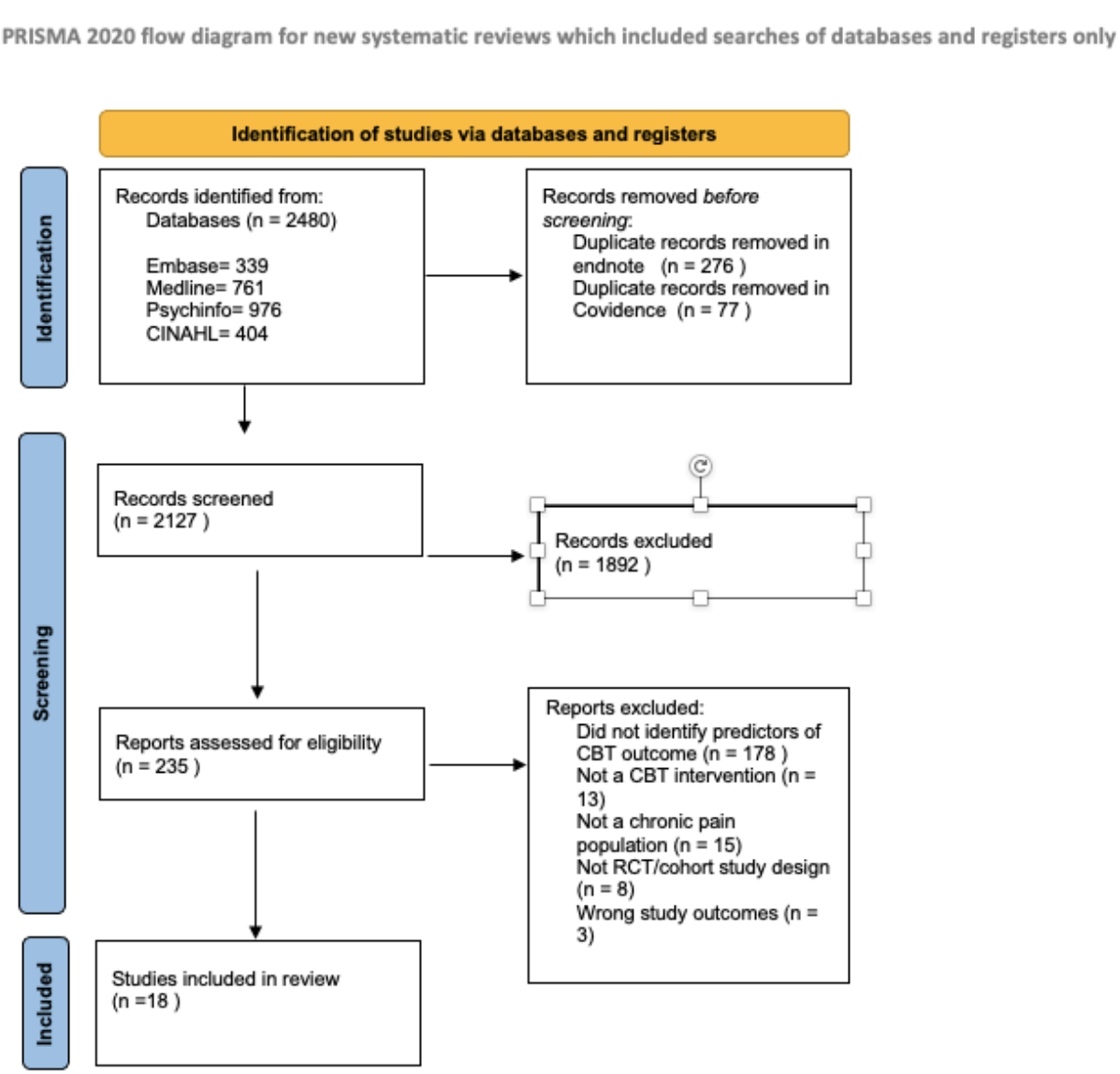
Studies of contextual cognitive behavioural interventions such as ACT, compassion focused therapy and mindfulness-based interventions were not eligible for inclusion, unless as comparators for CBT intervention. Text-delivered CBT interventions were also excluded.

Study Selection

Articles which were identified in the initial search strategy were screened by one reviewer (G.F.) on the basis of the title and abstract according to the inclusion criteria. Full text screening was carried out by two reviewers, with one discrepancy resolved following discussions between G.F and P.W. Figure 1 summarises the systematic search and study screening process using a Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flowchart.

Figure 1.

Prisma Flow Diagram



Data Extraction

Data were extracted from the studies on year of publication, study design, sample size, intervention delivery type, content of the intervention, duration of the intervention, outcome measures, and timing of outcome assessments. Significant predictors of outcome were recorded. To aid interpretation, we transformed relevant inferential statistics into correlation coefficients to attain standardisation (Borenstein et al, 2009). See below for characteristics of the included studies and summary of outcome measurement (Table 2).

Assessment of Study Quality

Study quality was assessed using the Hayden criteria (2006) which are designed to assess the quality of studies of prognosis or prognostic factors. The criteria focuses on six areas of potential measurement in prognosis studies: study participants, attrition, prognostic factor measurement, measurement of confounding variables, outcome measurement and analysis. Risk of bias was rated as low, moderate or high. Studies were classified as low quality if one or more areas of bias were rated as high risk, and high quality if risk of bias ratings or all six areas were low or moderate, in accordance with the protocol described by Hayden et al. (2006).

Of the 18 studies included in the review, eight were found to be 'low quality' and 10 'high quality' according to the Hayden criteria (2006). Two studies were rated as having low risk of bias across all areas (Akerblom 2021, Deroushers, 2010). The majority of the studies were not primarily designed to identify predictors or moderators of outcome and therefore the quality ratings of the statistical analysis of the studies was, in accordance with the criteria, reduced as a consequence. A rating of 'low' quality does not necessarily indicate that the study was of overall low methodological quality but that the methods used were not robust for identifying prognostic factors. See table 1 for a full summary of the risk of bias ratings and overall study quality rating for the 18 studies included in this review. To check for reliability of the quality ratings, G.F and P.W rated all of the studies (n= 18) and were in agreement.

Table 1.

Risk of Bias and Study Quality

	Risk of Bias						Study Quality
Study ID	Selection	Attrition	Prognostic Factor	Outcomes	Confounders	Analysis	Overall Rating
Akerblom 2021	low	low	low	low	low	low	High
Bellomo 2020	high	moderate	low	low	low	low	Low
Blanchard 2006	low	high	low	low	low	low	Low
Brotto 2020	low	moderate	moderate	low	low	moderate	Low
Buchner 2007	low	low	low	low	low	moderate	High
Burns 1998	low	high	high	low	low	low	Low
Desrochers 2010	low	low	low	low	low	low	High
Flor 1993	low	high	low	low	low	low	Low
Jensen 2001	low	moderate	low	low	low	high	Low
Jensen 2007	low	moderate	low	low	low	low	High
Lackner 2010	low	low	low	low	low	moderate	High
Lera 2009	low	moderate	low	low	low	low	High
McCracken 1998	high	low	low	low	low	low	Low
Pfingsten 1997	high	low	low	low	low	low	Low
Samwel 2009	low	moderate	low	low	low	low	High
Serrat 2021	low	low	low	high	low	low	Low
Turner 2007	low	moderate	low	low	low	low	High
Wetherell 2016	low	moderate	low	low	low	low	High

Data Synthesis

It was not possible to apply meta-analytic methods for this review due to the lack of replication across predictor and outcome variables in multiple studies. A narrative synthesis of quantitative data was therefore performed (Popay et al., 2006). To aid interpretation, relevant inferential statistics were transformed into correlation coefficients to allow for standardisation and enable synthesis.

Primary outcome measures were categorised under four subheadings to group the most prevalent outcome measures used: (1) pain intensity, (2) quality of life, (3) physical functioning and (4) depression symptoms. A further group of outcomes were categorised as ‘other’ for those studies

with outcome measures which did not fall under the four categories and where few other studies had reported the same outcome.

Results

Full characteristics of the 18 studies are presented in table 2. The majority were randomised controlled trials and seven were cohort studies. Studies were from the Netherlands, Spain, Germany, USA, Canada and Sweden. Sample sizes ranged from 66 to 405 participants. The samples consisted of adults with a mean age range of 42 to 55 years old. Four of the studies included women only (Lera, 2009; Desrochers, 2010; Brotto, 2020; Bellomo, 2020). All other studies included more women than men. Most studies used group CBT interventions, with just three studies offering individual CBT. The CBT interventions ranged from three to 15 weeks in duration. Four studies included a mixed sample of chronic pain (Wetherell, 2016; Samwei, 2009; Jensen 2007; Åkerblom 2021), three specified fibromyalgia (Serrat, 2021; Lera, 2009; Bellomo 2020), two focused on irritable bowel syndrome (IBS, Lackner, 2010; Blanchard, 2006), two included provoked vestibulodynia (PVD, Desrochers, 2010; Brotto, 2020), five included back pain (Pfingsten, 1997; McCracken, 1998; Jensen 2001; Flor, 1993, Buchner 2007) and one studied musculoskeletal pain (Burns, 1998) or chronic temporomandibular disorder (TMD; Turner, 2007).

Table 2: Table of Study Characteristics

Study	Design	Sample	CBT Intervention	Outcome	CBT Outcomes and Predictors
Åkerblom 2021	Cohort Study	Sweden: 232 people with chronic pain 86% females, mean age 41.6 (SD 9.88), 76% born in Sweden, mean pain duration 98 months. Years education not given.	5-week CBT group treatment with 18 active treatment days (5-7 hours / day), 2-month "homework" phase on individual goals and 2 further treatment days on progress, difficulties and future goals.	12 months	Pain interference (MPI) was predicted by higher pain inflexibility (PIPS) at baseline (p=.019) Depression (HADS) was predicted by higher pain inflexibility (PIPS) at baseline (p=.047)
Bellomo, 2020	RCT secondary analysis, comparing 3 groups: Emotional awareness expression therapy (N = 57), CBT (N = 51), and Pain Education Control (N = 46)	USA: 196 women with Fibromyalgia Mean age 49.7 (SD 11.88), 77% white, mean 15 years education. Pain duration not given.	Eight 90-minute weekly group CBT sessions delivered by Clinical Psychologists.	Post-treatment	Improvement in clinical pain severity (Multimodal Automated Sensory Testing (MAST) system) associated with low pain tolerance at baseline (CBT mean [95% CI] = .66 [.24, 1.07] BPI-S (Brief Pain Inventory- Severity) – no predictor identified.
Blanchard 2006	Cohort study	USA: 137 people with IBS 81% females, mean age 49 (SD 13.1), 94% white, mean years education 14.9, mean duration of IBS 18 years.	Ten 90-minute weekly group CT sessions delivered by doctoral-level clinicians.	3 months	Improvement in Post-Treatment Discomfort Index was predicted by having fewer baseline Axis I disorders at pre-treatment and lower baseline Daily Stress Inventory Improvement in Post-Treatment QOL was predicted by pre-treatment IBS-QOL score, race, baseline diarrhoea, pre-treatment state anxiety score.(p=.001) Improvement in Post-Treatment Global Severity Index (psychological distress) was predicted by trait anxiety,SF-36, level of education, Dysfunction Attitudes Scale(p=.001), Improvement in Post-Treatment Bowel Regularity Index was predicted by baseline GAD and SF-36 (Physical Functioning subscale)

Study	Design	Sample	CBT Intervention	Outcome	CBT Outcomes and Predictors
Brotto, 2020	Randomised Study comparing 2 groups: CBT (N = 63) and Mindfulness based cognitive therapy (N = 67)	Canada: 130 women with Provoked Vestibulodynia Mean age 32.35 (±8.21), 66.7% Euro-Canadian, mean duration of PVD 7.95 years	Eight 135-minute weekly group CBT sessions delivered by clinicians with specialist training in group therapy and PVD.	6 months	Sexual Function (Female sexual function index): Women in longer relationships had better outcomes (P=.01) Pain Intensity (NRS): Younger women (P=.01) Pain Catastrophizing (PCS): Primary PVD (P=.01)
Buchner 2007	Cohort study comparing three age groups; 18-34, 35-50 and 51-65.	Germany: 405 people with chronic lower back pain. 58% females, 18-65 years, sickness leave for <= 6 weeks.	3-week inpatient multidisciplinary therapy programme (8 hours / day, 120 hours total) providing biopsychosocial therapy including CBT.	6 months	Physical Function (SF-36): 18-34, 35-50 showed significant improvements (p=.029) Pain Intensity (VAS): 18-34, 35-50 showed significant improvements (p=.04) Functional Capacity (FFBH): 18-34, 35-50 showed significant improvements (p=.008
Burns 1998	Cohort study	US: 94 people with musculoskeletal pain	4-week, multidisciplinary program, including physical and occupational therapy, individual and group CBT, biofeedback, education about pain, and treatment by a physician.	6 months	Activity levels (GAS): Increased walking endurance (p=.03) Pain Severity (PSS): Lower pain helplessness (p=.0003)
Desrochers 2010	Randomised Study comparing 2 groups: CBT (N = 46) and Topical application (N = 51)	Canada: 97 women with provoked vestibulodynia aged between 18-45.	Ten 90-minute weekly group CBT sessions delivered by PhD level psychotherapists.	6 months	Pain Intensity (VAS): Baseline age of contraceptive use (6% variance), Pain self-efficacy (PSEQ, 9% variance) Pain severity (MPQ-PRI): Pain catastrophising (PCS, 13% variance).

Study	Design	Sample	CBT Intervention	Outcome	CBT Outcomes and Predictors
Flor 1993	Randomised Study comparing 3 groups: CBT (N = 26), Electromyographic Biofeedback (N = 26), and Conservative medical treatment (N = 26)	Germany: 78 people with chronic back pain and temporomandibular pain. Average age = 42 years, 60% female, 100% white, 75% married, 66% employed.	Eight 60-minute weekly group CBT sessions delivered by Clinical Psychologists.	6 months	Pain severity and interference (MPI): Those with pronounced cognitive distortions (PRSS catastrophising scale) profited least from CBT (p=.01). Chronicity of pain was negatively correlated with outcome (p=.01).
Jensen 2001	Randomised Study, comparing 4 groups: CBT (N = 49), Treatment as usual (N = 48) Behaviour-orientated physical therapy (N = 54) and Behavioural medicine group (N = 63)	Sweden: 214 people on sick leave with chronic non-specific spinal pain, Average age= 43.8 years (SD= 9.6), 54% female, 74% married, 86% employed.	Group intervention compromising of 13-14 hours per week aimed to improve subjects ability to manage their pain and resume activity levels.	18 months	QOL (SF-38): Gender, females (P=.004) Taking early retirement: Gender, females sig lower risk 0.1 (0.0±0.8) compared to males 0.6 (0.2± 2.1).
Jensen 2007	Cohort study.	USA: 141 people in chronic pain. 51% female, mean age 44.7 (SD 10.7), 90% white and median pain duration 3.2 years (range, 4 months - 48 years).	3-week outpatient chronic pain programme aimed at improving pain management skills and physical and psychological functioning.	12 months	Pain intensity (NRS): Changes in passive coping (p=.01) Depression (CES-D): Catastrophising (p=.001) Pain disability (RMDQ): Pain beliefs of medical focus (p=.05) and passive coping (p=.001)
Lackner 2010	RCT secondary analysis comparing 3 groups: 4-session CBT (N = 25), 10-session CBT (N = 23) and a waitlist control (N = 27).	USA: 71 people with irritable bowel syndrome aged 18-70.	CBT was offered as four or ten weekly 1-hour sessions.	12 weeks	Decrease in IBSSS score of 50 points of more Higher QOL impairment (IBSQOL, p=.01); Personal control beliefs (IBS-LOC, p=.01)

Study	Design	Sample	CBT Intervention	Outcome	CBT Outcomes and Predictors
Lera 2009	RCT comparing two groups: MDT treatment with CBT (N = 35) vs without CBT (N = 31)	Spain: 66 women with fibromyalgia Mean age 50 (SD= 9.3), duration of symptoms 16 years, 4.5 comorbid chronic disorders.	Group CBT, 15 group sessions,90 minutes per week led by a clinical psychologist	6 months	Functional status and symptoms (FIQ and SF-36) Fatigue (r=.29); lower number of tender points (r=.27)
McCracken 1998	Cohort study	USA 79 people with chronic lower back pain.	3 week group pain management programme, 5 days per week, of physical exercise and behavioural interventions.	Post treatment	Decreased depression, pain severity, interference, affective distress and activity: Pain related anxiety (p=.05)
Pfingsten 1997	Cohort study	Germany: 90 people with chronic lower back pain, 51% female, mean age 42 (SD= 8.7), average time off work 9 months.	8-week group program of functional restoration and behavioural support	12 months	Not returning to work was associated with already having applied for a pension (r=.95), a negative outlook about returning to work prior to treatment (r=.54), out of work for > 6 months (r=.46)
Samwel 2009	Non- Randomised Study comparing four groups: CBT (N = 21), Medical treatment (N = 19), Transcutaneous Electrical Nerve Stimulation (N = 50), Combined treatment: (N = 20) vs Control group: (N = 110)	The Netherlands: 220 people in chronic pain, mean pain duration 63 months, 64% female.	Ten 90-minute weekly sessions of group CBT, focused on reducing disability and depression	Post treatment	Pain intensity (VAS): Acceptance (ICQ, r=.20)

Study	Design	Sample	CBT Intervention	Outcome	CBT Outcomes and Predictors
Serrat 2021	RCT comparing two groups: Multicomponent treatment with CBT (N = 135) and Treatment as usual (N = 137).	Spain: 272 people with Fibromyalgia mean age 54, mean pain , duration 17 years, 22.4% employed.	Group multicomponent treatment, weekly 2-hour sessions for 12 weeks	6 months	Responder group (reduction in FIQR score of 20%): Higher depression score (p=.01)
Turner 2007	RCT comparing two groups: CBT (N = 55) and Educational/attention control group: (N = 50/55)	USA: 156 people with chronic temporomandibular disorder (TMD), 87% female, 85% White.	Individual bi weekly sessions over 8 weeks by Clinical Psychologists	12 months	Masticatory disability scores: Baseline masticatory scores (p=.001) Activity interference: Depression, somatisation, rumination, catastrophising, perceived stress
Wetherell, 2016	Randomised study, comparing CBT (N = 57) and ACT (N = 57)	USA: 114 people with non-malignant chronic pain conditions. Mean age 55 years, mean pain duration 15 years, 17.5% met criteria for depression.	Eight 90-minute group CBT, 90 sessions	6 months	Treatment response (defined as at least 30% decrease on BPI interference subscale): Younger age (when controlling for depression, p=.01)

ACT = Acceptance and Commitment Therapy, CBT = Cognitive Behavioural Therapy, RCT = Randomised controlled trial, VAS = Visual Analogue Scale, MPI = Multidimensional Pain Inventory, PIPS = Psychological Inflexibility Pain Scale, IBS = Irritable Bowel Syndrome, NRS = Numerical Rating Scale, QOL = Quality of Life, CES -D = Centre for Epidemiologic Studies Depression Scale, RMDQ = Roland Morris Disability Questionnaire, IBSSS = IBS-Severity Score, IBS-LOC = IBS-Locus of Control, FIQ = Fibromyalgia Impact Questionnaire. SF-36 = Short Form 36 Health Survey Questionnaire. VAS = Visual Analogue Scale, ICQ = Illness Cognition Questionnaire , FIQR = FIQ-Revised, MDT = Multidisciplinary Treatment PSS = Pain Severity Scale , GAS = Goal Attainment Scale

Predictors of CBT for Pain Outcomes: Pain Intensity

Nine studies investigated significant predictors of pain intensity outcomes (Desrouchers, 2010; Flor, 1993; Burns, 1998; Jensen, 2007; McCracken, 1998; Samwei, 2009; Bellomo, 2020; Wetherell 2016; Buchner, 2007). The studies identified 12 predictors of pain intensity outcomes for CBT for chronic pain (table 3). These were: younger age, pain helplessness, pain-related anxiety, lower pain tolerance, passive coping, lower pronounced cognitive distortions and lower pain self-efficacy. Two of these studies found younger age was linked to better pain intensity outcomes (Buchner 2007; Desrouchers 2010), however these effect sizes were small. The majority of psychological predictors had medium effect sizes, indicating that baseline variables such as pain-related cognitions and anxiety are consistent predictors of pain intensity outcomes following CBT for pain, however the quality of these studies is mixed. Three studies were rated as high quality (Samwei, 2009; Jensen, 2007; Desrouchers, 2010) and three were rated as low quality (McCracken, 1998; Burns, 1998; Flor, 1993). Table 3 shows the results of the studies including sample size, effect size (*r*) and a rating of the effect size for *r*.

Table 3

Predictors of Pain Intensity Post-treatment

Category of Predictors of CBT for chronic pain outcomes	*Study*	*N*	*Effect size (r)*	*Effect size rating (S/M/L)*
Demographics				
Age of 1st contraceptive use	Desrouchers 2010	46	-.270	S
Younger Age	Wetherell 2016	57	.227	S
	Buchner 2007	405	.087	-
Physical symptoms				
Lower pain tolerance	Bellomo 2020	51	.316	M
Chronicity of pain (Years)	Flor 1993	26	-.308	M
Psychological & Mental Health variables				
Pronounced cognitive distortions	Flor 1993	26	-.480	M
Pain-related anxiety	McCracken 1998	79	.440	M
Cognitions and beliefs about coping	Jensen 2007	141	.39	M
Pain helplessness	Burns 1998	94	.339	M

	Pain self-efficacy	Desrouchers 2010	46	-.310	M
	Acceptance	Samwei 2009	21	.20	S
	Pain catastrophising	Desrouchers 2010	46	.260	S

Depression

Three studies investigated predictors of depression outcomes of CBT for chronic pain (table 4). Lower pain-related anxiety at baseline was found to have a large effect size on outcomes of depression after CBT for pain in one study (McCracken, 1998). The study quality was low and the sample size relatively small (n = 79). Cognitions and coping beliefs predicted depression outcomes with a medium effect size in a study (Jensen, 2007) with a larger sample size (n = 141) but also of low quality.

Table 4.

Predictors of Depression Post-Treatment

Category	*Predictor Variable*	*Study*	*N*	*Effect size (r)*	*Effect size rating (S/M/L)*
Psychological & Mental Health variables					
	Pain-related anxiety	McCracken 1998	79	.57	L
	Cognitions and beliefs about coping	Jensen 2007	141	.41	M
	Higher pain inflexibility	Akerblom 2021	232	.16	S

Quality of Life (QOL)

One study identified multiple predictors of quality of life outcomes (table 5; Blanchard, 2006). The study focused on patients with irritable bowel syndrome (IBS) and identified that baseline diarrhoea, IBS QOL, race and anxiety were correlates of QOL post CBT. The effect sizes for all four predictors were large. This study was rated as high quality with a relatively large sample size of 137, however the study sample was overwhelmingly White (94%) and therefore predictors such as race should be interpreted with caution. These predictors were all in the context of IBS.

Table 5.

Predictors of Quality of Life Post-Treatment

Category	*Predictor Variable*	*Study*	*N*	*Effect size (r)*	*Effect size rating (S/M/L)*
Demographics					
	Race (Caucasian)	Blanchard 2006	137	.55	L
Physical Symptoms					
	Baseline Diarrhoea (IBS)	Blanchard 2006	137	.51	L
Psychological & Mental Health variables					
	IBS QOL	Blanchard 2006	137	.68	L
	State anxiety	Blanchard 2006	137	.59	L

Physical Functioning

Seven studies identified predictors of physical functioning outcomes of CBT for chronic pain (table 6; Akerblom, 2021; Buchner, 2007; Burns, 1998; Jensen, 2007; Lera, 2009; McCracken, 1998; Turner, 2007). As with pain intensity, younger age was found to be a predictor of outcome but this effect size was small (Buchner, 2007). A number of physical symptoms were found to predict outcomes on physical functioning including fatigue, walking endurance, and number of tender points and pain sites. Two studies found that the number of pain sites correlated with worse outcomes post CBT, however these effects were small (Lera, 2009; Turner, 2007).

A number of psychological factors were linked to worse physical functioning outcomes post CBT. Higher rates of depression, somatisation (measured using the Somatization Scale of the Symptom Checklist-90), rumination (measured using the Pain Catastrophizing Scale), catastrophising and stress were all found by one study to predict worse physical functioning outcomes post CBT. The sample size in this study was relatively small (n = 55) but the quality was rated as high (Turner, 2007). A medium effect size was found for negative pain cognitions and coping and increased pain related anxiety as

predictors of worse outcomes in physical functioning post CBT. The quality for these two studies was low (Jensen, 2007; McCracken, 1998). Higher pain flexibility was found to have a small effect size on predicting CBT outcome on physical functioning (Akerblom, 2021).

Table 6.

Predictors of Physical Functioning at post-treatment

Category	*Predictor Variable*	*Study*	*N*	*Effect size (r)*	*Effect size rating (S/M/L)*
Demographics					
	Younger age	Buchner 2007	405	-.09	-
Physical Symptoms					
	Fatigue	Lera 2009	35	.29	S
	Tender points	Lera 2009	35	-.27	S
	Walking endurance	Burns 1998	94	.26	S
	Number of pain sites	Turner 2007	55	.21	S
Psychological & MH variables					
	Cognitions and coping	Jensen 2007	141	.47	M
	Pain related anxiety	McCracken 1998	79	.37	M
	Depression	Turner 2007	55	.31	M
	Somatization	Turner 2007	55	.31	M
	Rumination	Turner 2007	55	.31	M
	Catastrophising	Turner 2007	55	.31	M
	Perceived stress	Turner 2007	55	.31	M
	Higher pain flexibility	Akerblom 2021	232	.20	S

Predictors of Other CBT Outcomes

Two studies investigated predictors of work-related outcomes after CBT (table 7; Jensen, 2001; Pfingsten, 1997). Females were found to be less likely to take early retirement post CBT (Jensen, 2001), and to therefore continue working, however the sample size in the CBT arm of the study was relatively small (n = 49). Being out of work for six months or more, having already applied for a pension (with the intention to retire) or having a negative outlook on returning to work was found to be correlated with not returning to work post CBT

(Pfingsten, 1997). In a study of provoked vestibulodynia (PVD) the length of relationships, in women, was found to predict in sexual function as an outcome of CBT (Brotto, 2020). This effect size was large. Primary PVD is categorised as women who have experienced pain since first having penetrative sex. Primary PVD was found to be correlated with improvements on pain catastrophising post CBT, compared to secondary PVD. Secondary PVD is categorised as woman who have experienced pain-free sex prior to the development of PVD.

A number of variables were found to predict physical outcomes in IBS. Disability, bloating, depression and anxiety, and hassles (measured using the Hassles scale) were found to be predictors of worse IBS symptoms outcome post CBT (Blanchard, 2006). However, higher IBS QOL and personal control beliefs were linked to better outcomes on IBS symptoms post CBT (Lackner, 2010). Blanchard and colleagues (2006) also found large effect sizes for baseline constipation, severity of symptoms and depression as predictors of worse IBS outcomes following CBT. In summary, worse IBS symptoms at baseline are correlated with poorer CBT outcomes.

In fibromyalgia patients, higher depression scores were correlated with worse outcomes on fibromyalgia impact scale, with a medium effect size (Serrat, 2021).

Table 7.

Predictors of 'Other Outcomes' Post-treatment

Category	*Predictor Variable*	*Study*	*N*	*Effect size (r)*	*Effect size rating (S/M/L)*
Demographics					
Not taking early retirement	Females	Jensen, 2001	49	9% Females 18% Males	
Not returning to work after CBT	1. Being out of work for 6 months 2. Already applied for a pension, 3. Negative outlook about returning to work	Pfingsten, 1997	90	1. 0.95 2. 0.54 3. 0.46	1. L 2. L 3. M
Sexual function (sexual function index)	Length of relationship	Brotto 2020	63	0.69	L

Physical Symptoms					
Improvement in GI symptoms	1. Disability severity inventory 2. Baseline bloating GI diary 3. DAS (Depression and anxiety) 4. Hassles frequency	Blanchard 2006	137	1. .39 2. .33 3. .33 4. .28	M M M S
Irritable Bowel Syndrome Severity Score (IBSSS)	1. Personal control beliefs (IBS-LOC) 2. IBS QOL	Lackner 2010	71	1. .30 2. .28	M S
Revised fibromyalgia impact questionnaire	Higher Depression scores (HADS)	Serrat 2021	135	0.45	M
Psychological & MH variables					
Pain catastrophising	PVD Type (Primary)	Brotto 2020	63	0.69	L
Global severity index	1. Baseline constipation GI diary 2. Global severity scale 3. BDI	Blanchard 2006	137	1. .54 2. .69 3. .66	L L L

Discussion

CBT is an effective psychological therapy for people with chronic pain, but not all people benefit. Studies have investigated a diverse range of variables that may influence outcomes of CBT in chronic pain. This review has identified a number of baseline cognitive, emotional, demographic and physical factors that correlate with outcomes of CBT for chronic pain.

Patient demographic factors identified as potential predictors of improved outcomes in CBT were gender (females), younger age, later age of first contraceptive use (in PVD), race (being White), being in a longer relationship (in PVD), being out of work for less than six months, not having applied for a pension, or having a more positive outlook about returning to work. Demographic variables such as age and gender as predictors of CBT outcome should be interpreted with caution, as the study samples in this review were

predominantly White and had high proportions of females, and the prevalence of chronic pain is widely accepted as being more prevalent in females (Fayaz et al, 2016).

Many samples included in this review are not representative of ethnic diversity in the UK and not representative of disparities of chronic pain prevalence and increased intensity across some ethnic groups. Several studies have reported greater pain intensity in Black American participants (McCracken et al, 2001; Ndao-Brumblay and Green, 2005). The Versus Arthritis chronic pain report (2021) suggested that Black communities in the UK are more likely to have chronic pain than people of other ethnicities and people who describe themselves as Asian are more likely to report chronic pain than people of other ethnic groups.

A large effect was found for the length of relationship and outcomes for sexual function in PVD. This reflects the literature in other pain conditions such as fibromyalgia where partnered patients reported less pain-related physical disability, which is mediated by more adaptive affective and cognitive responses (such a less pain catastrophising) to pain, than found in unpartnered patients (Taylor et al, 2013). Teasing apart the predictive or causality nature of relationship status and chronic pain is unclear. However, it is well established that psychosocial factors play a significant role in pain, for example episodes of loneliness have been associated with increased pain and negative social relations (Boersma, 2006; Hruschak, 2018; Vlaeyen, 2000).

Unsurprisingly this review identified predictors of returning to work such as chronicity of absence from work and negative beliefs about returning to work. This is in line with a study of sick leave more broadly, which found that those on short sick leave were more satisfied when returning to work than those who were on longer sick leave (Boštjančič & Galič, 2020). This fits with the literature and cognitive models of pain in that negative pain experience and beliefs can lead to increased disability over time (Fayad at al, 2004).

This review identified several physical symptoms which predicted outcomes of CBT in chronic pain. These included the number of pain sites, walking endurance, fatigue, IBS symptoms, chronicity of chronic pain and pain tolerance. The severity of symptoms prior to receiving CBT was found to impact on outcomes post CBT. Two studies identified that an increased number of pain sites were correlated with worse outcomes but these effects were small. These findings add to a larger literature which has failed to find consistent evidence that this variable predicts outcomes of treatment in chronic pain (Gilpin et al, 2017; McCracken & Turk, 2002; Akerblom, 2021).

The most common category of predictors identified overall were psychological variables, which was expected as CBT is a psychological intervention. Anxiety was the most prevalent predictor of poorer outcomes identified in four studies in this review with effect sizes in the medium to large range. Two studies identified a medium effect size for depression in predicting poorer outcomes after CBT. Higher levels of psychological distress such as anxiety and depression at baseline have been associated with poorer outcome in CBT for chronic pain (Linton et al., 2011) and can be understood by the fear avoidance model of pain as a maintaining or exacerbating factor in chronic pain (Vlaeyen, 2000). Anxiety and depression in pain are also associated with increased negative beliefs around coping, pain catastrophising and rumination which are all features of depression and anxiety in chronic pain. Three studies identified that higher levels of pain catastrophising at baseline predicted worse CBT outcomes, however the effect sizes varied from small to large.

In this review, higher pain flexibility was found to have a small effect on positive outcomes in CBT. This has been well studied as a predictor of positive outcome in ACT therapies for chronic pain (Gilpin, 2017) but less so in CBT and warrants further investigation.

Limitations

Of the 178 studies identified that investigated treatment outcomes for CBT in chronic pain, only 18 studies identified significant predictors of treatment outcome. In the studies included in this review there were a number of methodological weaknesses. Most studies were primarily designed to assess the effectiveness of an intervention and not to identify prognostic factors. There was variability in the design of studies between randomised controlled trials and cohort designs, between follow up time points, the outcomes measured and delivery of the CBT intervention. These inconsistencies make it difficult to make comparisons across studies. As previous research has highlighted, there is a need for outcomes in pain research to be consistently measured in a standardised way (Dworkin et al, 2005; Gilpin et al, 2017; Hann & McCracken, 2014). There was also variability in the types of chronic pain studied, some studies focused on all forms of chronic pain and others focused on specific types of chronic pain, such as IBS or PVD, which in turn linked to specific outcome measures such as IBS symptoms or sexual function. The samples included in this study are largely White and predominantly, if not completely, female, potentially limiting the generalisability of the findings.

In terms of delivery of CBT interventions. There were differences between methods of delivery (e.g. group or individual sessions) and the number of sessions offered. In many studies, the CBT intervention was delivered as part of a multi-package of several other components such as physical therapy, sleep education and nutrition. It is likely that these differences in treatment delivery impact on the differences in outcome found across the studies in this review. This highlights the methodological inconsistencies and the difficulty of synthesizing results across studies in CBT for chronic pain.

A key limitation of this review was the focus only on predictors and not moderators or mediators of CBT outcome in chronic pain. Understanding the role of mediators and moderators in CBT outcome may help create a more comprehensive picture of the variables that affect outcomes. There is also a risk of publication bias as only published studies were included in the review.

A recent review of predictors of outcome in ACT proposed that a focus on a theoretically driven approach to identifying predictors or moderators of outcome is needed (Gilpin et al., 2017). Arguably predictors of CBT for pain outcomes have largely fitted with the CBT fear avoidance theory of pain, in that they can be categorised into pain cognitions, pain experience and physical disability. However, some studies in the review were less theory-driven in terms of identifying predictors of CBT outcome. This could explain why some variables such as demographics are less likely to be replicated across studies. Gilpin and colleagues (2017) proposed that a fundamental difficulty in finding meaningful predictors of outcome in chronic pain may be the lack of theoretical grounding in the selection of potential predictors, or moderators, of treatment outcome. A theory driven approach to identifying predictors of outcome in chronic pain will help to reduce heterogeneity across studies and enable more consistent findings to emerge.

A recent article by McCracken (2023) highlighted the need to move towards more individualised treatments in chronic pain, and that individualised treatments should be tailored around the predominant symptom the individual is presenting with. Hofmann and Hayes (2019) also suggest a move towards personalised treatments based on functional analysis and targeting evidence-based processes of change, opposed to following manualised treatments based on a particular therapeutic approach such as CBT or ACT. A systematic review (Elbers et al., 2022) found, however, that most multidisciplinary treatments for

chronic pain show low levels of tailoring interventions (80%), and few were highly tailored (8%). Therefore, future research focused on symptom targeted interventions in chronic pain may provide useful insights.

A number of demographic, and baseline physical and emotional factors were identified which impact on the effectiveness of CBT. The most prevalent predictors of CBT for pain outcomes involved forms of emotional distress (anxiety and depression) and cognitions about pain and coping. Demographic predictors of outcomes demonstrated small effects and lacked replicability. There was heterogeneity across study designs, CBT interventions and importantly outcomes measures used. Future research is needed in chronic pain to identify the prognostic factors which influence treatment outcomes and consistency across study designs and outcome variables is needed to reduce heterogeneity, and enable robust meta-analyses of the data.

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Chapter Three

Bridging Chapter

Word Count: 825

Chapter 3: Bridging Chapter

The systematic review in Chapter Two identified predictors of treatment outcomes for Cognitive Behavioural Therapy (CBT) for chronic pain. The review identified a number of demographic and baseline physical and emotional factors which are associated with the effectiveness of CBT (Labarere et al., 2014). The predictors of outcomes, which were most often reported, across the studies were linked to emotional distress (anxiety and depression) and cognitions about pain and coping. Demographic predictors of outcomes demonstrated small effects and lacked replicability. Across the review there was a lack of homogeneity in study designs and statistical analysis methods used. Eleven of the 18 studies included in the systematic review were randomised controlled trials (RCTs), primarily investigating the effectiveness of an intervention with a secondary aim of exploring predictors of treatment outcome. Whilst this is a sound approach to identifying causal relationships to treatment outcomes, this design is not primarily focused on identifying predictors of treatment outcome (Wynants et al., 2017) . The Prognosis Research Strategy (PROGRESS) encourages a prospective rather than a retrospective design as this enables clear inclusion criteria, more complete baseline and follow up data and greater standardisation of primary factors and outcome variables. This reduces the potential for data dredging and therefore type one errors (Riley et al., 2013). The optimal study design for the derivation of prognostic outcome variables is a longitudinal cohort study (Wynants et al., 2017). Many studies included in the systematic review were retrospective study designs, associated with randomised controlled trials. In terms of statistical methods for studies of prognostic factors, regression models can make accurate predictions compared to other methods such as stratification and recursive partitioning, when model assumptions are thoroughly examined. This ensures that researchers do not over fit the data, by developing models using too many predictor variables and

insufficient sample sizes (Harrell et al., 1985). In the systematic review 12 of the 18 included studies used regression analysis techniques.

In the primary research study, reported in Chapter Four, a cohort study design was employed to identify the extent to which self-reported cognitive symptoms predict self-management in chronic pain. The analysis involved a hierarchical regression technique. Hierarchical regression analyses have previously been used to identify predictors of treatment outcome in chronic pain research. For example, McCracken & Gross (1998) used a hierarchical regression method to assess the impact of pain-related anxiety on the outcomes of a multidisciplinary treatment programme for chronic pain. In their study, demographic and background variables (age, duration of pain, education, gender, and pain severity) were entered as a block, followed by changes in pain-related anxiety. The regression suggested that decreased pain-related anxiety is associated with improvements across a range of outcomes including depression, pain severity, pain interference, distress and activity level. This method of analysis provided evidence that changes in pain-related anxiety are a significant predictor of outcome, even after changes in depression are taken into account.

A similar analysis method was used in Chapter Four to identify whether self-reported cognitive symptoms predict self-management of chronic pain, after accounting for the impact of well-studied variables such as anxiety, depression, pain catastrophising and pain symptoms. As with McCraken and Gross (1998), variables were entered into the model in a theoretically-driven stepwise manner.

Cognitive Behavioural Therapy (CBT) is based on the cognitive model of mental illness, initially developed by Beck (1964). It hypothesises that people's emotions and behaviours are influenced by their perceptions of events. The CBT approach to pain management is based on the premise that individual's cognitions (beliefs) and emotions affect their behaviours in response to pain, and that these behaviours and appraisals affect

their experiences of pain (Vlaeyen & Linton, 2000). The bidirectional relationship between depression and chronic pain is well-recognised in the literature, psychological predictors of improved outcome in chronic pain are associated with stronger beliefs in control over pain (Jensen et al., 2007), less catastrophising and negative thoughts related to pain (Desrouchers et al., 2010), and reduced anxiety and depression (Blanchard et al., 2006; Turner et al., 2007). To date, the impact of self-reported cognitive deficits on self-management in chronic pain has yet to be explored.

The primary outcome of interest in the study was self-management, as measured by the patient activation measure (PAM; Hibbard et al., 2004). CBT is intrinsically linked to the concept of self-management, and encourages patients to conceptualise pain as manageable and to move from a passive to active role in pain management (Taylor & Sirois, 2012). However, CBT and self-management strategies of pain do not explicitly consider cognitive deficits and the limitations they might have on managing chronic pain. Pain management services in the National Health Service (NHS) typically offer psychological approaches, such as CBT, as well as other interventions such as exercise and pain medication, to support self-management. Therefore the empirical paper will focus on self-management as a broader outcome than CBT alone. Chapter Four, therefore, examines the extent to which self-reported cognitive symptoms predict self-management in chronic pain.

Chapter Four

Primary Research Study

Word Count: 5540

Chapter 4: Primary Research Study

To What Extent Do Subjective Cognitive Symptoms Predict Self-Management in Chronic Pain?

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(Author guidelines for manuscript preparation in Appendix A)

Abstract

Background: Chronic pain is associated with an increased prevalence of anxiety, depression (Woo., 2010) and cognitive issues (Mazza et al., 2018). However, little is known about how much subjective cognitive complaints affect self-management in chronic pain.

Aims: We investigated the extent to which subjective cognitive symptoms predict pain self-management after controlling for sociodemographic, pain and mood variables.

Methods: 286 adults with chronic pain, recruited from pain services and online, completed measures of mood; pain symptoms and catastrophising; subjective memory and executive functioning; and the Patient Activation Measure (PAM).

Results: A hierarchical regression predicting the PAM13 was significant with sociodemographic, pain, mood and cognitive variables accounting for little variance in patient activation (R^2 = 4.9%, p >.049). A hierarchical regression model predicting the PAM10 was significant (R^2 =29.6%, p >.00), with mood accounting for the most variance. Subjective executive functioning was a significant predictor of patient activation (PAM10, p > .029).

Conclusions: This was one of the first studies to investigate the extent to which cognitive symptoms impact on self-management in chronic pain. Associations were found between sociodemographic and mood variables with the PAM10. The DEX-R was a significant predictor of patient activation.

Keywords'. Predictor(s), factor(s), cognitive-behavio(u)ral therapy, chronic pain, treatment outcome.

Introduction

Chronic primary pain is a long-term condition (LTC) which is often experienced alongside other LTCs (McQueenie et al., 2021), and affects approximately 20% of the world's population, with important physical, psychological, social and financial consequences (Mills et al., 2019; Yong et al., 2022). It is defined as persistent or recurring pain lasting for longer than three months, associated with significant emotional distress and/or disability, which is not better accounted for by another diagnosis (Nicholas & Vlaeyen, 2019). The distress associated with chronic pain frequently takes the form of depression and anxiety (Woo., 2010) with up to 85% of people with chronic pain estimated to be affected by depression (Bair et al., 2003) and the prevalence of anxiety in chronic pain doubled compared to the general population (McWilliams & Mood, 2003). Anxiety mediates other forms of psychological distress including pain catastrophising, hypervigilance and fear avoidance (Kneeland et al., 2019). Pain catastrophising, conceptualised as a negative cognitive affective response to pain (Quartana et al., 2009) is also associated with negative pain-related outcomes (Craner et al., 2016). A prominent psychological model of chronic pain, the fear avoidance model (Vlaeyen & Linton, 2012) suggests that pain catastrophising, fear of pain, avoidance of activity, negative cognitions, and hypervigilance intensify the pain experience and maintain emotional distress associated with pain.

Treatment of chronic pain involves pharmacological and non-pharmacological forms of supported self-management, defined as "the ways that health and care services encourage, support and empower people to manage their ongoing physical and mental health conditions themselves" (NHSE, 2023). Participation in active self-management of a LTC such as chronic pain can be influenced by many factors, including the chronicity of the condition, severity of the disease, age, social support and level of education. According to Barlow et al.

(2002) effective self-management depends on an individual's ability to self-monitor and flexibly make cognitive, emotional and behavioural adjustments and it is likely participation in self-management will fluctuate over time. Positive adjustment towards self-management strategies in people is known as "patient activation" (Hibbard and Cunningham, 2008) which reflects individuals readiness and capability to undertake health promoting actions (Hibbard et al, 2004). It can be assessed using the Patient Activation Measure self-report questionnaire (PAM; Hibbard et al., 2005). Research using the PAM indicates that patient activation correlates with positive health-related outcomes, including complication prevention, healthier lifestyle decisions and cost-effectiveness in healthcare (Hibbard et al, 2007). The PAM is available as a 13-item version including three items on the controllability and knowledge of health behaviours, or a shorter 10-item version without these items. The PAM-13 has been used to assess self-reported self-management of chronic pain. A recent study found that higher patient activation (PAM13) was associated with lower age, higher education and fewer comorbidities in people with chronic pain and increased pain intensity and chronicity were negatively correlated with patient activation (Yao et al, 2021). It is unclear, however, if this is the preferred version of the PAM to use for LTCs such as chronic pain, as the shorter version (PMA10) was found to be preferable in a qualitative study in the United Kingdom (UK) with people with cystic fibrosis. They suggested the additional items were not well suited to assess patient activation given the chronic nature of the condition (Gao et al., 2019).

Several non-pharmacological forms of supported self-management for chronic primary pain are recommended by the National Institute of Health and Care Excellence (NICE, 2021) including psychological therapies, Cognitive Behavioural Therapy (CBT) or Acceptance and Commitment Therapy (ACT), supervised group exercise programmes and in some cases, acupuncture. There is also strong evidence supporting Pain Management Programmes (PMPs), which combine elements of CBT and or ACT with exercise (The

British Pain Society, 2013). People with chronic pain are not a homogenous group and numerous studies of predictors of response to PMPS have found inconsistent results, often dependent on whether outcome is defined as pain, disability, distress, return to work or treatment adherence (Haazen et al., 1994).

It is unclear which subgroups of people with chronic pain are likely to show greatest patient activation and benefit most from supported self-management interventions for pain (Williams et al, 2013). Attempts have been made to identify biopsychosocial factors that predict successful pain management to identify whether treatment can be stratified by modifying these factors directly or modifying treatment to take them into account. Associations are reported between social variables and pain management outcomes including gender differences (MacFarlane et al., 1999; Jensen, 2001), age differences, with younger age linked to improved outcomes (Buchner et al., 2007; Wetherell et al., 2016) and differences in level of education and occupational status, found to predict self-management in chronic lower back pain (Kawi, 2014). Associations are also reported between psychological variables and better pain management outcomes including stronger beliefs of control over pain (Jensen et al., 2007), less catastrophising and negative thoughts related to pain (Desrouchers et al., 2010), reduced anxiety and depression (Blanchard et al., 2006; Turner et al., 2007) and unsurprisingly, lower initial pain intensity (McCracken & Yang, 2006). A review by NICE found no evidence for social prognostic factors. The review found low to moderate quality evidence, that pain management outcomes are predicted by biological factors such as level of physical exercise or having a comorbid condition, or psychological factors such as depression, anxiety, catastrophizing and kinesiophobia (NICE, 2021). It was concluded that identifying biological, psychological or social prognostic factors predicting successful pain management is an important area for further research to enable treatment stratification for chronic pain (NICE, 2021).

Cognitive ability, as a potential psychological prognostic variable, does not appear to have been included in the review of psychological factors predicting treatment outcomes (NICE, 2021) yet there are reasons to believe that cognitive complaints influence self-management of LTCs in general and pain management in particular. A framework by Ibrahim and colleagues proposes that cognitive impairments affect five key processes of chronic disease self-management; problem solving, decision making, finding and using appropriate resources, working with healthcare professionals to make decisions about treatment and taking action including monitoring, taking medication and making lifestyle changes (Ibrahim et al., 2017). For example, memory loss can affect ability to adhere to medication, attend appointments and learn new management strategies. Deficits in attention and frontal-executive function may reduce ability to self-regulate responses in order to manage a LTC (Reilly et al., 2010). It has been clear for some time that there is evidence for pain-related changes in attentional, executive and general cognitive functioning (Moriarty, McGuire & Fin,, 2011). Continued exposure to pain, negative emotions or psychosocial stressors may deplete cognitive resources leading to impairment in executive function (Raio, et al, 2013; Williams et al, 2009). Chronic pain affects long-term and working memory, as reported by a systematic review of 24 studies showing a moderate decline in working and long-term memory in chronic pain (Mazza et al, 2018). Pain-relief medications also affect cognition. A study of people with chronic pain. with and without opiate therapy, found both groups needed longer information processing time than a control group. Those with opiate therapy also showed reductions in spatial memory capacity, cognitive flexibility and working memory compared to those without opiate therapy (Schiltenwolf et al, 2014). Cognitive complaints have also been found to be associated with depression and pain catastrophising (Roth et al., 2004).

Given the need to identify potential barriers to self-management of pain and lack of research on the relationship between subjective cognitive complaints and ability to self-manage chronic pain, we aimed to test the extent to which subjective cognitive complaints predict self-management in chronic pain, as measured on the PAM. We focussed on subjective cognitive complaints (SCC), or "self- or informant-reported cognitive disturbances occurring in the absence of objective signs and known underlying pathological conditions" (Canevelli et al., 2013) for two reasons. Firstly, SCC are highly prevalent in people with physical multimorbidity (Jacob et al., 2019) and can act as sensitive preclinical markers preceding measurable changes in neuropsychological test performance (Oliver et al., 2022). Secondly, subjective appraisals of cognition may provide modifiable treatment targets for CBT to improve patient activation in the management of physical, emotional, cognitive and social components of chronic pain. If SCCs predict pain self-management it would be important for PMPs to consider cognition in assessments and stratify treatment accordingly. Given the known associations between cognition, depression and pain catastrophising, we aimed to test whether or not SCCs predict unique variance in patient activation in the context of chronic pain. As it is unclear which version of the PAM is best suited to assess self-management of LTCs, we examined which was most sensitive to predictor variables by conducting analyses using both versions.

Method

Participants

Adults with chronic pain (pain that has persisted for more than three months) were recruited from five NHS trusts in England (n=31), social media and chronic pain charity newsletters (n=255) between October 2021 and October 2022. All participants eligible to participate self-reported that they live with chronic pain, were aged between 18-65 and able

to read English in order to complete the study materials. Those identified by an NHS service were confirmed, by a clinician, to live with chronic pain.

Measures

Information was collected, via an online survey (JISC), on age, gender, ethnicity, education, occupational status, pain medication and pain chronicity. The following measures were also used:

Patient Reported Outcome Measure: The Patient Activation Measure (PAM; Hibbard et al., 2005). This is a 13-item or 10-item self-report measure with a maximum score of 100. Respondents indicate their level of agreement with up to 13 statements using a four-point scale ranging from 'disagree strongly' to 'agree strongly' scored as a 1 to 4, or 'not applicable'. The activation score is calculated with a potential range between 0-100. Lower scores indicate less understanding of health conditions, more passive response to care and a view of self-management as compliance, whereas higher scores are associated with working more actively in partnership with health professionals to manage a condition. The PAM-13 has been found to be a reliable (Cronbach α =0.87) and valid measure in people with chronic pain (Eyles et al., 2020). The content validity index was 0.91 in patients with multimorbid chronic disease (Schmaderer et al., 2015).

Predictor Variables: Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). The HADS consists of 14-items equally distributed between anxiety and depression subscales. The anxiety subscale includes aspects of generalised anxiety, worry and panic. The depression subscale mainly covers aspects of anhedonia and low mood. The items are scored on a 4-point Likert scale ranging from 0 to 3. The scale has been used in chronic pain and demonstrated good test-retest reliability (r =0.83) and construct validity in fibromyalgia patients (Bjelland et al., 2002, Turk et al., 2015).

Predictor Variables: The Pain Catastrophising Scale (PCS; Sullivan et al., 1995). The PCS is a 13-item self-report measure designed to assess catastrophic thinking among adults with chronic pain. The PCS has three-sub scores (rumination, magnification and helplessness) and a total score for catastrophising. The total score ranges from 0-52, where a higher score indicates high catastrophising. The PCS has good internal reliability (Cronbach alpha= 0.92) and test-retest reliability (r =0.88) (Sullivan et al., 1995). The PCS total and subscale correlated significantly with the Inventory of Negative Thought in Response to Pain (p <.01) providing evidence of concurrent validity for the PCS (Osman et al., 1997).

Predictor Variables: Numerical Pain Rating Scale (McCaffery et al., 1989). The Numerical Pain Rating Scale (NPRS) is a commonly used pain rating scale. The numerical scale asks the person to rate their pain from 0 to 10, with 0 being "no pain" and 10 being "the worst pain imaginable". An advantage of this scale is its simplicity with an estimated completion time of one minute. It has been found to have high test-retest reliability (r =0.96) in people with chronic pain (Ferraz et al., 1990), for construct validity the NPRS was shown to be highly correlated with the Visual Analogue Scale in patients with chronic pain conditions, correlations range from 0.86 to 0.95 (Ferraz el., 1990).

Predictor Variables: The Dysexecutive Questionnaires – Revised Version (DEX-R; Wilson et al., 1998). The DEX-R is a 37-item scale designed to measure everyday manifestations of dysexecutive problems following acquired brain injury (ABI). It is available as a self-report measure and has been found to be valid and reliable for use in people without ABI (Wakely, 2020). Respondents are asked to rate on a 5-point Likert scale how often they experience difficulties associated with control and direction of cognition, emotions and behaviours (e.g. planning, impulsivity and motivation). The DEX-R has been found to be a reliable measure with excellent internal consistency (Cronbach's α = 0.93) (Hermans et al., 2011). The DEX-R has good concurrent validity when compared to

responses given on another validated measure of dysexecutive problems, The Frontal Systems Behaviour Scale (FrSBE; Grace & Malloy, 2001). The correlation between the DEX-R and FrSBE is r = .83, <.01 (Wakely, 2020). The DEX-R has two forms, Self and Informant, which contain the same items but phrased as appropriate.

Predictor Variables: Everyday Memory Questionnaire Revised (EMQ; Royle et al., 2007). The EMQ is a 13-item self-report measure of retrieval and attentional tracking. It has been found to have strong internal reliability (Cronbach's α = 0.89) and good discriminatory properties between clinical and control groups, and good face validity (Royle et al., 2007).

Procedure

Participants who met the eligibility criteria and provided written or online informed consent completed the measures online via JISC, an online survey tool. An answer was required for each question in the survey preventing any missing data. Participants were given the option to provide details of an informant (relative or close friend) who would be contacted and asked to complete the DEX-R informant questionnaire online.

Ethical Considerations

The study received ethical approval from the UK Health Research Authority (HRA, REC:21/PR/1450) and the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee (Reference number ETH2122-1462).

Analysis

Hierarchical multiple regression analyses were used to examine the extent to which self-management, measured using the PAM13 and PAM10 can be predicted from sociodemographic, pain, emotional and cognitive variables. Predictor variables were added to the model in theoretically-driven hierarchical steps. In accordance with the literature sociodemographic variables and pain intensity were entered into models first. In the second step, pain catastrophising, anxiety and depression were added as psychological variables of

known association with chronic pain but not our specific focus. Finally, subjective cognitive complaint (SCC) measures (the DEX-R and EMQ) were added to test whether SCCs account for unique variance in patient activation in the context of chronic pain, over and above the influence of clinical and sociodemographic variables and pain catastrophising and depression. There was no missing data.

Before conducting the hierarchical regression analyses, the distribution of data was assessed using histograms and pair-wise associations between sociodemographic variables (age and education level, pain severity, depression, pain catastrophising, memory, executive function, and patient activation) using Pearson's correlation coefficients. Multicollinearity between variables was assessed using SPSS. A tolerance level of > 0.2 was used to assess that the variance of each predictor uncorrelated with other predictors was at least 20% (Chatterjee et al., 2006).

Statistical checks confirmed that the assumptions of regression models were met. Scatterplots suggested that the relationships between independent variables and dependent variables (PAM13 and PAM10) were linear in nature (Appendix I). Residuals were normally distributed, supporting the assumption of multivariate normality (Appendix J). Collinearity statistics were inspected for each regression model; there was no evidence of significant multicollinearity (i.e., no tolerance statistics <.2, no variance inflation factors > 5).

Results

Two hundred and eighty six participants completed the study of which the most common age group was 30-39 (n = 74), followed by 50-59 (n = 73), 40-49 (n =67), 18-29 (n =50), with the least prevalent age group being 60-65 (n =22). In terms of gender, 86.4% of study participants reported they were female, 12.2% male and 1.4% identified as 'other'. Most participants have experienced chronic pain for 10+ years (62.6%). Employment status ranged widely with the most prevalent responses being full time employment (28.7%) or

unable to work (24.8%). The most common level of education was undergraduate degree (29.7%) or A-levels/equivalent (23.8%). 92.7% of participants were White (92.7%), 2.8% mixed ethnic groups, 1% Asian, 1% Black African/Caribbean/British and 2.4% identified as 'other'.

Correlation Analyses

As shown in table 1, there were large positive correlations between scores on the PCS and the HADS-A (r = .617, < .01), and the PCS and HADS-D (r = .555, < .01), and between the EMQ and the DEX-R (r =.725, < .01). Positive correlations were also observed between PCS and NPRS (r = .38, < .01).

The two versions of the PAM differed in their correlations with potential predictor variables. Only pain chronicity showed a significant bivariate correlation with the PAM13 and this was small (r =-.124, < .05). In contrast, a range of larger correlations were observed between predictor variables and the PAM10, as shown in table 2. A small positive correlation was found between the years of education and PAM10 (r =.175, < .01) indicating that more highly educated people had increased ability to self-manage chronic pain. A moderate-sized negative correlation was found between the EMQ and PAM10 (r =-.293, < .01), and large negative correlations were found for the PCS (r =-432, < .01), DEX-R (r =-0.449, < .01), depression (r =-.442, < .01) and anxiety (r =-.415, < .01) with the PAM10. These indicate that increased ability to self-manage was associated with better subjective memory and executive functioning and lower levels of depression and anxiety.

Positive correlations were found between DEX-R (r =.228) and EMQ-R (r =.196) and the number of pain medications taken. This indicates that higher levels of subjective memory and executive functioning difficulties were associated with taking more pain medications. No significant correlation was found between medication use and patient

activation (PAM13, r =.011), suggesting that self-management is not affected by the number of pain medications taken.

Table 1.

Correlations between demographic, pain, mood and cognition variables with the PAM13

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	.	0.19**	0.01	0.02	-0.16**	-0.19**	-0.28**	-0.03	-0.23**	-0.01
2. Chronicity	.	.	-0.06	0.11	-0.04	0.01	-0.01	-0.08	-.047	-0.12*
3. Education	.	.	.	0.20**	0.25**	0.18**	0.12*	0.18**	0.13*	-0.02
4. NPRS	.	.	.	.	0.38**	0.27**	0.26**	0.35**	0.23**	0
5. PCS	.	.	.	.	0.58**	0.41**	0.55**	0.62**		-0.01
6. DEXR	.	.	.	.	.	0.73**	0.59**	0.69**		-0.03
7. EMQ	.	.		.	.	.	0.43**	0.51**		0.08
8. HADS-D	.	.	.	.	.	.	.	0.56**		0.01
9. HADS- A									.	-.07
10. PAM13	.	.	.	.	.	.	.	.		

Age (1) , Chronicity of pain (2) and Education level (3) are categorical variables; Numerical Pain Rating Scale NPRS (4), Pain Catastrophising Scale PCS (5), The Dysexecutive Questionnaire Revised DEXR (6), The Everyday Memory Questionnaire EMQ (7), The Hospital Anxiety and Depression Scale HADS (8) and The Patient Activation Measure PAM (9). Statistical comparisons, *< .05; **< .01

Table 2.

Correlations between demographic, pain, mood and cognition variables with the PAM10.

Variable	1	2	3	4	5	6	7	8	9	10
Age	.	.19**	0.01	0.02	-0.16**	-0.19**	-0.28**	-0.03	-.23**	0.47
Pain Chronicity	.	.	-0.06	0.12	-0.04	0.01	-0.01	-0.08	-.047	-0.03
Education Level	.	.	.	0.20**	0.25**	0.18**	0.12*	0.18**	.13*	.18**
NPRS	.	.	.	.	0.38**	0.27**	0.26**	0.35**	.23**	-.11
PCS	.	.	.	.	.	0.58**	0.41**	0.56**	.62**	-.43**
DEXR	.	.	.	.	.	.	0.73**	0.60**	.69**	-0.45**
EMQ	.	.	.	.	.	.	.	0.43**	.51**	-.29**
HADS-D	.	.	.	.	.	.	.	.	.56**	-0.44**
HADS- A									.	-.42**
PAM10	.	.	.	.	.	.	.	.		.

Age (1) , Chronicity of pain (2) and Education level (3) are categorical variables; Numerical Pain Rating Scale NPRS (4), Pain Catastrophising Scale PCS (5), The Dysexecutive Questionnaire Revised DEXR (6), The Everyday Memory Questionnaire EMQ (7), The Hospital Anxiety and Depression Scale HADS (8) and The Patient Activation Measure PAM (9). Statistical comparisons, * < .05; ** < .01

Regression Analyses

Hierarchical regression analyses were conducted to test if subjective memory or executive functioning (EMQ and DEX-R) predict patient activation after controlling for sociodemographic, pain and mood variables. This was examined in separate hierarchical regressions predicting PAM13 and PAM10. Tables 3 and 4 show the steps of the hierarchical regression.

In the first hierarchical multiple regression, sociodemographic and pain variables did not contribute significantly to the model (F (5,279) = 1.08, < .371) and accounted for 1.9% of variance in PAM13. Introducing mood variables explained a total of 2.8% variance but this change in R^2 was not significant (F (3,276) = .880, < .452). Finally, the addition of subjective memory and executive functioning explained a total of 4.9% of the variance in self-management and this model was significant (F (2,274) = 3.04, < .049). The highest beta coefficients in the model were found for memory (EMQ, B =.218), pain chronicity (B = -.0141) and anxiety (B =-0.136).

In the second hierarchical regression model, at step one, sociodemographic and pain variables contributed significantly to the regression model (F (5,279) = 2.437, < .035) and accounted for 4.2% of the variation in self-management, measured by the PAM10. Introducing the mood variables (depression, anxiety and pain catastrophizing) explained an additional 24% of variation in self-management, and this change in R^2 was significant (F (3,276) = 30.68, < .000). Finally, the addition of subjective memory and executive functioning explained an additional 1.4% of the variance in self-management, but this change did not reach significance F (2,274) = 2.76, < .066. The highest beta coefficients in the model were depression (B =-.233), DEX-R (B =-.207), pain catastrophising (B =-.179), pain intensity (B =.122).

Table 3.

First Hierarchical regression model predicting self-management (PAM13)

Variable	b	*B SE*	βeta	*t*	*P* value	*R*	R^2
Step 1						.138	.019
Gender	-2.527	2.529	-.063	-.999	.319		
Age	.415	.748	.037	.555	.580		
Chronicity	-2.063	.912	-.141	-2.262	.024*		
Education	-.014	.372	-.002	-.036	.971		
NPRS	-.017	.161	-.007	-.108	.914		
Step 2						.168	.028
PCS	.068	.100	.059	.679	.498		
HADS-A	-.373	.250	-.136	-1.495	.136		
HADS-D	.079	.270	.024	.295	.769		
Step 3						.222	.049
DEXR	-.075	.058	-.139	-1.279	.202		
EMQ	.224	.091	.218	2.462	.014*		

Note: *<.05

Table 4.

Second hierarchical regression model predicting self-management (PAM10)

Variable	b	*B SE*	βeta	*t*	*P* value	*R*	R^2
Step 1						.205*	.042
Gender	-.487	.774	-.034	-.630	.529		
Age	-.019	.230	-.005	-.083	.934		
Chronicity	-.394	.280	-.075	-.1.406	.161		
Education	.141	.114	.067	1.2331	.219		
NPRS	.105	.049	.122	2.115	.035*		
Step 2						.531*	.282
PCS	-.074	.031	-.179	-2.408	.017*		
HADS-A	-.078	.077	-.079	-1.017	.310		
HADS-D	-.271	.083	-.233	-3.275	.001*		
Step 3						.544	.296
DEXR	-.040	.018	-.207	-2.209	.028*		
EMQ	.017	.028	.045	.592	.554		

Note: *<.05

Discussion

This is the first study to assess whether subjective memory and executive functioning predict self-management of chronic pain after controlling sociodemographic, clinical and emotional variables. Although research has attempted to draw conclusions on the relationships between cognitive symptoms and chronic pain, or self-management, they have not been examined simultaneously.

Contrary to our expectations, the present study found small, non-significant correlations between sociodemographic data, pain, mood, cognitive variables and self-management, as measured using the 13-item version of the Patient Activation Measure (PAM13) with the exception of a small significant correlation with pain chronicity. The first hierarchical regression accounted for just 4.9% of variance in PAM13 scores. The additional items in the PAM13 items, not present in the PAM10, focus on 'preventing problems,' suggesting that aspects of the condition are within control and preventable. A study in the UK with cystic fibrosis patients found that these items (3,11) of the PAM13 may not be appropriate for conditions which are progressive or have aspects which are outside of personal control (Gao et al, 2019). This also applies to people with other long-term conditions (LTCs). For example, Armstrong et al (2017) reported that patients with inoperable cancer and motor neuron disease found the item of 'preventing problems' inappropriate to their situation. The small correlations found between the PAM13 and variables known to be associated with chronic pain (age, pain intensity and depression) may reflect a lack of relevance for these three items. Gao et al (2019) also found no significant correlation between the PAM13 scores and nebulizer adherence, an objective measure of self-management in cystic fibrosis patients.

Once the three questions regarding knowledge about health are removed, the remaining questions (e.g., PAM10) focus on self-management. Larger correlations between

sociodemographic, clinical, emotional and subjective cognition variables and self-management were revealed when self-management was measured using the PAM10, rather than the PAM13. Large negative correlations were found between the PAM10 and anxiety, depression and pain catastrophizing. A moderate-sized significant negative correlation was found for the EMQ, and a large significant negative correlation was found for the DEX-R, with the PAM10. This suggests that in addition to mood variables, subjective memory and executive functioning symptoms are associated with self-management in chronic pain.

Hierarchical regression found that sociodemographic variables and pain chronicity did not account for a significant increase in variance of self-management assessed on the PAM10. This is perhaps to be expected, given that associations reported between self-management assessed on the PAM13 and other health outcomes appear consistent across age, health conditions, sociodemographic variables and education (Greene & Hibbard, 2012). Pain intensity, however, was found to explain a small but significant amount of variance on the PAM10. In the second step of the model a significant amount of variance in the PAM10 was accounted for by depression and pain catastrophising. In the final step a significant amount of variance was accounted for by subjective executive functioning. Subjective dysexecutive difficulties predicted lower self-management. Unexpectedly, subjective memory explained little variance in the model and the association between subjective memory and self-management was positive. This would suggest that greater subjective memory difficulty was associated with better self-management on the PAM13. In a separate study, a factor analysis of the EMQ suggests that it reflects not only subjective memory functioning but also attention (Royle & Lincoln, 2009). It could be explained that once subjective executive functioning is included in the model, accounting for variance in self-management related to executive control of attention and memory, this leaves behind a small positive relationship between subjective memory difficulties and self-management on the PAM13. The same

positive relationship was found for the PAM10, however it was smaller. Consistent with this explanation, was the finding that the bivariate correlations between subjective memory difficulties and self-management (PAM13 and PAM10) was negative.

It is interesting to note that associations between the number of pain medications taken and higher scores on subjective memory and executive functioning difficulties were also found, although these correlations were small. These associations may reflect the impact of higher pain intensity, which results in increased use of medication. Small to moderate correlations were consistently found between pain intensity and subjective cognitive complaints. No correlations were found between self-management and pain medication use and therefore it is unlikely that medication use would have contributed to the variance explained by the regression models.

There are a number of limitations that should be taken into account when interpreting these findings. It was not possible to assess the accuracy of subjective cognitive complaints. The DEX-R can be completed by informants and the study included an informant measure of the DEX-R, but there were few informant respondents and therefore this was excluded from the analyses. However, the DEX-R has been found to perform reliably for self and independent ratings of subjective cognitive complaints (Simblett et al., 2012). Baker et al (2007) asked people with chronic pain to complete subjective and objective measures of cognition. They found self-reported cognitive concerns concurred with objective measures, independent of age, education and catastrophising, and that those with severe anxiety made more accurate predictions of their cognitive performance. Negative subjective appraisals of cognition may be associated with low mood, and constitute potentially modifiable targets for psychological therapies such as CBT, which in turn could improve self-management. Consistent with this, a study of older adults found that subjective appraisal of cognitive

complaints was significantly positively correlated with depression, with self-efficacy playing a mediating role (Su et al., 2022).

Research using the PAM13 has found that participants who are female, younger and have more education score significantly higher on this measure (Hibbard, 2005). However, in our analysis gender, age and education accounted for little variance in self-management assessed using the PAM13. When correlated with the PAM10, education was found to have a significant but small correlation. This could be explained by chronic pain being more prevalent among disadvantaged populations, who have lower levels of education and income (Goldberg & Mcgee, 2011), and is more prevalent in older age groups (Domenichiello & Ramsden, 2019). In comparison, Yao and colleagues (2021) found younger age and higher education, in people with chronic pain, was associated with higher action levels.

The sample size was relatively large and fully powered for the regression models. However, the participants were predominantly female (86.4%) and White (92.7%) potentially limiting the generalisability of the findings. This is commonly seen in research in chronic pain. A recent systematic review of multidisciplinary interventions for chronic pain found that of 27 studies, 18 had more female than male participants and two had female-only participants (Joypaul et al., 2019). Population-based studies in the UK have shown that self-reported chronic pain is more prevalent among ethnic minority groups (Allison et al., 2002; Choudhury et al., 2013). Whilst we took steps to increase recruitment of non-White participants by recruiting from Sickle Cell Disease clinics, recruiting from an inner London NHS Trust and adapting study materials to ensure inclusivity, there was insufficient statistical power to include ethnicity in the analysis. This study also excluded those who are unable to speak English. Race has been found to be significantly associated with self-management of health conditions assessed using the PAM13 (Hibbard, 2005). Further research is needed to explore the association between race and self-management in chronic pain.

There are number of variables which might influence self-management of a chronic health condition that were not included in the current study. Participants were not asked about previous psychological interventions, such as CBT, which can enhance self-management of chronic pain (Ehde et al, 2014). Data were not collected on long-term conditions and comorbidities which may influence reported self-management, due to increased treatment burden. Current evidence concerning the relationship between long-term or comorbid conditions and self-management is mixed. For example, a study of chronic kidney disease found that higher symptom burden was associated with lower patient action levels (Magadi et al., 2022). Whilst a large cohort study in the UK found no association between multimorbidity of health conditions and patient activation scores (Blakemore et al, 2016). Future research could therefore usefully consider the influence of symptom and treatment burden on self-management.

The current study did not collect data on neurodiversity or acquired brain injury, which can influence executive function (Demetriou et al., 2017; Perna et al., 2012) and therefore potentially self-management. As the PAM-13 has been found to be reliable and valid in populations with neurological conditions (Packer et al., 2015) future research on impact of cognitive symptoms on self-management in chronic pain might consider the implications of these factors.

Implications and Future Directions

The findings of this study highlight the complexity of identifying predictors of chronic pain management outcomes. Self-management showed smaller associations with sociodemographic and mood variables than expected. This has also been found for other disease groups (Humphries et al., 2022). Having removed three items on ‘disease knowledge’ from the PAM13, we found that the PAM10 was more highly correlated with variables known to be associated with chronic pain. It cannot be ruled out that using subjective

measures alone to identify levels of self-management may be insufficient. Capturing additional health data, such as appointment attendance to pain management services, or adherence to medication, may provide a more reliable picture.

Our findings highlight the importance of considering subjective cognitive complaints and particularly, subjective executive functioning, in the self-management of chronic pain. This is consistent with a recent systematic review of 28 experimental studies, which found that pain can disrupt executive functioning and poorer executive function might be a risk factor for high vulnerability to pain (Bunk et al., 2019). The review found that in objective testing of executive functions, the ability to inhibit responses had the strongest association with pain, but did not assess subjective appraisals of executive functioning. Given the results of this study, there is a need for future research to explore the impact of other cognitive deficits on self-management of chronic pain other than memory and dysexecutive function.

In clinical practice the use of self-report measures of cognition during assessment in chronic pain clinics may help to further tailor self-management approaches to those with chronic pain, negative appraisal of cognition and reduced executive function.

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Chapter Five

Inequality in Research and Chronic Pain

Word Count: 1793

Chapter 5: Inequality in Research and Chronic Pain

This chapter reports on the proactive steps which should be taken in research development, recruitment and dissemination to ensure research is inclusive and representative of the population it is designed to benefit.

Ethnic diversity is growing in the United Kingdom (UK); in the 2011 census 87.5% of the population identified as being White British, whereas by 2021, this had fallen to 74.4%, and 18% of the population identified as Black (4%), Asian (9.3%), mixed (2.9%) or from other minoritised ethnic groups (2.1%) (Office of National Statistics, 2022). This chapter reflects on the discrepancy between this increasing diversity and the underrepresentation of members from minoritised ethnic groups in chronic pain research, including that presented in this thesis.

The samples involved in the studies included in the systematic review and the cross-sectional survey presented in Chapters Two and Four showed under-representation of males and people from minoritised ethnic backgrounds. The Marmot Review, 10 years on (Marmot, 2020) identified that over the last decade health inequalities have worsened and improvements in life expectancy reduced; particularly for women in the most deprived areas. The report recognised that ethnicity intersects with socioeconomic position leading to much poorer outcomes for some minoritised ethnic groups. This gap in health outcomes has widened since COVID-19, when diverse boroughs in London, such as Southeast London saw the highest proportion of deaths from COVID-19, particularly for those from a Black and/or minoritised ethnic background (Laccobuci, 2020). The Marmot review also recognised that a lack of data is an ongoing limitation in understanding healthcare inequalities between ethnic groups and that efforts are needed to gather more data to support analyses, inform policy and intervention and strengthen accountability.

Disparities in chronic pain experience have been reported across different ethnic groups. In the United States (US), several studies have reported greater pain intensity in Black American participants (McCracken et al., 2001; NdaoBrumblay & Green, 2005). In these studies, participants were matched in age, pain location, gender, education level, pain duration and work status. Differences in pain intensity may have been caused by several factors including differing pain beliefs such as pain catastrophising (Green et al, 2004), greater levels of psychosocial distress in Black women (NdaoBrumblay &Green, 2005) or higher levels of anxiety and depression (McCracken et al, 2001).

Population-based studies have also identified that the prevalence of chronic pain, such as musculoskeletal pain, is higher in minoritised ethnic groups in the UK (Allison et al., 2002; Choudhury et al., 2013). In a survey study in Tower Hamlets, London, it was reported that there was a higher prevalence of chronic pain in Bangladeshi groups (16%) than in White (10%), or Bangladeshi British (9%) groups (Choudhury et al., 2013). Choudhury and colleagues concluded that lower levels of acculturation were associated with more pain and identified that those who arrive in the UK after their 14th birthday, were likely to have left full-time education before the age of 12, had a higher prevalence of chronic pain.
Studies which have focused on trying to explain the racial and ethnic disparities in chronic pain experience in the US, have suggested that access to health care, patient attitudes and behaviours may be an explanation (Shavers & Sheppard, 2010; Meghani et al, 2012)

It has been reported that members of minoritised ethnic groups are less likely to seek professional help for problems with mood, despite the prevalence of depression being higher in these groups in the UK than White ethnic groups (Bhui et al., 2004). Williams et al. (2015) found the prevalence of depression in Black Caribbean participants (17.7%) to be almost double that of White participants (9.7%) and that socioeconomic disadvantage had the most effect on the elevated prevalence of depression in Black Caribbean participants. Increased

prevalence of depression may impact self-management of long term conditions like chronic pain, as self-management is limited by symptoms of anxiety and depression, due to a bi-directional relationship between mood and self-management (Cramm & Nieboer, 2012).

The Patient Activation Measure is a self-report measure of self-management of a long-term condition (PAM, Hibbard et al., 2001). Patient activation has been shown to differ by ethnicity and race, with African Americans reportedly having lower levels of patient activation than White Americans, after other characteristics such as age and disease are controlled for (Hibbard et al., 2008). Kendrick et al (2003) found that health literacy was associated with race and patient activation, and that this could be a causal factor in disparities in patient activation, particularly for African American men. They suggest that one way of increasing activation would be to develop policies and interventions to improve health literacy. A study demonstrated that a literacy sensitive self-management programme for people with Chronic Obstructive Pulmonary Disease (COPD) was effective (Kendrick et al., 2003). The programme included appropriate videos and booklet educational materials and demonstrated improvements in self-management outcomes (Kiser et al., 2011).

In order to gain further understanding of disparities in self-management of chronic pain among members of minoritised ethnic groups, it is vital that participants in chronic pain research reflect the wider chronic pain community. In Chapter Two, the systematic review presented found that ethnicity was not reported in most studies included in the review. Seven of the 18 studies which did report the ethnicity of participants, stated that between 66% and 100% of their samples were White. On average, 83% of participants across these studies were White (Bellomo et al., 2020; Brotto et al., 2020; Flor & Birbaumer, 1993; Jensen et al, 2007; Lackner et al., 2010; Turner et al., 2007; Wetherell et al., 2016). In Chapter Four, despite the increase in ethnic diversity in the UK, the cross-sectional survey study found that of 286 participants recruited, 92.7% of the sample reported their ethnicity to be White.

In the study reported in Chapter Four, multiple steps were taken during recruitment to recruit a representative sample of the UK population. Recruitment was extended from East Anglia to an inner London NHS chronic pain service and a London Sickle Cell Disease Service. Study materials, such as the recruitment poster and online study adverts, were adapted to be representative of minoritised ethnic groups and explicitly welcoming to those identifying as Black, Asian or from other minoritised ethnic communities. Patient public involvement was sought from minoritised ethnic groups to review study materials and processes, however this was initiated too late in the recruitment period once the researchers had become of aware of the predominately White sample. Whilst efforts were made to increase representation of ethnic diversity in the study sample, there were also limitations that need to be considered. All study materials were only available in English and therefore required participants to be able to speak or read English. Most participants were recruited from online forums and social media which may have excluded those without access to the internet or a computer. While there are many potential benefits from increased use of digital tools, including recruitment of participants from different geographical areas, there is also an acknowledged risk of some people being excluded. Despite the pandemic and subsequent increased use of digital tools, 29% of the UK population still has "very low digital engagement" (Middle, Welch., 2022). In the study described in chapter four steps were taken to mitigate this risk. Participants were recruited from NHS clinics as well as online forums. The option to complete paper versions of the survey was offered, and where needed people were able to complete the questionnaires over the telephone with the support of the researcher. Despite these offers the vast majority of participants were recruited using digital platforms and therefore it is possible that people with chronic pain, who were digitally excluded, were underrepresented in the study sample.

A recent document from NHS England (2023) which sets out guidance for "Increasing Diversity in Research Participation" identified three primary reasons for underrepresentation: language barriers, accessibility, and mistrust. The guidance suggests that language used in research should be easy to understand and studies should have access to good translation services. In the studies reviewed in Chapter Two, a common participant inclusion criterion was fluency in English language. Some studies reviewed did not report if this was an inclusion criterion. English language was also a requirement of the study reported in Chapter Four. The Core Standards for Pain Management Services in the UK set out that suitability for a pain management programme is based on the impact of pain and there must be no discrimination on the basis of language spoken (Faculty of Pain Medicine, 2021). Nevertheless, in chronic pain research those whose first language is not English are often excluded. This leads to a misleading bias in the outcomes of research and a reporting gap in chronic pain literature. A review of studies published in the British Medical Journal over a two year period identified that 84% of studies did not mention language at any point (Murray & Buller, 2016). Over half of these studies reported that an inability to speak or understand the primary language was an exclusion criterion. They conclude that when exclusion from a study on language grounds is deemed necessary it should be reported clearly alongside a rationale for this. A systematic review of chronic pain studies highlighted that a limitation of the included studies in the review was the variability of reporting of participant ethnicity (Fayaz et al., 2016).

The other barriers identified by the guidance for "Increasing Diversity in Research Participation" were access and trust. The review suggested methods to overcome these barriers which involve investing research and time into building connections with minoritised communities, finding opportunities to learn from underrepresented groups and building partnerships with trusted advocates. In the study reported in Chapter Four, during the

recruitment phase attempts were made to contact charitable organisations which support people with Sickle Cell Disease in the UK, but these were unsuccessful due to the lack of time to pursue this. The guidance suggests allowing a significant amount of time, and resources, to build these connections early on in research with charities, faith and grassroot organisation. It also suggests directly paying a trusted advocate to be part of the research team during inception of the project, or at the very least covering expenses for their participation.

This highlights some wider problems with representation in research. The National Institute of Health Research (NIHR; Imison et al., 2022) highlights the importance of including representation of diversity in funding panels and research proposal committees, and that the NIHR should challenge proposals which fail to demonstrate a clear understanding of ethical partnerships or whose study design is not appropriate for the cultural context (George et al., 2014). Therefore, including patient public involvement from diverse groups, reflective of the UK chronic pain population, is an important part of developing research questions and proposals.

Evidence suggests that dissemination of research also lacks inclusive public partnerships (Dawson et al, 2018) which in turn can limit future research partnerships. It is important that communities involved in research can see the outcomes of their engagement through dissemination. Effective dissemination needs to be accessible in terms of language and media, jargon free and involve the use of trusted organisations to communicate results. Whilst in the study reported in Chapter Four steps were taken to increase representation of participants from Black and/or minority ethnic groups, these were largely unsuccessful, and the final sample is not representative of the UK population or people who use chronic pain services in the UK. Given the literature reviewed here it is possible this lack of representation

may reflect factors such restricted time and resources available to make connections with relevant communities or the restriction of study language to English.

However, the lack of representation of participants from Black and/or minoritised ethnic groups, was also likely influenced by wider factors related to structural and systemic racism in the NHS, in chronic pain policy and the research that informs it. Systemic and structural racism are forms of racism that are chronically embedded in and throughout systems, polices, practices, beliefs and attitudes that perpetuate the unfair treatment of people of colour (Bonilla-Silva., 1997). In England, people from Black and minoritised ethnic groups face a range of inequalities compared to White groups in health, access to services and experience of and outcomes from healthcare (Raleigh and Holmes, 2021). A UK survey study of over 2000 people found that 65% of black people have experienced prejudice from doctors and other healthcare professionals in the NHS (Lacobucci., 2022). There are case examples of racial discrimination in people with pain such as a case in 2019 in which a patient with sickle cell disease was denied oxygen and a blood transfusion by healthcare professionals despite reporting symptoms of a sickle cell crisis, The coroner found the patients cause of death was due to delays in appropriate and timely treatment (Sickle Cell Society, 2021). Disparities in maternal healthcare for Black women was also highlighted in a report in 2020, concluding that Black mothers are four times more likely to die in childbirth in comparison to White mothers. The report highlighted concerns that minoritised ethnic groups are denied pain relief, their concerns are ignored by healthcare staff and pervasive microaggressions are causing harm and distress (Knight et al., 2022).

Future research on chronic pain should consider key explanatory factors for disparities in healthcare, including those at a macrolevel such as racism and discrimination, as they likely play a role in inequalities in chronic pain patient experience and outcomes.

Chapter Six

Discussion and Critical Evaluation

Word Count: 2532

Chapter 6: Discussion and Critical Evaluation

Overview of Findings

This thesis aimed to identify predictors of self-management of chronic pain. The systematic review in Chapter Two identified predictors of successful management of chronic pain in adults who received cognitive behavioural therapy (CBT). This highlighted that to date, research on CBT for pain management has not considered whether and to what extent subjective cognitive complaints (SCCs) affect outcomes. The survey in Chapter Four investigated if SCCs influence self-management of chronic pain in general, after other predictors of self-management are taken into account, such as depression and pain catastrophising.

This chapter begins with an overview of the findings of each study, followed by discussion of the limitations of the research in this thesis and recommendations for future research directions. Finally, the chapter ends with a discussion on the clinical and theoretical implications of the findings.

Predictors of Treatment Outcome in Cognitive Behavioural Therapy for Chronic Pain

A broad range of biological, psychological and social factors were identified as possible barriers to successful self-management of chronic pain, by recent NICE guidance for chronic pain (2021). To our knowledge, this is the only recent study to examine which factors predict CBT outcome in chronic pain using systematic review methodology. This question was previously investigated in 2002 (McCraken & Turk) but has not been re-evaluated in relation to CBT, since this time. Four electronic databases (Medline, EMBASE, PsychINFO

and CINAHL) were systematically searched from inception to March 2022. Eighteen studies met criteria to be included in the current review, involving a total of 1787 participants who had been offered a CBT intervention, aged over 18 years old, with chronic pain. Results indicated a number of sociodemographic, physical and emotional factors which are associated with the effectiveness of CBT for pain. The most prevalent predictors of outcomes across the studies involved forms of emotional distress (anxiety and depression) and cognitions about pain and coping. Sociodemographic predictors of outcomes demonstrated small effects and lacked replicability. There was heterogeneity across study designs, CBT interventions and, importantly, the outcome measures used. Future research in chronic pain should continue to identify the prognostic factors which influence treatment outcomes, with a focus on consistency across study designs and outcome variables. This will reduce heterogeneity and allow for future meta-analytic study designs.

The Extent to which Subjective Cognitive Complaints predict Self-Management of Chronic Pain

The relationship between depression and chronic pain is well-recognised in the literature. Psychological predictors of improved outcomes for chronic pain are associated with stronger beliefs of control over pain (Jensen et al., 2007), less catastrophising and negative thoughts related to pain (Desrouchers et al., 2010) and reduced anxiety and depression (Blanchard et al., 2006; Turner et al., 2007). To date, however, the impact of subjective cognitive complaints (SCC) on self-management of chronic pain has yet to be explored. The large cross-sectional online survey in this thesis aimed to address this gap in the literature by testing whether subjective memory and executive functioning predicted self-management, as measured by the Patient Activation Measure, after controlling for sociodemographic characteristics, mood, pain and pain cognitions. The results suggested that a small amount of variance in self-management, as measured by the 10-item Patient

Activation Measure (PAM10), was predicted by self-reported executive functioning in addition to sociodemographic characteristics, pain symptoms and anxiety and depression. The number of analgesics used was found to correlate significantly and negatively with SCC, but not with self-management as measured by the Patient Activation Measure. It could be that whilst analgesics have a negative impact on self-reported cognitive complaints, they also improve self-management as they elevate pain symptoms. Less variance was accounted for by sociodemographic, mood, pain or cognitive variables in the PAM13 (4.9%) than the PAM10 (29.6%). The DEX-R was found to be a significant predictor of the PAM10.

Critical Appraisal of Strengths and Limitations and Future Directions

Systematic Review

Firstly, it is important to acknowledge that the conclusions of the systematic review are limited by inconsistencies in the designs of the studies included. Only some of the research included was designed to identify prognostic predictors of outcome whereas some involved efficacy studies. Some studies investigated single predictors of outcome, whereas others investigated combinations of predictors. Regardless of the number of predictors identified it is important that the study design is aimed at identifying subgroups of patients who respond best to CBT.

According to the literature the optimal study design, to identify predictor variables, is a longitudinal cohort study (Wynants et al., 2017). The literature has identified clinical prediction rules (CPRs) which can guide research when identifying subgroups of patients who respond well to an intervention, such as CBT (Beattie & Nelson, 2006; Childs et al., 2004). The three main stages of the developments of CPRs include derivation, validation and impact analysis. The derivation stage involves using a study design which is relevant to the identification variables which predict the outcome of interest, with prospective cohort studies

being preferred to retrospective studies. Many studies included in the systematic review were retrospective study designs, and were frequently follow-up studies from other main trials.

Regression techniques and recursive partitioning techniques have been identified as suitable statistical methods for identifying prognostic CPRs (Labarere et al., 2014). Methods based on univariate analysis, where individual risk factors are assigned arbitrary weightings should be avoided as they are less accurate. This is because the final model may include predictors which are associated with each other and not independently associated with the outcome of interest (Grobman & Stamilio, 2006). A limitation of this systematic review was the lack of specificity in the exclusion criteria regarding study design and statistical analysis. Future systematic reviews exploring predictors of outcome in chronic pain should carefully consider fidelity to identifying CPRs in the study inclusion criteria. Pragmatically, however, this could limit the number of studies which can be included in future reviews.

Another limitation of the systematic review was the heterogeneity between outcome measures and the predictor variables investigated. The Task Force on Records and Data Retrieval of the International Association for the Study of Pain (IASP, 1995) developed a pain database questionnaire with the aim of facilitating uniform data collection across research and clinical practice. However, since its inception, international studies and clinical services continue to use a broad range of measures and variables to assess outcomes in chronic pain. This is likely further complicated as understanding of which variables are important outcomes for people with chronic pain has changed since the inception of this database. For instance, there is increasing focus, in pain management programmes, on improving quality of life and daily functioning, as opposed to reducing pain symptoms. However, in 2019 the British Pain Society (BPS, *Outcome Measures, 2019*) developed a joint document with the Faculty of Pain Medicine of the Royal College of Anaesthetists outlining standardised outcome measures which should be used in services in the National Health

Service (NHS). Research and services should follow such guidance to ensure validity, reliability and consistency across services and research.

Finally, other limitations of the systematic review include that the inclusion criteria being limited to studies published in English and therefore the findings are not generalisable across non-English speaking countries and cultures. The Cochrane Handbook (Higgins & Green, 2017) acknowledges the risk of bias in systematic reviews containing only English language studies and recommends a 'case-by-case' decision concerning the exclusion of non-English studies.

The quality of the studies included in the review ranged from high to low, with eight low quality studies included in the review. The quality was assessed in relation to prognostic study design and though not necessarily of poor quality overall, eight studies were less suitable for identifying prognostic variables. A strength of the review was that the full text screening, to ensure study inclusion criteria were met, and quality assessment of all papers were completed independently by two researchers.

Cross-Sectional Survey

In terms of the cross-sectional survey, there were limitations in using the PAM13 measure to assess self-management in chronic pain. The PAM measures patient activation for self-management, including knowledge, skills, and confidence in managing their personal health or illness on a 5-point scale (Hibbard et al., 2004). Higher scores are positively associated with self-management behaviours. The PAM13 includes three items regarding knowledge about the patients' health condition. Once three items regarding knowledge about health were removed, leaving questions focused more on self-management, higher correlations were found between the PAM10 and predictor variables. It could be that these questions are less relevant for people with chronic pain than those with other chronic health conditions such as heart failure. With a condition such as heart failure there are more self-

management strategies that can be used to mitigate or manage the condition such as cardiac rehabilitation exercises, knowledge about medication titration or monitoring fluid retention. Therefore, having knowledge about these conditions is an integral part of self-management. A study in the United Kingdom (UK) with cystic fibrosis patients found that these items (3,11) of the PAM13 may not be appropriate for conditions which are progressive and have aspects to them which may be outside of the person's control (Gao et al, 2019). This also applies to patients with other long-term conditions, for example, Armstrong et al (2017) reported that patients with inoperable cancer and motor neurone disease found the item of 'preventing problems' inappropriate to their situation.

Pain intensity was found to account for a significant amount of variance in the PAM10. This is consistent with other studies which have found increased pain intensity correlated with lower scores on the PAM13 (Yao et al, 2021). However, unlike other studies, level of education was not correlated with the PAM13 (Aung et al., 2016; Algeria et al., 2006).

A strength of this study was the relatively large sample size, which exceeded the power required for this study design. However, the underrepresentation of men and those from minoritised ethnic backgrounds was prevalent across both studies in this thesis. Gender was found not to be associated with the PAM measure in this study, however this result is limited by the bias towards females in the sample (86.47%). The sample surveyed was predominately White (92.7%) and female. This limits the generalisability of the study results to men and to people from minoritsed ethnic communities. Research has found that women are at substantially greater risk for multiple chronic pain disorders compared to men (Fillingham et al., 2009). Racial and ethnic disparities in chronic pain have also been reported, with people from minoritsed ethnic groups at increased risk for more severe pain and disability, as well as undertreatment of their pain (Anderson et al, 2009; Green et al,

2003). Given the disparities in pain symptomology across gender and ethnicity it is important that underrepresented groups are included in chronic pain research, and that efforts to increase recruitment in these groups are prioritised.

A strength of the survey study is that it set out to measure subjective cognitive complaints (SCCs) in chronic pain. In addition to contributing to the literature on SCCs, self-report assessments of cognitive abilities are a means of overcoming some of the practical and economic limitations associated with cognitive testing as they are less expensive, more time efficient and easier to administer (Moore et al., 2007). Research into the use of subjective measures of cognition in other chronic disease groups has sometimes identified a discrepancy between subjective and objective cognitive outcomes, thus using objective measures only, may present a missed opportunity to understand subjective perceptions of cognitive experience. A study of people with Multiple Sclerosis found that those experiencing depression reported greater subjective cognitive complaints than detected in objective performance (Julian, 2007). Subjective measures of cognition present an opportunity to identify individual negative appraisals of cognitive function, which may provide modifiable targets for interventions such as CBT. In comparison, Baker et al (2007) asked people with chronic pain to complete subjective and objective measures of cognition. They found SCCs concurred with objective measures, independently of age, education and catastrophising, and that those with severe anxiety made more accurate predictions of their cognitive performance. Whilst SCC are viable measures of cognition as they concur with objective measures, they may also provide an added opportunity to identify individual negative appraisals of cognitive function.

The DEX-R is a subjective measure of dysexecutive problems, designed to predict everyday activities. There are 20 items measuring behavioural, cognitive, motivational and emotional changes from pre-morbid function. It is accompanied by an informant measure.

Unfortunately, this was not analysed as part of the empirical study due to the limited responses received from informants. The DEX-R was designed as a measure of dysexecutive function post acquired brain injury, therefore its use and validity in a chronic pain population is less well understood. One limitation of this study is that it did not collect information about other potential causes of SCCs, such as a history of head injury in participants.

The relationship between SCCs and self-management assessed on the PAM, may have also been clouded by small but significant correlations between the number of medications used and performance on the DEX-R and EMQ. Sjorgren et al (2000) found that chronic pain patients on long-term opioid therapy had reduced performance on vigilance, attention and working memory tasks compared to a control group. Some studies, however, suggest that impairment in cognition may be less severe in individuals with chronic pain following opiate use, than those not using pain opiates (Haythornthwaite et al., 1998). Pain can negatively affect cognition and therefore pain relief has the potential to improve cognitive functioning. This association warrants further exploration in future research.

Clinical and Conceptual implications

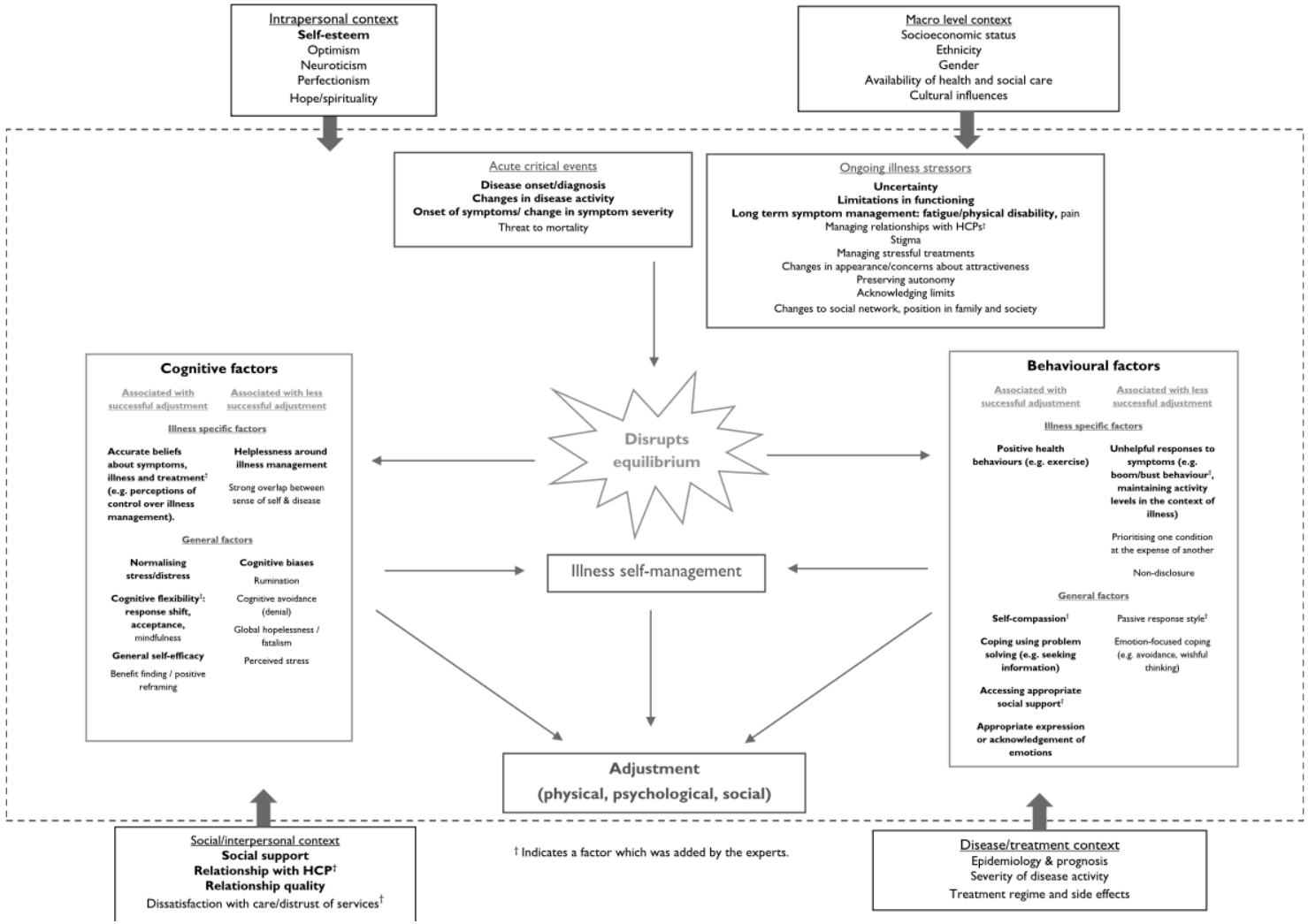
Findings from the systematic review and empirical paper revealed that a number of patient characteristics, emotional, behavioural and physical factors influence self-management of chronic pain outcomes. Both studies outline the complexities with matching and refining treatments to individuals or subgroups within chronic pain, and the need for personalised care (NHS, 2019).

Across the systematic review and cross-sectional survey, a number of factors which influence self-management of chronic pain have been discussed. Whilst the Fear Avoidance CBT model of chronic pain formulates the impact of emotional, behavioural and physical maintenance factors, it does not explicitly consider cognitive deficits, or the influence of contextual social factors such as ethnicity or interpersonal context.

A recent systematic review collated pre-existing evidence-based models of adjustment across long-term health conditions (LTCs). The models were taken from existing papers, including those focusing on rheumatic diseases, and were collected and synthesised into a new preliminary theoretical model of adjustment for long-term conditions (Carroll et al, 2022). The model proposes that on-going illness stressors can disrupt emotional equilibrium, and that whether a person returns to equilibrium and achieves good psychological adjustment to an illness depends on emotional, cognitive and behavioural factors as well as interpersonal, intrapersonal, environmental and illness-specific factors. The model highlights factors which precipitate disrupted equilibrium in health conditions; such as contextual factors (ethnicity, gender, employment), illness symptoms (pain intensity, illness prognosis) and social context. The model then goes on to consider factors which perpetuate disrupted equilibrium and affect illness-self management such as behavioural factors (activity levels, problem solving ability, avoidance) and cognitive factors (illness beliefs, cognitive biases, cognitive flexibility and cognitive dysfunction).

Figure 1.

TMA-LTC summarising the biological, social, and psychological etiological mechanisms of adjustment. TMA-LTC = transdiagnostic model of adjustment to long-term physical health conditions; HCPs = health care professionals. Variables in bold were ranked as particularly important by experts.



The findings of the systematic review and cross-sectional survey are consistent with this model. The model builds on CBT models of adjustment, such as the Fear Avoidance Model (Vlaeyen & Linton, 2012), by expanding on the consideration of systemic factors and cognitive deficits that can influence self-management of an LTC. An overarching comprehensive model, such as this, adds clinical value to understanding the vast array of individual and contextual factors which may limit self-management of a chronic condition. An extensive model such as this also provides a theoretical basis for exploring associations between other variables and pain management outcomes.

The implications of the findings from this thesis are consistent with other systematic reviews in this field (Gilpin et al, 2019) which have suggested that future research should continue to investigate predictors and moderators of treatment outcomes for chronic pain and explicitly link these to treatment theory and mechanisms. A theoretically driven approach, such as the use of the transdiagnostic model of adjustment to long-term physical health conditions (TMA-LTC model), may narrow the focus and further increase our understanding of who might respond best to which treatments.

Dysexecutive function was found to be a significant predictor of patient activation in this thesis. Whilst these results are preliminary, they may have implications for clinical assessment and the management for people with chronic pain. A self-report assessment of dysexecutive function has clinical utility in chronic pain services as, in comparison to objective testing, it is more cost and time effective. The use of subjective dysexecutive measures in chronic pain services, particularly during assessments, may help clinicians to identify further targets for intervention and adapt interventions to individual cognitive ability.

Chronic pain interventions include a combination of education, guided exercise, activity management, medication and psychological therapies. Psychological therapies recommended for chronic pain include CBT and Acceptance and Commitment therapy

(NICE, 2020). Safran and Segal (1990) list suitability factors for CBT, stating that CBT is most useful for those who can understand the rationale, assess and work through cognitions and emotions, maintain focus and attention, and demonstrate a good alliance potential. These factors all place demands on individuals' executive abilities, related to frontal lobe functioning (James et al., 2008). Therefore, screening for deficits in executive function in chronic pain services may allow clinicians to adapt and tailor psychological interventions to individual needs. For example, the DEX-R asks questions which are focused on concentration "I find it difficult to keep my mind on something, and am easily distracted" and "I find it difficult to do or concentrate on two things at once". If a chronic pain patient scores highly on these items a clinician may consider reducing the complexity of material, shortening the session, covering fewer topics and frequently checking for feedback and understanding. An individual may also highlight difficulties with independent problem solving by scoring highly on the following DEX-R items "I find it hard to complete tasks or activities without structure or direction" and "I have problems understanding what other people mean unless they keep things simple and straightforward". This may indicate a rationale for the clinician to 'chunk' psychoeducation, or teaching new skills, into component parts to simplify the task. Scaffolding techniques could be used to help generate solutions, or behavioural experiments could be used to build skills in problem solving.

Future research on the predictors of self-management of chronic pain should use a consistent set of outcome measures to reduce heterogeneity. This thesis also highlights a need for future studies of predictors of pain outcomes to adopt study design and analysis methods that are optimal for identifying prognostic factors. In addition, future studies should ensure that the identification of predictive variables of outcome in chronic pain are theoretically derived from models such as the transdiagnostic model of adjustment to long-term physical health conditions.

An implication which emerged from this thesis, that appears relevant to chronic pain research in general, is the importance of ensuring studies are representative of the service users attending chronic pain clinics. There is a need for future research to proactively ensure that study samples are inclusive of males and people from minoritised ethnic groups.

Overall Conclusions

Many factors influence outcomes of self-management of chronic pain. The systematic review identified a number of physical, emotional and sociodemographic factors which predict the effectiveness of CBT, the most commonly reported being anxiety, depression and cognitions about pain and coping. The survey study reported here found that subjective ratings of executive functioning predict self-management of chronic pain. However, this finding was small and limited to the PAM10, and therefore warrants further exploration.

There is a need for future studies to have a degree of uniformity across outcome measures, such as those identified by the British Pain Society (2019). This will enable more precise analysis methods by reducing homogeneity across variables and studies. Future research on predictors of chronic pain outcomes should also be developed in relation to theoretically-driven models of adjustment to LTCs. Further study, and use of more advanced research methods, will aid the identification of specific prognostic variables associated with outcomes in chronic pain, and therefore enable interventions to be tailored and adapted to individuals needs and differences.

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Thesis Portfolio Appendices

Appendix A: Journal of Disability and Rehabilitation Author Guidelines

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

Case reports - CARE

Diagnostic accuracy - STARD

Observational studies - STROBE

Randomized controlled trial - CONSORT

Systematic reviews, meta-analyses - PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

Word count

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

Style guidelines

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Alt Text

This journal is now including Alt Text (alternative text), a short piece of text that can be attached to your figure to convey to readers the nature or contents of the image. It is typically used by systems such as pronouncing screen readers to make the object accessible to people that cannot read or see the object, due to a visual impairment or print disability. Alt text will also be displayed in place of an image, if said image file cannot be loaded. Alt Text can also provide better image context/descriptions to search engine crawlers, helping them to index an image properly. To include Alt Text in your article, please follow our Guidelines.

Formatting and templates

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

A LaTeX template is available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact us here.

References

Please use this reference guide when preparing your paper. An EndNote output style is also available to assist you.

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To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: what to include

Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

A structured abstract of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.

You can opt to include a video abstract with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

5-8 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

A feature of this journal is a boxed insert on Implications for Rehabilitation. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

Example 1: Leprosy

Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.

Reconstructive surgery is a technique available to this group.

In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).

People with MS have complex reasons for choosing to exercise or not.

Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Acknowledgement. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .

Declaration of Interest. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* Further guidance on what is a conflict of interest and how to disclose it.
Data availability statement. If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
Data deposition. If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
Units. Please use SI units (non-italicized).

Using third-party material in your paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in Disability and Rehabilitation , all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. The clinical trial registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

Consent

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting your paper

This journal uses Taylor & Francis' Submission Portal to manage the submission process. The Submission Portal allows you to see your submissions across Taylor & Francis' journal portfolio in one place. To submit your manuscript please click here.

By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a

further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.
On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.
Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.
Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.
At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.
Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Appendix B: Search Strategy

Search Strategy:

Cognitive behavio* therapy OR cognitive therapy OR CBT.ti,ab

((enduring* or chronic* or persistent* or longstanding* or longterm* or syndrome*) adj1 pain*).ti,ab OR complex regional pain syndrome OR muscoskeletal pain OR backache OR lower back pain OR fibromyalgia OR chronic primary pain OR neuropathic pain OR Osteoarthritis OR enduring pain OR pain or Chronic primary pain OR generalised pain OR generalized pain OR referred pain OR complex regional pain syndrome OR CRPS OR back pain OR low back pain OR shoulder pain OR knee pain OR hip pain OR complaints arm neck shoulder OR CANS OR whiplash associated disorder OR WAD OR repetitive strain injury

Appendix C: REC ethical approval confirmation

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Georgina Forden
Trainee Clinical Psychologist
CPFT
Department of Clinical Psychology
Norwich Medical School
NR4 7TJN

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

19 November 2021

Dear Miss Forden

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

Study title:	**To what extent do self-reported cognitive symptoms predict self-management in chronic pain?**
IRAS project ID:	**305643**
Protocol number:	**v.01**
REC reference:	**21/PR/1450**
Sponsor	**University of East Anglia**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **305643**. Please quote this on all correspondence.
Yours sincerely,

Harriet Wood
Approvals Specialist
Email: approvals@hra.nhs.uk

Copy to: *Miss Polly Harrison*

Appendix D: Consent to Contact Form

University of East Anglia

Consent to Contact Form

Study Title:
To what extent are self-reported cognitive symptoms associated with self-management of chronic pain?

I hereby give my permission for ..... (study site name) to share my name and contact information with researchers from the University of East Anglia, regarding the research study named above.

Statement of Consent:

- I understand that my information will be shared with a researcher from the University of East Anglia and that they will contact me to discuss the research.
- I have had the opportunity to discuss the implications of sharing or not sharing my information.
- I understand that sharing personal information is entirely voluntary and you may withdraw your consent at any time.

☐ I agree to my information being shared for the purpose of this research project

Should you have any questions about this process, or wish to withdraw your consent please contact: Georgina Forden (g.forden@uea.ac.uk)

Name .....

Telephone number .....

Email address (optional).....

Signature .....

Date .....

Appendix E: Participant Information Sheet

University of East Anglia

Ethics Reference Number: 305643

PARTICIPANT INFORMATION SHEET

Study Title:
To what extent are self-reported cognitive symptoms associated with self-management of chronic pain?

Why have I been given this information sheet?

Thank you for taking the time to look at this information about the research we are doing. We are inviting you to take part in our research. Please have a good look at the following information and carefully think if you would like to take part. It is completely up to you whether or not you take part and taking part or not will not affect your care within your NHS trust.

Why are we doing this research?

We aim to increase understanding about how cognitive symptoms (such as concentration, attention and memory) are associated with the ability to manage chronic pain. We are also interested in whether low mood and the way we think about our pain are associated with the ability to manage chronic pain. We think that learning more about these relationships will help services to understand how to better support people to manage their pain.

Why have I been asked to take part?

We are asking if you want to take part because you have told someone that you are interested in taking part in research. We are looking for people who have a diagnosis of chronic pain. It doesn't matter what type of chronic pain you have been diagnosed with. You must between the age of 18-65 take part in the study and speak English.

Who is organising and funding the research?

The lead researcher is Georgina Forden, who is a Trainee Clinical Psychologist from the University of East Anglia (UEA) employed by Cambridge and Peterborough NHS Foundation Trust, this research will contribute towards her doctoral thesis.

The research team also includes, Dr Catherine Ford, a Clinical Neuropsychologist and Clinical Lecturer at the UEA; Dr Sarah Fish, a Clinical Psychologist working at Norfolk and Suffolk Foundation Trust (NSFT) and a Clinical Lecturer at the UEA; and Dr Sarah Ronaghan, a Consultant Clinical Psychologist in Chronic Pain Service at Stamford and Rutland Hospital.

Who has checked the study?

All research by UEA in the NHS is looked at by another group of people, called the Health Research Authority. This is a national organisation that makes sure that all research that is done in the NHS is of good quality, abides by all the relevant laws and guidance, and is safe for everyone involved it in it. They have said that this research meets their very strict criteria and is safe to do. We have also been given permission by you healthcare provider to conduct the research in their organisation.

Do I have to take part?

No. It is entirely up to you. There is absolutely no pressure to take part and everyone involved will fully respect all decisions you make. There will be no changes made to any treatment, care or rights should you decide to take part or not. You do not have to give anyone a reason for not taking part if you do not want to. You can also change your mind at any point in the study.

What will happen if I take part?

The information on this sheet is to help you to make a decision as to whether you want to take part in the research. It will be sent to you at 72 hours before you will need to make a decision as to whether you want to take part.

If you decide to take part, Georgina Forden (the lead researcher) will contact you by telephone to answer any questions you might have about the research and to explain in more detail about what is involved. This will take roughly 20 minutes but can be longer if you have more questions.

If you decide you do want to take part you will be asked to sign a consent form. You will have been given the consent form by staff at your hospital or you can complete it online. You will be asked to post the form using a prepaid registered envelope or sign a consent form online, to say you are happy to take part and that you have had the study explained to you.

Once you are happy with that you will be given a set of questionnaires to complete. These will be given to you by your chronic pain team in either a paper format, or you can complete them online, or you can chose to do them over the phone with Georgina Forden (the lead researcher).

Your safety will be the most important thing so we will only the research team will have access to the questionnaires you complete. The answers you give to the questionnaires will be stored electronically on an encrypted device.

Once that is done your part in the research will be finished. You will be contacted after the study is written up to provide you with a copy of the results and offered the opportunity to discuss it by telephone, if that is your wish.

Where and when will the study be done?

The questionnaires will be given to you in either a paper or online format so that you can do them at home or in a private place of your choosing. If you have any problems accessing or completing the questionnaires then you can do them over the telephone with Georgina Forden (lead researcher).

How much of my time will it take?

We estimate that the questionnaires may take up to 30 minutes to complete in total. They do not need to be completed in one go but we ask that you try to complete them within the same day.

What information will be collected and how will it be used?

We will be collecting different types of information from you to help us with the project.

- People will use this information to do the research or to check your records to make sure that the research is being done properly.
- We will collect your name and contact details initially, as well of the name of the lead professional involved with your care and you GP. This is so we can contact you throughout the study. When the study is finished these details will be deleted.
- Your age, gender, ethnicity, employment status, sexuality and education and whether or not you have a disability, will be collected to help us understand some of the differences between participants, however, it is your choice whether you tell us this.
- People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
- We will keep all information about you safe and secure.
- Once we have finished the study we will keep some of the data so that we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

- To find out more about how your information is used at the University of East Anglia please contact the data protection officer: Ellen Patterson at dataprotection@uea.ac.uk or 01603 592431

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Will anyone else know I'm doing this?

The people in our research team and your GP will be aware you are taking part. We ask this so that they are aware of your involvement in the study and to help if you require any additional support when taking part in the study. We will only disclose what the study is investigating and not your answers to the questionnaires.

We will also let your GP know if, by answering the questionnaires, you indicate you have symptoms of low mood or anxiety. We will inform your GP so that they are able to offer you some support with this. Whilst we aim to maintain your confidentially in the study, we may have to break confidentiality if you tell us something that suggests that you or someone else is at significant risk of harm. If you disclose something to us in the study which indicates, that you or others are at risk of harm, then we have a duty of care to inform your GP and other services of this. This is so that we can keep you and others safe. In the unlikely event that happens, we will do everything we can to try to discuss this with you first.

All information collected during the study will be treated as strictly confidential. The research team follow the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. All paper information, like paper consent forms, will be kept in a locked cabinet and locked office at the UEA. Any information about you will be kept on a secure online drive called OneDrive. We will change your name on the all the stored information as soon as reasonably possible and to make sure you cannot be identified. Only researchers at the University will be able to look at your personal information collected for the study and all identifiable information will be deleted once the study is complete in August 2023. Any anonymised data will be stored for up to 10 years and deleted after this time.

When the research is written up and published all your data will be unidentifiable so that people reading will not know who you are. We may also share the anonymised data collected in the study with other researchers who are interested in this area, from our

organisation and other organisations. These other organisations may be universities, NHS organisation's or companies involved in health and care research in this country or abroad. This information will not identify you and will only be used for the purpose of health and care research.

Is there anything I should be worried about if I take part?

Your rights and wellbeing are our top priority and the research team will make sure that everyone involved in the study is kept safe, especially in light of the COVID-19 pandemic. For this reason, we will offer all the research to be completed online to all participants to make sure there is no risk of infection though close contact with the researcher.

During the contact with the study you will be asked whether you want to take part in the in the study. Should you feel upset or distressed in any way then please let us know and you will be asked if you wish to continue and we will support you with whatever you decide to do. The researcher you will be speaking with is trained and experienced in providing support to people who are experiencing distress. They can also help you seek further support from your healthcare provider or other mental health support agencies.

You will need to take some time to take part in the study. We will endeavour to keep this time to a minimum and hope that the benefits of taking part will outweigh this cost.

Will taking part help me?

This study is explicitly focused on understanding how people experience Chronic Pain and the impact it has on their ability to manage the condition, this will help to guide services on how to work more effectively with people with Chronic Pain. However, there are no predicted benefits of taking part in the research, apart from a potential benefit of helping to inform the services you use.

By taking part you will be entered in a draw to receive a £20 Amazon voucher for your time. If you have won the draw you will be contacted after the study is completed.

It is important to know that this is a research study, not a form of treatment for mental health problems. Therefore, if you are worried about your mental health or wellbeing, please speak to your GP. Or you can contact either:

Samaritans – 24/7 confidential emotional support

Tel: 116 123

What happens when the study finishes?

Once all the questionnaires have been collected the data will be typed up and analysed by the research team at the UEA. These findings will be written up and published.

What happens to the results of the research?

We plan to look at the information gathered from the study and share the results in presentations, publications and using social or national media. When we share the results, no one will be able to know you took part as we will make sure it is all anonymous and unidentifiable.

You will be asked if you want a copy of findings once the project is finished and ready to be published and if you do this will be sent out to you by post or email. You will also be able to discuss it with the lead researcher by phone if you wish.

Following UEA guidance, information collected during the study will be kept safely for at least 10 years following any publications before being destroyed.

What if there is a problem or something goes wrong?

If you are worried about anything relating to the research, please speak to someone from the research team and we will try our best to help you.

If you have a complaint about the research or researchers, please contact Professor Niall Broomfield, Director of the UEA ClinPsyD Programme (N.Broomfield@uea.ac.uk or Tel: 01603 593 061). Professor Niall Broomfield is separate from this research study so you can speak to him confidently.

How can I find out more?

You can contact the research team:

Georgina Forden, Trainee Clinical Psychologist
Email: g.forden@uea.ac.uk Tel: 07785395689

Catherine Ford, Clinical Psychologist and Clinical Associate Professor
Email: Catherine.ford@uea.ac.uk Tel: 01603 456 161

You can find out more about how we use your information at
www.hra.nhs.uk/information-about-patients/

What happens next?

Thank you for taking your time to read this information sheet. Please get in touch if you have any questions or want more information.

After giving you this information sheet, you will hear nothing from us for at least 72 hours (3 days). This is to make sure that you have time to read the information through and consider fully if you would like to take part. You will then be contacted by Georgina Forden (the lead researcher) by telephone to discuss it further and to see if you want to take part.

If you decide that you would rather not take part in this study, you do not need to give a reason and no further contact will be made.

Thank you very much for considering this research,

The Research Team

Appendix F: Consent Form

University of East Anglia

IRAS ID: 305643

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Research Study: **To what extent are self-reported cognitive symptoms associated with self-management of chronic pain?**

Name of Researcher: Georgina Forden

	Please initial box
1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant sections of data collected during the study, may be looked at by individuals from the University of East Anglia and from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐

4. I give permission for my Lead Care Professional and General Practitioner to be informed of my participation in the research and given a copy of the 'participant information sheet'. I also confirm that they can be contacted with regards to any concerns that the researcher has. ☐

5. I understand that my anonymous data may be used by other organisations involved in research in health and social care. ☐

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

Optional:

7. I agree to an informant (a close friend or family member who knows you well) being contacted about the study (if you do not initial in this box then you are still eligible to take part in the research) ☐

Name of Participant	Date	Signature

Name of Participant's GP

Name of Person taking consent	Date	Signature

One copy of this signed consent form will be provided to you and one copy with be kept by the research team.

Appendix G: Recruitment Poster

Recruitment Poster
09/06/2022
Version 3
305643

Chronic Pain Research Study

University of East Anglia

We are looking for people with a diagnosis of Chronic Pain, who are over the age of 18, to take part in research investigating the relationship between managing chronic pain and cognitive difficulties (such as memory, concentration and attention).

This will be useful because understanding what is difficult about managing chronic pain can help us to better support people with pain in the future.

We especially welcome participation from those who identify as Male and those from Black, Asian and Minority Ethnic communities.

The research involves completing some questionnaires about mood, pain, memory and attention and will take 15-30 minutes to complete.
If you are interested in taking part then please email Georgina Forden at g.forden@uea.ac.uk

Georgina Forden is a Trainee Clinical Psychologist, this study is part of her doctoral thesis project.

Appendix H: Site Confirmation of Capacity and Capability

Dear All,

RE: IRAS 305643. Confirmation of Capacity and Capability at Lewisham & Greenwich NHS Trust.

Full Study Title: To what extent do self-reported cognitive symptoms predict self-management in chronic pain?

This email confirms that **Lewisham & Greenwich NHS Trust** has the capacity and capability to deliver the above referenced study. Please find attached our agreed Organisational Information Document as confirmation.

We agree to start this study on a date to be agreed when the sponsor gives the green light to begin.

You will be required to update your recruitment activity to the EDGE local portfolio management system. It is expected that this data is updated as close to real time as possible, but at least by the end of each week.

Please let LH.RD@nhs.net know who will be responsible for updating this data for LGT.

If you have any queries throughout your project, please do not hesitate to contact me. Meanwhile, may I wish you success in your project.

BW
Vicke

Victoria Simpson
Senior Research Facilitator

Lewisham & Greenwich NHS Trust
R&D Department, Queen Elizabeth Hospital
Education Centre, Room EC.1,
Stadium Road, Woolwich,
London, SE18 4QH

Working hours 8am-4pm

OID_NNUH.docx.pdf
735.5 KB

305643__-Confirma...
138.5 KB

Download All • Preview All

Dear all,

Confirmation of Capacity and Capability: To what extent do self-reported cognitive symptoms predict self-management in chronic pain? 305643

I am pleased to inform you that the Norfolk and Norwich University Hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our confirmation letter and the fully executed agreement for your records.

Please let me know when the sponsor has given the green light to begin.

Kind regards,

Lauren Clarke
Research Study Officer

Research Operations Office (NNUH)
Quadram Institute
Rosalind Franklin Road
Norwich
NR4 7UQ

Email: lauren.clarke@nnuh.nhs.uk
Phone: 01603 647256 (x7256)

Dear All,

RE: IRAS. 305643 Confirmation of Capacity and Capability at North West Anglia NHS Foundation Trust

Full Study Title: To what extent are self-reported cognitive symptoms associated with patient activation in the context of pain self-management and do they predict patient activation over and above measures of pain catastrophizing and low mood?

Ref: S/2021/305643

This email confirms that North West Anglia NHS Foundation Trust, **Stamford Hospital** has the capacity and capability to deliver the above referenced study. Please find attached our signed agreed Organisational Information Document as confirmation.

We agree to start this study on **10/01/2022**.

Sponsor responsibilities:

It is the sponsors' responsibility to ensure that we are made aware of any amendment to the study in a timely manner and supply relevant documentation to enable continued Capability and Capacity to be granted.

It is the sponsors' responsibility to ensure that the R&D department are made aware of the end of involvement for North West Anglia NHS Foundation Trust.

Local Site responsibilities:

The NIHR Contract requires providers of NHS services to submit performance on delivering our recruitment target planned within the recruitment period:

Milestone	
Recruitment period contract end date	01/10/2022

Draft saved just now

Dear Emma and Georgina,

Please see attached the letter which confirms the capacity and capability for the study referenced below. Please also note the site signed OID.

With best wishes

Mary-Beth

RE:
Study title: To what extent do self-reported cognitive symptoms predict self-management in chronic pain?
IRAS project ID: 305643
Protocol number: v.01
REC reference: 21/PR/1450
Sponsor University of East Anglia

Dear Polly Harrison,

This email confirms that West Suffolk NHS Foundation Trust has the capacity and capability to deliver the above referenced study.

Please find attached our signed agreement the OID, as formal confirmation of this.

List of up-to-date study documents:

• HRA Approval letter		19th November 2021
• Poster	V2	21st October 2021
• GP Notification Letter	V2	21st October 2021
• Consent Form	V2	21st October 2021
• Informant Consent Form	V2	21st October 2021
• PIS	V3	10th November 2021
• Informant PIS	V3	10th November 2021
• Protocol	V2	29th October 2021

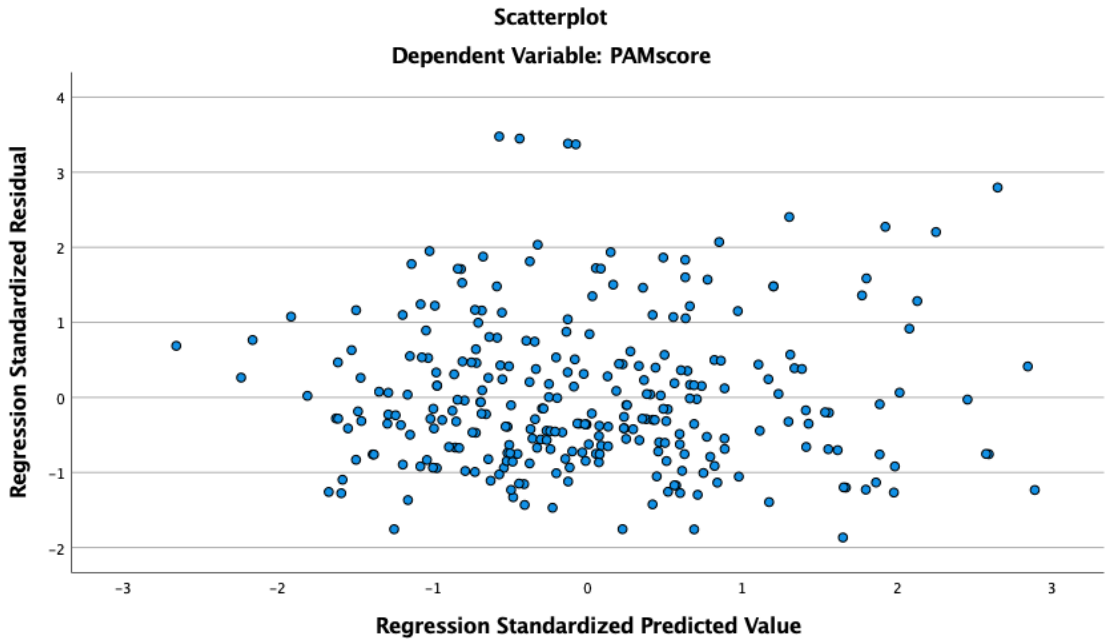
We agree to start screening for eligible participants after you have granted the Green Light.

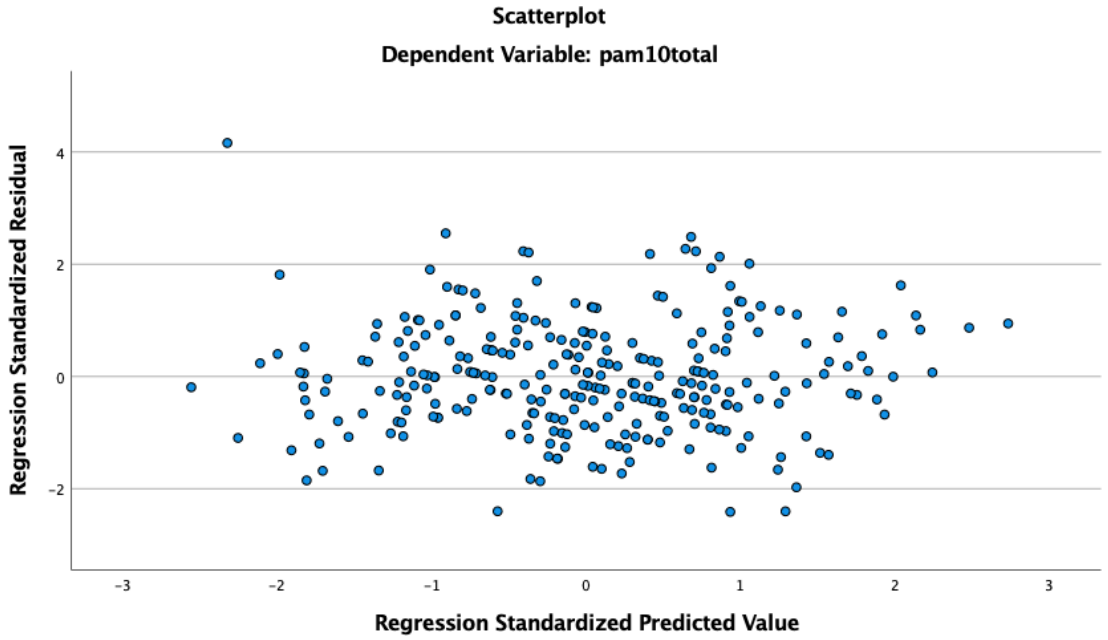
We look forward to working with you and delivering the trial.

If you have any queries in the meantime, please do not hesitate to contact us.

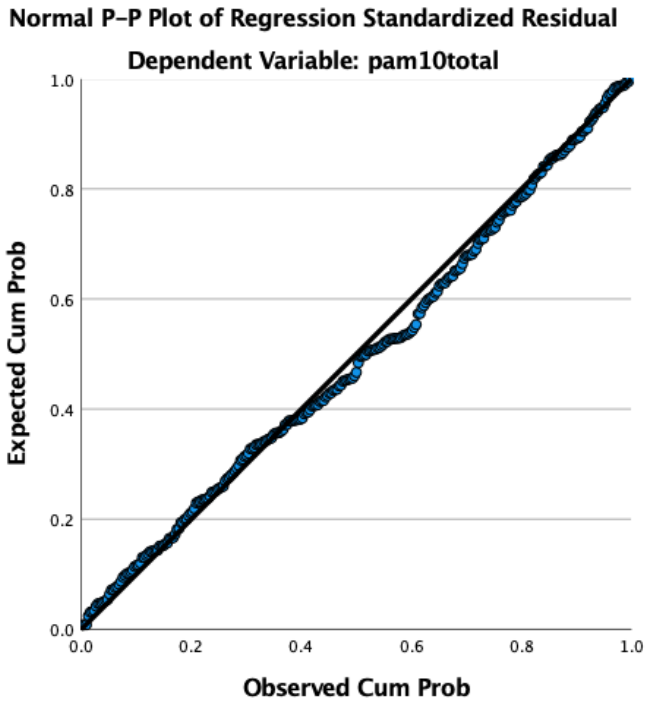
Kind regards

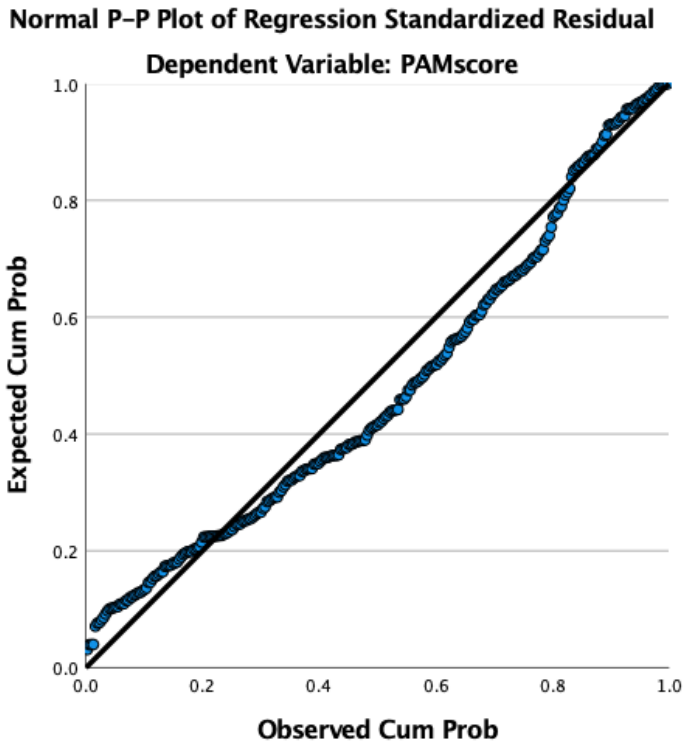
Appendix I: Scatterplots between Independent Variables and PAM13 and PAM10





Appendix J: A Test of Normality with PAM as a Dependant Variable





Appendix K: Implications of Rehabilitation: Systematic Review

- This review synthesised research identifying factors predicting outcomes of CBT for chronic pain.
- The most commonly reported predictors of CBT outcome, with medium to large effect sizes, were anxiety, depression and negative cognitions about pain and coping. sociodemographic predictors of outcomes demonstrated small effects and lacked replicability.
- There is a move towards more individualised treatments in chronic pain. Our results suggest that decisions regarding CBT for chronic pain should carefully consider baseline levels of anxiety, depression and negative cognitions about pain.

Appendix L: Implications of Rehabilitation: Primary Research study

- Chronic pain is highly prevalent and associated with physical, emotional and financial burden.
- Our research found that sociodemographic, pain, mood and cognitive variables accounted for significant variance in self-management, with subjective executive functioning a small but significant predictor of self-management of pain.
- Assessment of subjective cognitive complaints regarding executive functioning in pain clinics may support the provision of more individualised treatments in chronic pain.