Doctoral Thesis

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

Stigma, Fear of Compassion and Chronic Pain

Doctorate in Clinical Psychology

Lancaster University

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2017 Intake

Word count

Section	Main text	Appendices, including References, Figures and Tables	Total
Abstract	299	-	299
1. Thematic synthesis	7998	5602	13,600
2. Empirical paper	7975	4815	12,790
3. Critical Appraisal	3929	928	4857
4. Ethics Section	4469	7358	11,827
Total	24,670	18,703	43,373

Stigma, Fear of Compassion and Chronic Pain

Abstract

Section one details a thematic synthesis that sought to understand men's experiences of chronic pain. Systematic searches of CINAHL, MEDLINE, PubMed and PsycINFO identified 14 qualitative studies. Five domains were identified: 'The effort and unpredictability of being in pain', 'Becoming a burden', 'Being judged as less of a man', 'Trying to hold on to a 'masculine' identity' and 'Rebuilding and rehabilitating'. Domains were interconnected and represented a process following pain onset. Men initially described a wish to control both the pain and its impact on their daily lives. Reductions in daily functioning and the effect of social judgements led men to feel burdensome and the prevailing Western masculine hegemony shaped men's responses to these stigmatising experiences. Over time, men built a new understanding of the self, renegotiating their masculinity and sought to rebuild and rehabilitate.

Section two describes correlation analyses, hierarchical linear regressions and moderation analyses that sought to understand if: (1) stigma, fear of compassion from others (FOCO) and fear of compassion from self (FOCS) independently predict outcomes of pain-related anxiety, depression or pain interference, and (2) FOCO or FOCS moderate the relationship between pain intensity or stigma and outcomes of psychological distress. FOCO and FOCS significantly correlated with depression, anxiety and pain interference. Pain intensity and stigma were independent predictors of depression, anxiety and pain interference. FOCO significantly predicted depression and anxiety but not pain interference. FOCS predicted depression but not anxiety or pain interference. For the first time in chronic pain, FOCO was demonstrated to moderate the relationship between stigma and depression.

This study demonstrates that FOC is an important psychological factor in the experiences of individuals with chronic pain.

Section three provides a critical appraisal of the work presented in this thesis, including an exploration of the impact of the COVID-19 pandemic on the process.

Declaration

This thesis documents research undertaken for the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University.

The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: John Timney

Signature:
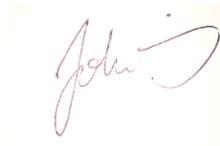
Date: 31st July 2020

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Thank you, firstly, to the participants of this study. Thank you for giving your time and for being willing to engage in this research, answering potentially difficult questions during an anxiety provoking period of time. Thank you to all the experts by experience at PainAway who generously gave their time to support the development of this work.

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For my wonderful Dad

I miss you every day

Contents

Section 1. Thematic synthesis

Men's experiences of chronic pain: a thematic synthesis

John Timney

Word Count: 8000 words excluding Tables and References

Formatted to journal guidelines: *Chronic Illness*

(See Appendix 2)

Lancaster University Doctorate in Clinical Psychology

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Abstract

Objectives. Chronic pain is now well established as a multi-dimensional phenomenon, comprising biological, emotional, cognitive and social factors. Men and women experience pain differently, and currently, diagnosis of chronic pain is higher for women than men. An in-depth understanding of the sociocultural and psychological factors that contribute to the male experience of chronic pain remains absent. This study aims to understand men's qualitative experiences of chronic pain.

Methods. A systematic literature search of four databases (CINAHL, MEDLINE, PubMed and PsycINFO) was performed. Overall 14 qualitative research studies exploring men's experiences of chronic pain were identified and underwent thematic synthesis.

Results. The experiences of men living with chronic pain were characterised into five domains: 'The effort and unpredictability of being in pain', 'Becoming a burden', 'Being judged as less of a man', 'Trying to hold on to a 'masculine' identity', and 'Rebuilding and rehabilitating'. Men described experiencing stigma related to what was socially understood to be a women's condition. This stigma was implicit for many men in their interactions with healthcare professionals.

Discussion. Men's experiences were often framed within the Western social narratives relating to masculinity. Negotiating a new understanding of masculinity was often required to facilitate acceptance and rehabilitation.

199/200 words

Keywords: Chronic pain, pain management, masculinity, social stigma, health behaviour,

Introduction

Persistent pain (often referred to as chronic pain), is pain that lasts for 3 months or more, or, pain that persists beyond the time of tissue healing.[1] The burden of persistent pain globally is significant; it is now considered a public health priority with some estimates suggesting up to 10% of adults receive a diagnosis of 'chronic pain' annually.[2] In the UK, persistent pain is an issue for approximately 14 million people.[3] Individuals with chronic pain are significantly more likely to experience low mood or anxiety compared to the general population,[4] and report experiencing reductions in quality of life and feelings of fear and isolation.[5] Chronic pain is associated with common conditions (which include but are not limited to fibromyalgia, chronic lower back pain [CLBP] and complex regional pain syndrome [CRPS]) and is viewed as complex phenomena that is challenging to address, both for those experiencing the pain and their treating healthcare professionals.[6-9] The healthcare costs and wider economic impacts associated with chronic pain are significant and the financial burden (in-terms of direct costs or ability to maintain employment) on the individual experiencing pain can be substanstial.[6, 10, 11] Thus, there are wide socio-economic factors that can impact the emotional well-being of an individual with chronic pain.

Interventions for chronic pain tend to rely on symptom management, typically comprising prescriptions of analgeasic medications as a first-line treatments.[12] The overprescription of opiod-based medications since the late 1990s for chronic pain has, however, led to a devestating epidemic of addiction, overdoses and fatalities worldwide.[13] Consequent actions to reduce painkiller prescriptions are now being brought into clinical practice. As part of this effort there is increasing recognition of the psychological factors that precipitate and

maintain an individual's experience of chronic pain, and the need to prioritise psycholoical

support and patient education.[14-17]

Chronic pain is now well established as multi-dimensional, and is influenced by

biological, psychological and social factors.[18-20] Predominantly quantitative approaches to

understanding pain experiences have identified several psychological factors such as

psychological flexibility, catastrophizing, and prosocial affiliative states (e.g. self-compassion

and adult attachment style),[21-23] as important modulators of the relationships between a person's

pain and their levels of physical disability, low mood and anxiety.[22, 24] However, given the

multidimensional and uniquely personal experience of chronic pain, a body of qualitative

research aiming to understand the lived experiences and realities of individuals is also growing.

A systematic review and thematic analysis of qualitative studies of the experiences of

people with chronic pain (performed in 2010) identified three key themes: maintaining a valued

sense of self and experiencing pain as an "assault" on the self, the difficult experiences of

seeking help, and the social unpleasantness and fears of the judgement of others.[25] A common

thread in the findings of the review is that people who experience chronic pain report having had

experiences of being stigmatised by others. They often feel that their friends, families, or partners

do not believe the extent of their pain and it's personal impact,[26] they feel healthcare

professionals think that they are imagining or exaggerating their pain, and some have reported

feeling blamed or dismissed by their healthcare professionals.[27, 28] The workplace is also a

significant challenge, with many reporting hostile reactions from colleagues, and poor

accomodations being made by employers.[26] As well as experiencing such judgements from

others, people experiencing persistant pain often report hypervigilence to the threat of social

rejection.[29].[30] Experiences of being stigmatised can lead to feelings of embarrassment and

humiliation, which, together with changes in physical ability, can lead to negative reappraisals of the self within one's social context, such as self-criticism, anxiety, and shame.[31]

Differences in pain experiences that are dependent on an individual's biological sex are well characterized.[32,33, 34] Alongside biological differences, sociocultural and psychological factors related to gender are widely acknowledged to play a part in explaining some of this variance. Keogh (2015) suggests that little is understood about the impact of masculinity on pain, or the masculine hegemony of gender roles on pain-related behaviours, coping strategies, or interpretations of the reactions of others to one's pain.[32] Health behaviours of individuals are significantly influenced by gender, and the standards society holds for the hetero-normative gender roles of men and women are often considered important drivers of these behaviours.[35-37] This influences men with chronic pain to adopt a stoic "wait and see approach", and express an understanding that they need to "take their pain like a man".[36, 37] Understood barriers to men seeking support for chronic pain often relate to feelings of worry and embarrassment regarding a perception of 'weakness' for seeking help, with the relationship between pain and the prevailing and longstanding hegemony of Western masculinity being an important current focus of health research.[32, 38] However, an in-depth understanding of the sociocultural and psychological factors that contribute the male experience of chronic pain remains absent. A better understanding of male experiences of pain, could help inform psychological assessment and interventions, inform medical practitioners of how to work with this group, and contribute to social initiatives.

Qualitative explorations of specifically men's experience of chronic pain have not been a focus of researchers.[32] However, there is now a small body of research that exists which would benefit from synthesis in order to understand men's experiences of chronic pain. This review

aimed to perform a systematic thematic synthesis of studies investigating in order to answer the

question: What are men's experiences of chronic pain?

Methods

Search strategy

A systematic literature search of four databases (CINAHL, MEDLINE, PubMed and

PsycINFO) was performed. These databases allowed for coverage of the psychological impact of

chronic pain (PsychINFO), qualitative research methodology, gender-based experiences of

chronic pain and health psychology (CINAHL and PsychINFO), and medical and community

management of chronic pain (CINAHL, PubMed and MEDLINE).

A Boolean methodology was utilised for the systematic literature search, based on the

specific Medical Subject Heading (MeSH) system or the equivalent subject heading hierarchy

specific to each database, as well as free text searches. The focus of the search terms was placed

on the following areas: (1) pain and chronicity (2) chronic illnesses typically associated with

pain, (3) qualitative research methodology, (4) male study participants (Table 1.1). Following

search term optimisation for specific databases, the search strategy was reviewed by a specialist

librarian at Lancaster University to confirm its appropriateness. All searches were performed for

the final time on 1st April 2020. A full description of the search terms used for each database and

the numbers of results returned for each search are shown in Appendix 1.

Insert Table 1.1

Criteria for study inclusion were:

- English language version available

- Publication in peer reviewed academic journals

- An explicit focus in the study aims of understanding the male experience of chronic pain

- Exclusively male participants, or, clear delineation in the results sections of manuscripts which text related to the experiences of male study participants (e.g. quotations that were from participants identified as male)

- Studies which used qualitative methodology and inductive analyses to understand and discuss male participants' experiences of living with chronic pain.

No inclusion limits were placed on the specific diagnosis received by study participants; however, the study must have included exploration of male experiences of a chronic health condition that is commonly associated with pain, and contain in the results section discussion of participants' experiences of chronic pain.

Exclusion criteria were:

- Studies exploring male experiences of chronic conditions typically associated with chronic pain, but not containing explicit discussions of pain in their results section

- Studies in which the experiences of female participants cannot be clearly delineated from male participants.

Critical appraisal of data

Recognising and defining the epistemological standpoint of the authors prior to data acquisition and analysis is a fundamental requirement in the process of synthesising qualitative study results.[39] This thematic synthesis was carried out from the epistemological stance of 'critical realist',[40] applying the wide-ranging applications of a critical realist understanding to qualitative research focused on individual experience.[41] In brief, critical realism in the context of

health and social research derives components of both constructivist and positivist approaches to describe social events, seeking to understand their cause and allowing for practical suggestions regarding addressing social issues to be made.[41]

Several tools which aim to minimise biases during metasyntheses are available for the appraisal of qualitative studies.[42] During this thematic synthesis, the Critical Appraisal Skills Programme (CASP) tool [43] was utilized to understand the strengths and weaknesses of those studies which were included. The CASP tool is extensively used to evaluate aspects of methodological quality, reporting standards, ethical conduct and scientific value of published studies.[44] In order to reduce inevitable rater subjectivity in the evaluation process, all studies included in this synthesis were rated independently by both the author of this report and a colleague experienced in qualitative research analysis. Few between-rater disparities were present; identified differences were discussed to reach a consensus in the final rating provided.

Certain limiting factors can influence the reporting quality of qualitative studies at the point of publication e.g. journal word limits, thus, research quality may not be accurately reflected in the information that is publicly available. Moreover, empirically validated methods for excluding studies from meta-syntheses based upon their perceived quality are lacking.[45] Consequently, the CASP scores attained for each study were not used as a mechanism for excluding studies from our metasynthesis. However, a record of the prevalence of themes across included studies was used as a measure of the amount of overall correspondence of any individual study with the data sample as a whole. The issues of study quality and concordance across the data sample will have affected the results of the thematic synthesis and are discussed in the 'Limitations' section.

Analysis and synthesis of data

A thematic synthesis of included studies was undertaken using the principles outlined by Thomas and Harden,[45] as well as other reviews of the methodologies employed during the meta-synthesis of qualitative data.[46, 47] Due to reporting differences across qualitative studies, using solely the participant quotations included in publications as source data during thematic synthesis would limit the utility of this study. It would remove important contextual factors relevant to each study and not allow for the findings of the study authors to be considered.[45, 48, 49] During this study, and in line with Thomas And Harden's recommendations, those results presented in included studies that were considered 'data' in our synthesis, comprised any text included in 'Results' or 'Findings' sections of the publication.[45]

All the results sections of published reports were imported directly into the qualitative data analysis software (NVivo 11.0, QSR International, Melbourne, Australia). Subsequently, three stages of thematic synthesis were undertaken: (1) coding text, (2) developing descriptive themes, and (3) generating analytical themes.

During stage one, each line of imported text was coded according to its content and meaning. An example of the coding process undertaken is shown in Figure 1.1. This process allowed for the translation of concepts from one study to another, with a bank of codes being created and the synthesis of studies increasing as they were sequentially coded.[45] Stage two of the analysis involved the development of descriptive themes using a hierarchical tree structure, facilitating the grouping of initial codes and the modelling of the relationship between them (Figure 1.2). Finally, during stage three, analytical themes were generated from the descriptive themes in order to provide a thematic synthesis of the original study content. Analytical themes related to the specific research questions investigated during this study. The content of these

analytical themes were inferred by the researcher. Results from coding process were reviewed by supervising members of the research team.

Insert Figure 1.1

Insert Figure 1.2

The analyses, discussions and interpretations presented here represent the work of the researcher. I am a 38-year-old who identifies as a cis-gendered man and I am a Trainee Clinical Psychologist. During my training I have provided therapeutic psychological interventions for both men and women experiencing chronic pain that focused in part on their understanding of shame and self-compassion. I have also experienced mild and intermittent, lower back pain for the past 8 years. Throughout this research process I have maintained a reflexive diary to provide an auditable record of the analyses and my interpretations.

Results

Search results

In total, 833 hits were returned when the results of the four database searches were combined. Of these, 572 were unique and their manuscript titles underwent screening. A total of 75 hits underwent a screen of abstracts and 12 hits were then considered for full text review. A hand search of the reference lists of these 12 papers was undertaken and a further two additional studies were identified. A forward search of the citations of these 14 papers was undertaken, and two further suitable studies were identified (making 16 in total). Following full text review, 2 studies were excluded, and 14 studies were taken forward to be included in this thematic synthesis (Figure 1.3).

Insert Figure 1.3

Study characteristics

Key study characteristics are presented in Table 1.2 Of the included studies, all 14 reported qualitative accounts of men's experiences of living with chronic pain. All studies were from Western societies, including eight from Scandinavian countries, three from the United Kingdom, and two from the United Sates. Topics of research interest included men's engagement with pain rehabilitation programs, a gendered understanding of pain experiences and explorations of the impact of living with a chronic and debilitating condition.

Insert Table 1.2

Appraisal of study quality

An appraisal of study quality using the CASP tool is presented in Table 1.3. All studies were of good quality with only slight variation between them. The CASP tool was used as a qualitative measure of the rigour and validity of the results of the included studies; since no study was identified as substantially lower in quality than the others, the results of the CASP tool appraisal were not used to weight the inclusion or interpretation of data in this analysis.

One study did not provide a clear rationale for its mixed methods approach,[50] and seven gave no explicit mention to the interviewer-participant relationship   Universally, participants were men of white western backgrounds. Overall, despite the limitations described, the strength of the studies included mean that a robust synthesis of relevant data was possible.

Insert Table 1.3

Male experiences of living with chronic pain

The experiences of men living with chronic pain were characterised into the following domains: (1) The effort and unpredictability of being in pain, (2) Becoming a burden, (3) The Being judged as less of a man (4) Trying to hold on to a 'masculine' identity, and (5) Rebuilding and rehabilitating (Table 1.4). The domains overlapped and were reflective of the pain journey that the men had experienced over time. The concept of men's personal identities and how these interacted with the prevailing societal narratives of masculinity were evident in several themes. When this concept overlapped across themes this has been explicitly acknowledged and explored.

Insert Table 1.4

The effort and unpredictability of being in pain

The chronic pain described by men across studies was understood to require effort to endure. Men described that their pain was not constant, and that it could vary from being almost absent to completely debilitating. This unpredictability of how one might feel from one day to the next was difficult for men to adjust to, as it meant making plans and agreeing to future activities became impossible for many. The uncertainty of this 'pendulum swing' was frustrating and contributed to feelings of fear regarding men's "bad days". The fluctuations reduced men's feeling like they could deal with their illness.

Living day by day with a body in pain. The bodily pain fluctuated and consisted of both calm (daily life described as being more relaxed) and difficult phases (daily life described as

being dreadful). It was impossible to make plans, as the men did not know from one day to the next if they would have enough energy to carry out their jobs or chores...[52]

Throughout, men expressed a wish to take back control of their lives from the unpredictable pain; and experienced frustration that this control eluded them. The inability to be able to feel in control often left men experiencing a sense of powerlessness. Inevitably, this resulted in men feeling vulnerable and experiencing a fragility they had not previously encountered. To counter this, many described the need to take control of their cognitions in relation to their situation, often insisting that they 'think positively' wherever possible, as a way of maintaining control and agency in their lives.

Males engaged in cognitive activities by thinking positively and experiencing simple pleasures of life as they participated in family outings, despite the physical limitations of rheumatoid arthritis.[53]

Attempts to take control away from the pain were effortful, and feelings of anger and frustration were commonplace when the experience of trying to live one's daily life in constant pain resulted in a sense of being tormented. The sense of torment emphasised how many men often initially saw their pain as an external force rather than integrated into their own experience. Socially acceptable ways in which men could discuss this torment and allow it to show were by describing the anger they felt, and they often displayed this anger to those close to them.

"I go around with the ache and try to tell myself not to be angry and complain about everything, but the pain makes me irritable." Even the people around them could be affected. The men found that they were easily angered when things did not go as hoped and that they easily got into disputes with others.[52]

Of note, feelings relating to low mood, sadness and depression were expressed less often. As with the later themes relating to social judgement, this may represent an example of men

omitting from their descriptions of inner experiences those emotions which are considered less socially acceptable for men to discuss.[54, 55]

Becoming a burden

The loss of the life lived before pain was felt acutely due to daily reminders of new limitations on activities and the reduced roles that men could undertake within their social contexts.[50, 54, 56] A sense that men considered themselves a burden in their new lives was evident in two principle domains, that of their role in the workplace and their role in the home.

Having a job was perceived as a man's role. Ensuring that they could 'provide', do work of value and be productive were important benchmarks by which men judged their self-worth. When the ability to work was compromised or taken away by chronic pain, feelings of burdening others often become prominent.[50, 52, 57] The struggle to work and the stress that underperforming in tasks, as compared to life before chronic illness, often exacerbated men's experiences of their pain and further compounded reductions in self-esteem. The loss of the ability to perform often led to men needing support from those who they used to provide for or feel senior to, reducing social status and significantly impacting self-esteem.

> *"yes it was ... it was bad for my ego ... really bad ... it was ... it is hard ... when you are not able to do 'man-things' anymore ... that you were able to do earlier ..."[56]*

Elements of grief for their previous selves were present in men's accounts of their changed role at home, for example, when they could no longer play with their children in the garden, or perform as a partner or husband as they felt they should. The daily reminders that they could not undertake the activities that men 'should' carry out contributed to feelings of weakness and being a burden. Inevitably, friendships and family relationships become strained, and many study authors acknowledged the growing sense of isolation men felt, and the active steps men

took to withdraw from relationships rather than maintain feelings of being burdensome to their

loved ones.

> *At the same time, the men could not tell their wives or partners everyday that they were*
> *feeling ill because that would only make things worse for both of them…"I just cannot wake*
> *her at night. She has to get up early and go to work; I try to keep it to myself".[52]*

Being judged as less of a man

The complex prosocial elements of chronic pain were evident throughout the studies. The

role of others and their implicit and explicit opinions that were brought into interactions with

men experiencing pain were consistently foregrounded. The impact of social narratives, stigma

relating to men's experiences of pain and the dismissal of their experiences were common to all

studies. Throughout, men experienced not feeling believed regarding the extent of the pain they

felt due to the invisible nature of their illness, and the social understanding that 'men shouldn't

get sick like this'.

Men's narratives of what it means to be a man were situated in their past by study

authors, giving primacy to content which acknowledged the role of participants' early

experiences and role models in their personal understanding of how to deal with pain.

> *I remember my dad; he never stayed home even one day from work, no matter how bad he*
> *felt.[52]*

The impact of the social judgement on men was such that they were perceived as being 'weak' or

'a whiner' if they discussed their feelings; or their pain reduced the likelihood they would engage

in help seeking behaviours, and it reduced their ability to psychologically process the challenges

that chronic pain presented.

"Men are expected to 'suck it up and tough it out' and, as I learned, this only makes matters worse"[50]

Unfortunately, the experience of men seeking help from healthcare professionals was reported alongside a description of being dismissed or disbelieved. Men reported often long paths to diagnoses in studies describing fibromyalgia patient experiences, with the commonly reported understanding that 'this is a women's disease'.

In the beginning of the symptoms, the doctors had repeatedly told Martin to "pull himself together" or "think positively". One doctor had expressed his opinion clearly: "I will never give fibromyalgia diagnosis to a man!" Martin was annoyed by the comments of some doctors who implied that he was malingering...[56]

Men felt that as the chronicity of their pain increased it was clear that healthcare professionals became disinterested in them as a patient. The type of treatment and social reactions of healthcare professionals that men received was overtly understood through the lens of gender, with the dismissal of their experiences being met with feelings of frustration, and an understanding that other people must consider them 'a malingerer'.[56]

"I have been told men don't know what pain is like in women. Or told to suck it up and it is not a real thing just all in my head. Then everywhere in between. I have a friend (female) with [fibromyalgia] and people are so much more supportive including doctors.[50]

As pain became chronic and men were unable to participate in their normal social routines, a stigma surrounding their condition was evidenced by many people in their lives 'backing off' from them. Those who could not see the invisible illness and demonstrate an empathy or understanding towards men with chronic pain were often termed 'outsiders' by study authors, demonstrating an implicit social divide between people with chronic pain and those

without. Men were treated differently once they lost the ability to engage in their usual ways, and

inevitably isolation from those once close to them could occur.

> *Some men who were able to return to work felt that they were given meaningless tasks. They worked their number of hours and no one commented on how they came and went. This situation made them feel like outsiders, which sometimes led to suicidal thoughts.*[52]

Inevitably, men's internal interpretations of themselves began to integrate the

stigmatizing actions of others. When others "backed away", this led to experiences of anger,

frustration, and loneliness.[50, 52, 58] Men often described consequently avoiding others and "going

into a shell" and some named feelings of depression.[53, 55] Others described the impact of their

isolation on their internal experiences using language that related to the actions of others, for

example feeling "shamed" or "abandoned".[50, 52, 58, 59]

Trying to hold on to a 'masculine' identity

Several elements relating to masculine identity explored in this theme overlap with those

explored in the theme of "Being judged as less of a man". However, here, it is the internal beliefs

expressed by the men relating to ideas of masculinity that are given primacy, rather than the

masculine hegemony situated in the actions of others.

A consistent theme discussed by study authors was men's struggles to maintain a sense of

'being a man' despite the changes resulting from chronic pain. The concept of maleness and

masculinity being linked to maintaining one's role as a father, partner, or breadwinner was

fundamental in this process. Evidence that men passed judgement on themselves using the

prevailing social narratives surrounding masculinity and ways in which it is acceptable or not

acceptable to be ill 'as a man' was commonplace. Inevitably, the high threshold for succeeding at

being 'strong' or 'providing' in the context of chronic pain cannot be met and a sense of failing

in this quest leads many to question their masculine identity.

Throughout, the internalised narrative ascribing how men should cope with their pain was one of stoicism and not complaining. An avenue by which suffering might be alleviated, that being the chance to reach out to others and discuss one's struggles, is often closed off to men due to their experiences and understanding of what it means to be a man who should silently cope with adversity.

The third narrative strand was around barriers to coping with the illness, including a variety of factors such as being overwhelmed, feeling unable to talk about it because of 'being a man'.[58]

Authors of studies acknowledged the 'unsaid' thoughts and feelings during their interviews as being conspicuous by their absence. Despite recognising their own feelings of inadequacy and failings at reaching social expectations of being a man, the drive to not appear weak leads many men to continue to play the role and to 'man up', at significant personal cost to their psychological wellbeing.

Men's initial pain journeys were consistently reported as either occurring after beginning slowly and worsening following onset, or, as pain persisting following an acute injury. Physical responses to pain were common; men felt that keeping moving and remaining active were key to their ability to cope with and control their pain. Men often interpreted their pain as 'normal aches and pain' initially, and their tendency to seek help was curtailed by worry that they may be perceived as not 'pushing through' as a man should. The need to seek help was perceived by many men as a sign of weakness, and that pain was something to be endured.

The theme 'feeling afraid of being looked upon as being a whiner' highlights the fact that the men first endured a lot of pain before they sought health care. There were men who even struggled to continue at work until they collapsed and had to be taken to hospital by ambulance.[59]

Pain in general, and the resulting inability to perform tasks or work at the capacity required, were not felt by men to be reasons that they could give to justify the reductions in daily function that they were experiencing.

...he's been troubled by headaches almost all his life. This may be problematic for a man because in our culture, headaches have feminine connotations and are sometimes seen as a vague and groundless pain[54]

In most cases men's original reaction to fibromyalgia diagnosis was described as disbelief; "I cannot have it, I am a man!"[55]

The loss of masculine identity as chronic pain persists and levels of disability increase is experienced as a loss of one's dignity by many. Increasing physical weakness can result in social connections and rituals becoming embarrassing for some.

Participants explained that this reduction in strength and ability leads to the need to ask for help, which some men view as a challenge to their masculinity: "It puts you in a position where you have to ask for help and it's not a very sort of macho thing"[57]

Rebuilding and rehabilitating

Men's pain journeys were broadly experienced as a process, with their initial reports including a strong drive to ameliorate the pain and "get on" with their lives as they had been before pain. As pain became their everyday experience and an acceptance grew that it was not likely to be curable, men described its integration into their understanding of themselves and what they would be able to achieve alongside their pain.

During the early course of men's pain journey, they understandably reported being preoccupied with looking for a cure and experiencing frustration at a lack of explanation for their illness. The process of using the internet to perform research led many to try 'alternative' medicine routes, some reported the process as frustrating due to the lack of effective remedies

found, others reported finding social connections through forums and online support groups that

provide support and understanding.

Approaches to rehabilitation remained heavily influenced by social understandings of

how men should rehabilitate (with a heavy focus on painkillers and physical activity).

Ultimately, an understanding that life must change to match the limitations that their illness

brings was often gained. Reductions in activity levels, changes in job roles or accepting the need

to leave one's job was greeted by some with feelings of relief.

> *The first model narrative "Adjusting life to match the illness" was a description of finding a*
> *gentle balance between health and illness and between work ability and disability. In this*
> *model narrative, current situation was experienced as manageable and satisfactory…*[56]

With a growing sense of acceptance, thoughts turned to rebuilding a new identity of a

'man with chronic pain'. As part of this process, men reported the importance of redefining what

it means to still 'be a man' with pain. Rebuilding an understanding of the self, and an

understanding of masculinity was considered by many authors to be integral to the journey of

many men. Understanding life as a man using the predominating social narratives of masculinity

was inevitably challenging for men as their daily functioning was reduced due to pain. A process

of redefining their masculinity was therefore often evident.

> *When you have constant pain, you become so self-centred and tied up in your own little*
> *world that everyone else just seem stupid – but then I started therapy with the psychologist.*
> *This helped to open doors slightly, but I had to open them completely myself, which enabled*
> *me to literally get myself out and about, and find other values in life other than just those*
> *relating to work*

Being given permission by others to think differently about 'how to be a man' was

important. Men's experience of multidisciplinary rehabilitation programmes for chronic pain

were reported positively. Alongside the value placed by men on having a 'training programme',

study authors identified that increased social connections with 'people who understand' were

invaluable in gaining men's trust and allowing them to discuss their feelings of fragility, sadness

and grief. Ultimately, feeling believed and validated was fundamental to this journey of personal

growth.

Discussion

This thematic synthesis aimed to synthesize results from qualitative studies which

investigated the experience of chronic pain reported by men. Fourteen studies were included, and

five core themes were identified: The effort and unpredictability of being in pain, becoming a

burden, being judged as less of a man, trying to hold on to a 'masculine' identity, and rebuilding

and rehabilitating. Although these five themes were distinct, overlap in their contents was

identified and during coding several quotes fitted into more than one theme. Thus, these themes

can be considered as interconnected and dynamic. The themes can be considered to represent

different elements of a chronological experience, beginning with the onset of pain and men's

desire to control its intensity and impact, through to the social judgements men experience as

their pain begins to influence their daily functioning, the internal judgements that are made, and

a subsequent process of building a new understanding of the self and engaging in attempts to

rebuild and rehabilitate. A thematic schema representing this journey, and the interactions

between themes is presented in Figure 1.4.

Insert Figure 1.4

Men reflected on the initial effort involved in managing their pain, the frustration and fear

relating to its unpredictability, and the knowledge that they would experience pain when they

tried to complete their normal daily activities. The fear-avoidance model of pain describes the

cycle of events that can begin with fear of pain and lead to avoidance of activities, and the

consequent onset of negative affects including low mood and pain related anxieties.[60] However,

alongside pain avoidance behaviours a desire to strive and push through pain was also evident,

with the predominant feelings when this was no longer possible being those of anger and

frustration. Expressions of feelings such as sadness, depression or despair, which can be

conflated with concepts of weakness and fragility within the Western masculine hegemony,[61]

were described less often. While it is possible men experiencing chronic pain may not be

experiencing feelings of weakness and fragility and are therefore not in need of discussing them,

the results presented here suggest this would be unlikely. Moreover, this would be expected

based on previous meta-syntheses and reviews of pain studies which include women as

participants, and identify openness to discussing emotions as a recognised coping strategy

commonly available to women but less so to men.[35, 62, 63]

Men's feelings of becoming a burden were experienced in two principal domains of life,

their role at home, and their employment. Explicit discussion of changes in job role or loss of

employment were common throughout studies. This theme is common in primary and meta

studies of pain,[63, 64] and the themes frequently reported relate to issues such as a fear of not

coping with pain flares at work, job loss or excessive absenteeism.[54-56, 63-65] Here, the issue of

employment was explicitly understood within the framework of men struggling to adapt to

reductions in status in the workplace, and their inability to maintain their role as the "bread

winner" or provider.[36, 66] Ultimately, the burden of not working was understood by men through

an underlying guilt and shame of not "providing as a man should", and this may reflect previous

findings that men experience significantly higher levels of emotional distress compared to

women when having to stop work due to chronic illness, but lower levels than women while sustaining work despite experiencing pain and disability.[67] Consequently, changes in the masculine role at home were in part impacted by changes in employment. However, additional stressors that spoke to men's feeling of being burdensome such as no longer being able to fulfil the physical roles of playing with children or perform home maintenance were evident. A changing role within the family consequent to chronic pain has been widely reported.[68] Although discussion of relationship breakdown was evident in the synthesis, a topic notable by its presence in previous studies including both men and women[64] and its absence here, was any changes in intimate physical relationships that men experienced.

Fundamentally, 'being judged as less of a man' and 'trying to hold on to a 'masculine' identity' represent an experience of an assault on the self that is often reported by people experiencing chronic illness.[29, 69, 70] The practices that facilitate men's construction of their masculine identity vary depending upon culture, age and social contexts.[71] Male gender identity is understood to develop through engagement in gendered social practices over time, often described as 'doing masculinities'.[36, 72] Socially understood masculine health practices of not seeking help from health professionals, and remaining stoic and silent when experiencing illness, are challenged by the severity and longevity of men's pain. Wider masculine practices relating to 'being a father' or 'being a man at work', are all challenged or attacked by the onset of chronic debilitating pain. This synthesis recognised these attacks as evident in two broad ways. Firstly, men's experiences of social judgement when they were not able to 'do masculinity' according to socially understood norms.[50-56, 73] Secondly, men underwent a period of renegotiation in which they tried to hold on to their masculinity, and experiencing internalised feelings of personal shame at not being able to 'do masculinity' as previously.[53, 54, 56, 58, 59, 65]

Being judged by others as less of a man, represents a form of enacted stigma,[74] which is a well-understood barrier to health seeking behaviours generally.[75-77] Here, men struggled to avoid the appearance of being weak and vulnerable. Social isolation associated with appearing weak was evident in men's descriptions of a loss of dignity and a withdrawal from those closest to them. Such an impediment towards the fostering of social relationships and subsequent pain related health behaviours such as pain avoidance, all contribute to a worsening of psychological distress. [78, 79] These observations are not unique to a male experience of chronic pain, and concordant themes have been identified in studies relating to male experience of illnesses such as chronic heart disease and prostate cancer.[36, 37] Perhaps one unique feature of this synthesis is a recognition that an underlying assumption exists that chronic pain, and fibromyalgia specifically, have been shown to be considered as 'women's' illnesses, by participants. This perception was often felt by men in the context of interactions with healthcare professionals, and was experienced as especially stigmatizing. These reports add to the existing weight of evidence that people experiencing chronic pain often feel unheard or disbelieved by healthcare professionals.[27, 28]

Keogh (2015) posited that the interaction between pain and masculinity, and the impact of gender roles on pain-related behaviours and the reactions of others to one's pain,[32] remain poorly understood. Here, men's social understanding of pain is that it is an experience that should be endured, and one should be seen to cope in silence. Such 'practiced masculinities' can often serve as barrier to accessing support from others, including healthcare professionals, when pain becomes chronic and debilitating. This understanding may explain some of the gender differences in diagnosis rates for chronic pain.[32]

The reactions of others are often interpreted as a challenge to men's masculine identity and the loss of gendered social roles serves to promote a period of renegotiation of men's masculine identity. Only two of 14 studies explicitly explored the experience of men's rehabilitation from chronic pain.[54, 65] Rehabilitation approaches that best fit the understood masculine hegemony were found most helpful, in particular, a physical activity programme and a schedule that could be viewed as 'work to be done'. More widely, men described a period of rebuilding one's identity and the acceptance of a new life 'after chronic pain'. The adaptation of one's life to fit in with a pain that will not be cured was an outcome experienced by many. An explicit acknowledgement was present in many studies that stoicism and coping in silence were ultimately counter-productive approaches to addressing one's pain, and recognised as such by the men. Thus, an implicit consequence of this realisation is the requirement to 'do masculinity' in a way that is counter to previously internalised social norms.

People who experience chronic pain routinely describe experiencing stigma, which combined with increasing disability and social isolation often results in a challenged identity, irrespective of gender.[35] A renegotiation of one's identity following a diagnosis of chronic pain is not unique to men.[35] Women often describe their pain in the context of their family roles as a spouse and mother, moreover, their household responsibilities such as cleaning were often prioritised over needing to remain in paid work.[35] This was reflected in interactions with healthcare professionals and the gendered prioritisation of questions that were asked during consultations related to housework.[35]

Understanding the gendered differences that influence how men and women experience chronic pain is important for informing how the condition is managed by healthcare professionals. A recent integrated review of qualitative and quantitative studies aimed to

understand the role of gendered norms in chronic illness.[35] Samulowitz[35] described broad male categories of 'Stoic men', 'Men's gender identity in jeopardy' and 'This is not me' when comparing the experience of men with women who experience chronic pain. These themes share commonalities with those identified here, specifically, in relation to the understanding that men had of what it means to "be a man" in pain and the socially acceptable behaviour of enduring in strong silence. Again, as seen here, discussion by male participants of emotional distress or vulnerability among men was less prevalent across the reviewed literature.[35-37] Key differences identified between the perception of men and women experiencing chronic illness, both by participants and health care professionals, was in the social understanding which was applied to their condition.[35] It was considered more socially acceptable for women to seek help and talk about their pain, however, women were also viewed as "emotional", "sensitive" and "hysterical".[35] The mechanisms which people have available to cope with chronic pain (which often results from conditions which are poorly understood in terms of pathological aetiology), are gendered and often stigmatised. For both men and women, the result is often the same and presents as feelings of social isolation and distress.

Clinical practice implications

Healthcare professionals routinely report feeling uncertain or unprepared to manage patients presenting with chronic pain.[26] People who experience chronic pain routinely report stigmatising experiences in relation to their interactions with healthcare professionals.[27, 28] Here, several of these accounts were described by men as examples of their masculinity being challenged or feeling threatened.[55, 56] Unconscious biases of healthcare professionals inevitably play a role in the way in which they interact with those who they treat.[80, 81] For people with chronic pain, it appears that biases relating to their gender influence both the nature of the

interaction and the subsequent treatment, with gender differences in management decisions made by healthcare professionals being evident that cannot be explained by differing medical need.[35] At the individual level, the first step health care professionals can make in reducing gender related stigma during consultations when assessing and treating men with chronic pain is to acknowledge that such biases exist and engage in bias-reducing strategies such as perspective taking, and focusing on the individual experience of their patient/client, rather than focusing on social grouping.[81] Whilst being mindful not to generalise regarding how any one individual is likely to feel or present when seeking help, clinicians need to consider the important gender differences in reporting rates of pain, and be aware of the coping behaviours that are considered socially acceptable for men to engage in. As described here, men often seek to take control of their cognitions in relation to their pain, thinking positively,[53] and utilising distraction techniques.[82] Moreover, men also report higher rates than women of using alcohol to cope with their pain,[32, 83] presenting in higher numbers with conditions relating to combined alcohol and opioid use.[84] Such coping strategies may be harmful in relation to long-term management.

Clinical psychology

Clinical guidelines in the UK (NICE) for the management of chronic pain remain in development,[17] however, the scoping document for these guidelines is clear that psychological therapies are a central part of the treatment pathway.[16] At present, multidisciplinary pain management programmes that utilise a cognitive and behavioural approach for their psychological intervention component are recommended in guidelines published by UK pain advocacy groups.[15] Such cognitive and behavioural approaches have tended to focus on well understood patterns of behaviour in pain, such as the catastrophic thinking or the fear avoidance cycle. [85-87] However, several psychological modalities with slightly different theoretical

standpoints, including Acceptance and Commitment Therapy (ACT)[88] and Compassion Focused

Therapy (CFT),[89] have now also demonstrated effectiveness in improving psychological well-

being outcomes of mood, psychological flexibility, catastrophic thinking and self-efficacy, as

well as reducing levels of disability.[85-87] The results of this study support the utilisation of these

approaches and they provide insight into the considerations that clinical psychologists should

make when working alongside their male clients who experience chronic pain. For example, CFT

(which focuses on reducing feelings of threat resulting from perceived social isolation, shame

and self-criticism[89]) may be an appropriate intervention in addressing feelings of internalised

stigma resulting from noticing changes in how colleagues and friends may react to increasing

levels of pain-related interreference in functioning.[50, 52, 57] Approaches such as ACT may allow

psychologists to support men in identifying their individual values which they can live by, rather

than those they may feel are imposed by social narratives. It will be important to consider and

discuss men's readiness to engage in a group-based intervention, given the evidence of men's

internal drive to not appear weak in front of others, whilst holding in mind the potential that the

process of hearing other men with similar experiences may be particularly useful and

normalizing.

Limitations

Several limitations existed during the synthesis of available studies. Although research

supervision and a reflexive diary were used throughout to reduce potential confounders, both my

unconscious and conscious biases will inevitably colour the content of the themes that have been

identified.[90]

All studies were retrospective in nature and sought to understand men's experiences

across a range of cultures, medical diagnoses, and some had explicit aims related to aspects of

specific conditions. It is important to note that research that was not published in an English language form was excluded and all studies were performed in what would be typically understood as 'Western developed cultures'. The voices of men from black and minority ethnic background is notably lacking. Of the 14 studies, only one reported enrolling participants from black or minority ethnic backgrounds,[53] with all other studies reporting the ethnicity of participants having exclusively white study populations. Ethnicity was not universally reported, rather study authors focused on the age, marital status and duration of participant's pain. Also absent in this synthesis is any study from countries outside of Europe and the United States. As such, this research is heavily situated in an understanding of the Western masculine hegemony, and does not account for cultural variation from this.

Of the 14 studies identified, nine research teams were responsible for their generation and publication, the majority of which were Scandinavian. Therefore, overlap in methodological approaches and research focus for specific groups has likely influenced the results of this synthesis. No attempt was made in this synthesis to apply weight to the prominence of data from specific research groups as there was no reliable way to achieve this aim. That over reliance on studies from specific research groups is a key limitation of this synthesis is reflective of the fact that men's experiences of stigmatising illnesses remains a niche area of exploration.

Future research

Future research in this area must foster greater cross-cultural understanding of men's pain related behaviours and seek to include non-white, non-western voices from across the lifespan into evidence base. The research community should consider why men's experiences of highly stigmatised illness that has a significant social and healthcare burden is not currently a research priority. Is research community complicit in propagating the stigma by not talking more about

men's experience? Understanding if social narratives of masculinity mean men are less likely to participate in research should also be considered. Studies which aim to utilise therapeutic approaches tailored to address the barriers to treatment identified would seem important, such as acceptance regarding pain chronicity. Finally, studies which seek to understand the experiences of men who have participated in pain management programmes would be of use. Specific topics of interest might be post-traumatic growth in men's re-evaluation of priorities, is there evidence of men being able to live their life in line with their values despite the chronicity of their pain?

Conclusions

This systematic thematic synthesis identified 14 qualitative studies that described men's experiences of chronic pain. Overall, 5 domains were identified, and these appeared to occur as a process, whereby men initially struggled to deal with the experience and effort of being in chronic pain. Subsequently, the social challenge of not being able to perform what men considered to be their role was experienced as particularly difficult for men. A renegotiation of one's understanding of their masculinity followed for many, due to the innate challenge of being a man within the well understood western social narratives of strength and stoicism. Throughout, men reported experiencing social stigma, including from health professionals. Men with chronic pain described barriers to seeking help that are in line with understood masculine health behaviours. Negotiating a new understanding of masculinity was often required for men in order to facilitate acceptance of their pain and rehabilitation.

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90.   Atieno O. An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century* 2009; 13: 13-38.

91.   Flurey C, White A, Rodham K, et al. 'Everyone assumes a man to be quite strong': Men, masculinity and rheumatoid arthritis: A case-study approach. *Sociology of Health & Illness* 2018; 40: 115-129.

92.   Madsen M, Jensen KV and Esbensen BA. Men's experiences of living with ankylosing spondylitis: a qualitative study. *Musculoskeletal care* 2015; 13: 31-41.

Figures and Tables

Figure 1.1 Generating codes line-by-line from source data text using NVivo

Image of coding approach using NVivo 11.0 (QSR International, Melbourne, Australia)

Figure 1.2. Generation of themes
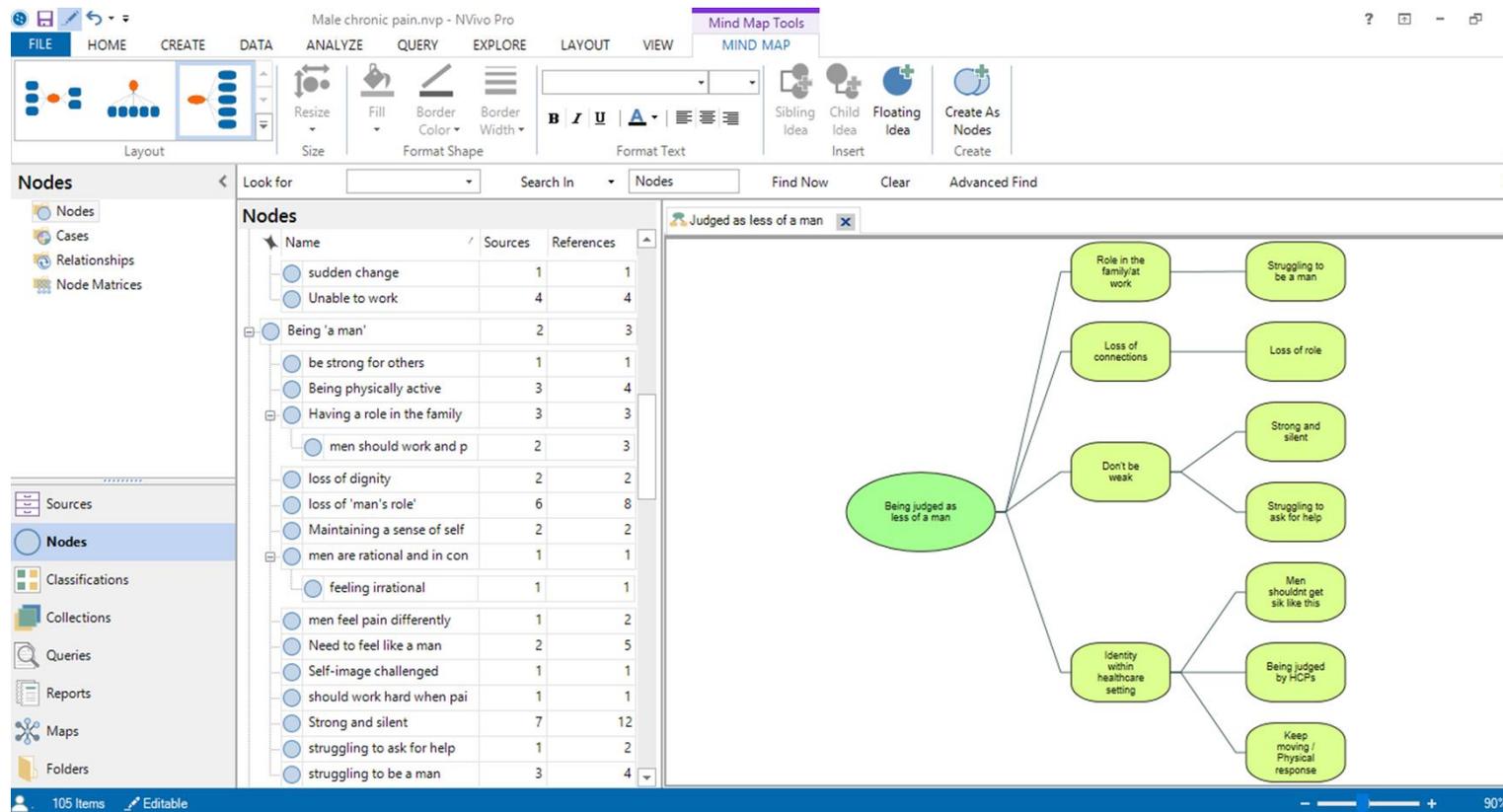
Mapping of codes to generate descriptive and analytical themes using NVivo 11.0 (QSR International, Melbourne, Australia)

Figure 1.3. PRISMA diagram for literature searching process

Identification

Records identified through database searching
(n = 833)

Screening

Records after duplicates removed
(n = 572)

Records excluded after Title screen
(n = 498)

Titles and abstract screened
(n = 75)

Records excluded
(n = 62)

Eligibility

Full-text articles assessed for eligibility
(n = 12)

Articles identified from a forward search and a hand search of reference list of full-text articles to be screened
(n = 4)

Number excluded
(n = 2)
- No explicit content relating to experience of pain
- Thesis dissertation

Included

Studies included in the review
(n = 14)

Figure 1.4. Thematic schema

Western masculine hegemony

Being judged as less of a man
- Don't be weak, don't whine
- Being dismissed by healthcare professionals
- Losing connections and becoming isolated

The effort and unpredictability of being in pain

Becoming a burden
- Loss of employment
- Loss of family role

Trying to hold on to a 'masculine' identity
- Men should be strong and silent
- Men shouldn't ask for help or get sick "like this"
- Losing dignity

Rebuilding and rehabilitating
- Looking for a cure
- Becoming a new kind of man

Table 1.1. Summarised search terms*

#	Search area to be probed	Search terms used
	Search area to be probed	**Search terms used**
#1	Chronic pain and Pain related conditions	ABSTACT OR TITLE [Pain OR Chronic Pain OR Arthritis OR Low* back pain OR Rheumatoid OR Fibromyalgia OR Osteoarthritis OR Musculoskeletal Diseases OR Arthritis OR complex regional]
#2	Research methodology	DATABASE METHODOLOGY TAG [Qualitative]
#3	Research focus	ABSTACT OR TITLE [lived OR life OR living OR interview* OR narrative* OR narration* OR semi structured OR thematic OR focus OR open ended OR grounded OR hermeneutic* OR semiotic* OR data saturation OR social OR post structural* OR poststructural* OR cooperative inquir* OR co operative inquir* OR humanistic OR existential OR experiential OR paradigm OR field OR ethnonursing OR action research OR phenomenol* OR subjective OR story OR stories OR experience*]
#4	Research participants	ABSTACT OR TITLE [men or males or man or male or masculinity]
#5		**#1 AND #2 AND #3 AND #4**

*Note: search terms were adapted and individualised for specific databases to align with database specific terminologies e.g. MeSH terms

Table 1.2 Study characteristics

Author (Year)	Country	Topic/focus	Methodology	Sample	Theoretical approach	Primary Themes Identified / Main Findings
Ahlsen, Mengshoel 2012	Norway	Examining the meaning of participation in a rehabilitation clinic programme for men with chronic pain	Semi-structured interviews	10 men with chronic neck or muscle pain.	Narrative analysis	Three main narratives were explored: • "Rebuilding a self" • "Being comforted" • "Being connected"
Ahlsen, Mengshoel 2012	Norway	Examining how men present themselves as patients and investigating how subjective experience of chronic muscle pain interacts with dominant masculine hegemony	Semi-structured interviews	10 men with chronic muscle pain.	Narrative analysis	Summary of main findings: Human suffering, in the form of chronic pain, a "loss of control" and the "loss of oneself" were consistently reported in accounts that principally described a story of feeling vulnerable as a man

Beaton, Hodge 2012	United States	Understanding the "the physical, psychological and social context" of pain experienced by male veterans with RA	Semi-structured interviews	12 men (service veterans) with RA	Grounded Theory	Six concepts two domains related to RA pain adaptation:
						
						• Movement
						  ○ Keep moving
						  ○ Consequences of not moving
						  ○ Staying physically active
						• Emotions
						  ○ Thinking positive thoughts
						  ○ Doing jobs
						  ○ Focusing on male identity

Author (Year)	Country	Topic/focus	Methodology	Sample	Theoretical approach	Primary Themes Identified / Main Findings

Flurey, Hewlett 2017	United Kingdom	Exploring experiences, coping styles, and support preferences of men with RA	Facilitated semi-structured focus group discussions using a topic guide which was iteratively adapted with emerging themes	Six focus groups (22 men total)	Inductive thematic analysis.	Core concepts included:
						
						• Challenges to masculinity
						  o Reduction in strength and abilities
						  o Loss of independence,
						  o Challenges to masculine identity and role
						  o Loss of power and control
						• Getting through life with RA
						  o Just getting on with it
						  o Information seeking
						  o Engaging in "destructive behaviours,"
						  o Withdrawing socially

Flurey, White 2018	United Kingdom	Exploring masculine identity for men with RA	Case study interviews with men who had previously taken part in focus group research[57]	5 men	Thematic analysis	Main themes included: • Importance of paid work • Renegotiating masculine identity • "Pushing through pain to retain masculine activities" • Replacing masculine roles • Rejecting masculinity
Kvam, Eide 2013	Norway	Understanding participation and changes in participation in a vocational rehabilitation programme in men and women experiencing chronic musculoskeletal pain	In-depth interviews	6 women 4 men[a]	Constant comparative analysis "inspired by grounded theory"	The only theme that could be attributed to analysis of male participants data exclusively was "Participating as before – the masculine way", as related to engaging in activities of daily life.

Author (Year)	Country	Topic/focus	Methodology	Sample	Theoretical approach	Primary Themes Identified / Main Findings
Madsen, Jensen 2015	Denmark	Understanding men's experiences of AS and the challenges they experienced in living with the chronic disease.	Semi-structured interviews	13 men	Content analysis "inspired by Graneheim qualitative methodology".	An overarching category of "An invisible companion for life" was comprised of 4 sub-categories: • Approaching a diagnosis • Ill in a social context • Challenged as a man • The importance of remaining physically well
Muraleetharan, Fadich 2018	United States	Understanding the impact of fibromyalgia on men in both health service and wider social contexts:	Qualitative free text survey (administered both online and in-person)	1,163 participants, of which 805 were men[a]	Thematic analysis	Main findings: Men experience negative impacts on their physical and mental health, quality of life, relationships, and careers due to fibromyalgia. Men were deterred from seeking help from healthcare professionals due to the potential for misdiagnosis, dismissal of symptoms, and the stigma of having a 'women's condition'.
Paulson, Danielson 2001	Sweden	Understanding men's descriptions of their fibromyalgia related pain	Narrative interviews	14 men	Inductive content analysis	Men's descriptions of their pain fell into two main themes: • Perceptions of diversified Bodily pain • Perceptions of fluctuating pain Men reported specific experiences and used metaphor to make pain visible to others
Paulson, Danielson 2002	Sweden	Understanding the meaning men make of their lives whilst experiencing fibromyalgia type pain	Narrative interviews	14 men	Phenomenological hermeneutic interpretation	Three major themes were: • "Experiencing the body as an obstruction" • "Being different man" • "Striving to endure"

Author (Year)	Country	Topic/focus	Methodology	Sample	Theoretical approach	Primary Themes Identified / Main Findings
Paulson, Norberg 2002	Sweden	Understanding men with fibromyalgia's experience of the Swedish healthcare system	Narrative interviews	14 men	Inductive content analysis	Five key themes identified: • Feeling afraid of being looked upon as being a whiner • Feeling like a guinea pig • Feeling hopeful • Feeling neglected • Feeling no recovery
Sallinen and Mengshoel 2019	Finland and Norway	Understanding the impact of fibromyalgia on men's daily life and ability to work	Life-story interviews	5 men	Narrative analysis	Two model narratives were elucidated: • "Adjusting the life to match the illness" • "Being imprisoned by the pain"
Sallinen, Mengshoel 2019	Finland and Norway	Understanding the interaction of illness and gender through the life-stories of Nordic men with fibromyalgia	Life-story interviews	8 men	Narrative analysis	Main findings: • Masculine identity was re-negotiated by comparisons to other men, life before symptom onset, and by "discussing expectations and beliefs of how men should act in contemporary societies" • Transitioning from a strong and reliable body to a painful, vulnerable and one was perceived as fundamental.
Wood, Qureshi 2017	United Kingdom[b]	Understanding men's accounts of living with CP/CPPS	7 semi-structured interviews 5 written narrative accounts	12 men	Narrative analysis	Three major themes were identified: • "Medical stories: Blame and shame" • "The Erratic nature of CP/CPPS" • "Ongoing struggles for coping and cures and the search for meaning"

[a]*Only findings identifiable as provided by male participants (i.e. quotations) were included in this synthesis. [b]Study was conducted in the United Kingdom, however no indication is given regarding the location of participants providing written accounts. AS, ankylosing spondylitis; CP/CPPS, Chronic prostatitis/chronic pelvic pain syndrome; RA, rheumatoid arthritis.*

Table 1.3 Quality appraisal of included studies using qualitative CASP tool[43]

Study	Clear research aim?	Methodology appropriate?	Design appropriate for aims?	Recruitment strategy appropriate?	Relationship between researcher and participant considered?	Ethical issues considered?	Data analysis	Findings	Value of research
Ahlsen, Mengshoel 2012	Y	Y	Y	Y	Y	N	Y	Y	Y
Ahlsen, Mengshoel 2012	Y	Y	Y	Y	Y	N	Y	Y	Y
Beaton, Hodge 2012	Y	Y	Y	Y	N	N	Y	Y	Y
Flurey, Hewlett 2017	Y	Y	Y	Y	N	Y	Y	Y	Y
Flurey, White 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kvam, Eide 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y
Madsen, Jensen 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y
Muraleetharan, Fadich 2018	Y	N	Y	Y	N	N	Y	Y	Y
Paulson, Danielson 2001	Y	Y	Y	Y	N	Y	Y	Y	Y
Paulson, Danielson 2002	Y	Y	Y	Y	N	Y	Y	Y	Y

Study	Clear research aim?	Methodology appropriate?	Design appropriate for aims?	Recruitment strategy appropriate?	Relationship between researcher and participant considered?	Ethical issues considered?	Data analysis	Findings	Value of research
Paulson, Norberg 2002	Y	Y	Y	Y	N	Y	Y	Y	Y
Sallinen and Mengshoel 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sallinen, Mengshoel 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wood, Qureshi 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y

CT, Cannot tell; N, no; Y, yes

Table 1.4. Domains of male experiences of chronic pain

Domain
The effort and unpredictability of being in pain
Becoming a burden
Being judged as less of a man
Trying to hold on to a 'masculine' identity
Rebuilding and rehabilitating

Appendices

Appendix 1: Search strings

PsychINFO

#	Search terms	Hits
#1	AB Pain OR Chronic Pain OR Arthritis OR Low* back pain OR Rheumatoid OR Fibromyalgia OR Osteoarthritis OR Musculoskeletal Diseases OR Arthritis OR complex regional	27, 531
#2	MA qualitative	15, 377
#3	AB lived OR life OR living OR interview* OR narrative* OR narration* OR semi structured OR thematic OR focus OR open ended OR grounded OR hermeneutic* OR semiotic* OR data saturation OR social OR post structural* OR poststructural* OR cooperative inquir* OR co operative inquir* OR humanistic OR existential OR experiential OR paradigm OR field OR ethnonursing OR action research OR phenomenol* OR subjective OR story OR stories OR experience*	681,547
#4	AB men or males or man or male or masculinity	141,684
#5	**#1 AND #2 AND #3 AND #4**	**31**

AB, abstract; MA, Method of analysis

MEDLINE

#	Search terms	Hits
#1	AB Pain OR Chronic Pain OR Arthritis OR Low* back pain OR Rheumatoid OR Fibromyalgia OR Osteoarthritis OR Musculoskeletal Diseases OR Arthritis OR complex regional	722,891
#2	AB (lived OR life OR living OR interview* OR narrative* OR narration* OR semi structured OR thematic OR focus OR open ended OR grounded OR hermeneutic* OR semiotic* OR data saturation OR social OR post structural* OR poststructural* OR cooperative inquir* OR co operative inquir* OR humanistic OR existential OR experiential OR paradigm OR field OR ethnonursing OR action research OR phenomenol* OR subjective OR story OR stories OR experience*)	6,536,014
#3	AB men or males or man or male or masculinity	1,665,985
#4	#1 AND #2 AND #3	38,619
#5	**#4 Limiters - Sex: Male; Clinical Queries: Qualitative - High Specificity**	562

AB, abstract.

CINAHL

#	Search terms	Hits
#1	AB Pain OR Chronic Pain OR Arthritis OR Low* back pain OR Rheumatoid OR Fibromyalgia OR Osteoarthritis OR Musculoskeletal Diseases OR Arthritis OR complex regional	**246,496**
#2	AB (lived OR life OR living OR interview* OR narrative* OR narration* OR semi structured OR thematic OR focus OR open ended OR grounded OR hermeneutic* OR semiotic* OR data saturation OR social OR post structural* OR poststructural* OR cooperative inquir* OR co operative inquir* OR humanistic OR existential OR experiential OR paradigm OR field OR ethnonursing OR action research OR phenomenol* OR subjective OR story OR stories OR experience*)	**1,517,591**
#3	AB men or males or man or male or masculinity	376,246
#4	#1 AND #2 AND #3	13,340
#5	#1 AND #2 AND #3 **Limiters - Sex: Male; Clinical Queries: Qualitative - High Specificity**	220

AB, abstract.

PubMed

#	Search terms	Hits
#1	Title/AB Pain OR Chronic Pain OR Arthritis OR Low* back pain OR Rheumatoid OR Fibromyalgia OR Osteoarthritis OR Musculoskeletal Diseases OR Arthritis OR complex regional	**295608**
#2	Title/AB (lived OR life OR living OR interview* OR narrative* OR narration* OR semi structured OR thematic OR focus OR open ended OR grounded OR hermeneutic* OR semiotic* OR data saturation OR social OR post structural* OR poststructural* OR cooperative inquir* OR co operative inquir* OR humanistic OR existential OR experiential OR paradigm OR field OR ethnonursing OR action research OR phenomenol* OR subjective OR story OR stories OR experience*)	**6814573**
#3	Title/AB men or males or man or male or masculinity	**1798749**
#4	MeSH Terms Qualitative research	**53086**
#4	#1 AND #2 AND #3 AND #4	**66**

AB, abstract; MeSH, Medical Subject Headings

Appendix 2: Formatting and style guidelines for authors - submission for *Chronic Illness*

The following sections of the author guidelines are taken from the full guidelines, which can be found online: https://journals.sagepub.com/author-instructions/CHI#ArticleTypes

Article Types

The journal publishes original papers, reviews, discussions of topical issues and case studies. The suggested word counts only refer to the body of the text and exclude references etc.

Summary of manuscript structure:

Chronic Illness adheres to a double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Your title page should be submitted **separately** and there should be **no author identifiers** in the manuscript.

When preparing your paper:

Review papers, discussion papers, and papers including substantive qualitative research should be no more than 5,000 words in length, excluding structured abstracts, quantitative tables and figures, and references. We welcome systematic reviews and syntheses on areas of interest and importance to those concerned with *chronic illness*. A clear research question and a description of methods, including search strategies and quality appraisal, should be provided. Methods for synthesis, including meta-analysis, narrative summary, meta-ethnography etc., should be clearly explained. Quantitative research papers should be no more than 3000 words in length, excluding structured abstracts, tables and figures, and references.

Short reports, commentaries on classic papers and patients' comments should be no more than 1,000 words in length, **excluding** abstracts, tables and figures, and references. These are a useful method for reporting circumscribed research where the study or the results may not justify a full report. It does not imply a lower standard for the quality of the work reported. The guidance is the same as for original articles with the following exceptions: the summary need not be a structured abstract; authors should limit themselves to no more than ten references and two figures or tables.

Original papers

Should include:

- Title page: (1) title of the article; (2) first name(s) or initial(s) and surname of each author; (3) address of the department or institution to which the work should be attributed; (4) full postal address of each author; (5) name, telephone, email address and fax number of the author responsible for correspondence and to whom requests for offprints should be sent. (This is particularly important where the corresponding author is not the first named author.)
- Abstract (<200 words): a short inclusive statement suitable for direct electronic abstracting identifying the purpose of the study, key methods, the main results and the main conclusion. Structured abstracts are essential for research and review papers, and should be submitted under the headings: objectives, methods, results, and discussion.
- Key words: maximum of 5 key words for indexing.

- Introduction: concise description of background, sufficient for the non-specialist to appreciate the context of the work. Clear statement of the purpose of the study. Authors should avoid obviously partisan selection and quotation of literature.

- Methods: should demonstrate a clear and documented design or strategy directed towards a specific research question. The study design should be appropriate to the aims of the study and be clearly described. The criteria for selecting the sample should be clearly described and justified. A clear description of sampling, recruitment to the study, data collection, and data analysis should be provided. Full details of interventions should be given for intervention studies. This section should also include details of approval from a named Research Ethics Committee, and any arrangements for data oversight.

- Results: should contain all the information required by referees and readers to assess the validity of the conclusions. The characteristics of the sample included in the study should be clearly described. For quantitative studies, the section should include details of the response rates and numbers lost to follow-up. The analysis should be clear and systematic. Results of statistical tests should be reported with confidence intervals in order to provide an estimate of precision. No more than six tables should be included.

- Discussion: an interpretation of the study placed within the context of current knowledge leading to specific conclusions where possible. We recommend that this covers the following sections, using sub-headings: summary of main findings; the strengths and the limitations of this study; how and why it agrees or disagrees with the existing literature, in particular including any papers published since the study was designed and carried out; the implications for future research or clinical practice.

- Each of the above sections should use subheadings as appropriate.

- Acknowledgements.

- References (ideally max. 25), figures and tables (see 9.4.3 for more details).

- Patient comments: we welcome submissions of articles, including comments on published papers, from people who experience *chronic illness* or their carers

- Commentaries on classic papers: these will normally be commissioned, but the Editor will also be pleased to consider unsolicited copy.

PREPARING YOUR MANUSCRIPT FOR SUBMISSION

All submissions should be written in a clear and succinct manner, following the style of the journal. The title page should include a descriptive title, authors' surnames and forenames, address of each author and full address, telephone, fax and email contacts for the corresponding author. In text: tables and figures are either inserted as part of a sentence, for example table 1 or in parentheses for example (figure 1). Each table should carry a descriptive heading. Each figure should be submitted electronically.

4.1 FORMATTING

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

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4.3 SUPPLEMENTARY MATERIAL

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

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Section 2. Empirical paper

Understanding stigma, fear of compassion from others and fear of compassion from self and

psychological outcomes in chronic pain

John Timney

Word Count: 7999 words excluding Tables and References

Formatted to journal guidelines: *Journal of Health Psychology*

(See Appendix 3)

Lancaster University Doctorate in Clinical Psychology

July 2020

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Abstract

Background. Stigma, fear of compassion from others (FOCO) and fear of compassion from self (FOCS), are of increasing interest for understanding experiences of chronic pain.

Aim. To understand if stigma, FOCO and FOCS independently predict depression, pain-related anxiety and pain interference. Moreover, if FOC moderates the relationships between pain intensity or stigma and outcomes of psychological distress.

Method. Hierarchal regression and moderation analysis.

Results. FOCO and FOCS significantly predicted depression and pain-related anxiety but not pain interference. FOCO significantly moderated the relationship between stigma and depression.

Conclusions. FOC as an important factor when working with individuals with chronic pain.

(99/100 words)

Keywords: Chronic pain, fear of compassion, stigma, depression, compassion

Introduction

Persistent pain (or chronic pain) is understood to refer to pain that lasts for 3 months or more, often in the absence of any ongoing injury or tissue healing (Fine, 2011). Chronic pain is a significant societal and individual issue. Prevalence estimates in the UK, for example, range between 8% and 60% (Phillips, 2009) and the cost to UK society in terms of lost productivity is estimated to be many billions of pounds (Maniadakis and Gray, 2000). Across Europe, costs to individuals, carers, health care systems and reductions in economic productivity combined is thought to represent 1.5-3% of the continent's gross domestic product (Barham, 2012).

Individuals experiencing chronic pain have reported significantly greater levels of negative emotions, including shame, guilt, and fear of negative evaluation compared to a pain-free control group (Turner-Cobb et al., 2015). Low mood is frequently reported, and the co-occurrence of persistent pain with depression is known to elicit a greater burden at both the individual and societal level when compared to either condition alone (Goesling et al., 2013). Anxiety is the second most commonly reported symptom of psychological distress associated with persistent pain, frequently occurring co-morbidly with depression (Woo, 2010). Long-standing pain reduces an individual's ability to engage in physical activities, social activities and employment. These reductions in activities of daily living have a broad impact on the emotional wellbeing of the individual, as well as their partner, family and social group (Dueñas et al., 2016).

Ongoing efforts to better conceptualise the definition of persistent pain have begun to include recognition of the multi-dimensional and biopsychosocial aspects of the condition (Melzack, 1999; Darnall et al., 2016; Moseley, 2017; Williams and Craig, 2016). The International Association for the Study of Pain have proposed a new definition for pain as *"An*

unpleasant sensory and emotional experience associated with actual or potential tissue damage,

or described in terms of such damage" (International Association for the Study of Pain, 2019).

These sensory and emotional components are of interest to psychological enquiry, and factors

relating to targets of therapeutic interventions such as pain related cognitions, psychological

flexibility, prosocial affect and relational style have all been investigated as important

psychological factors which contribute to distress (Carvalho et al., 2019b; Lee et al., 2015;

Meredith et al., 2008; Scott et al., 2016; Williams et al., 2012). The effect of experiencing

chronic pain is for many experienced as a threat to one's prosocial affiliative states and existing

relationships (Smith and Osborn, 2007).

Stigma and chronic pain

Prosocial affiliative states evolved in mammals as part of a care giving system that

promotes nurture. The human brain has evolved under the pressure of social interaction and the

need to process and understand relationships. People experiencing chronic pain often report

hypervigilence to the threat of social rejection, due to fears of being disbelieved or a burden to

others (Smith and Osborn, 2007). Experiences of embarassment, social exclusion, and

humiliation can be encountered and associated changes in physical ability can lead to negative

reappraisals of the self within one's social context (Arnold et al., 2008). In short, people with

chronic pain report high levels of stigmatisation.

Early work by Goffman (1963), which was later expanded within the context of the

public heath setting (Link and Phelan, 2006), conceptualises stigma as resulting from devaluing

and discrediting responses towards an individual attribute, or a group who are understood to have

attributes that differ from the socially understood norms, resulting in loss of social status, social

exclusion or embarrassment (Link and Phelan, 2006; Goffman, 1963; Link and Phelan, 2001).

Stigma has been characterised as comprising two components, enacted stigma, which is experienced due to the negative actions/attitudes of others (Scambler, 2009), and internalised or 'felt' stigma, whereby an individual progressively begins to, expect and fear enacted stigma, (Corrigan et al., 2006; Molina et al., 2013) believing the negative attitudes they experience and directing these inwardly towards the self (Scott et al., 2019; Link and Phelan, 2006). The psychological pain experienced by stigmatised individuals is considered to be rooted in an understanding and recognition that 'others' view the 'self' negatively, impacting therefore on one's social attractiveness and giving rise to feelings of low self-esteem and shame (Gilbert, 2003; Matos et al., 2015; Link and Phelan, 2006).

Individuals experiencing chronic pain often report high levels of disability, and in this context where differences from societal norms may be highly visible, the risk of stigmatization is high (Campbell and Deacon, 2006; Joachim and Acorn, 2000). Those with chronic pain report feeling misunderstood by friends, romantic partners and family members (Toye and Barker, 2010; Holloway et al., 2007; Monsivais, 2013). Individuals often describe feeling healthcare professionals underestimate their experience of pain, or feel stigmatised by them (Nguyen et al., 2013; Slade et al., 2009), which can interfere with care-seeking behaviours (Slade et al., 2009).

Understanding the role of stigma as part of the emotional underpinning of mental distress is important if therapeutic approaches are to be effective in combatting the current healthcare burden presented by chronic pain – a condition where high rates of enacted stigma and shame are commonly reported (Scott et al., 2019). Stigma correlated in bivariate analyses with pain intensity, and in multivariate analyses with measures of daily function and depression (Scott et al., 2019). Stigma scores remained significantly associated with key outcomes of psychological distress after controlling for pain intensity, pain acceptance, and perceived injustice during

multivariate analyses (Scott et al., 2019). Notably, levels of stigma were not seen to change

significantly pre-and post- an acceptance and commitment therapy (ACT) based intervention,

despite improvements in other measures of psychological distress (Scott et al., 2019). Changes in

psychological well-being following intervention can occur not as a result of reducing stigma,

rather as a result of changing how stigmatizing beliefs are percieved and related to by an

indiviual (Link et al., 2002). These results point to the potential for probing new psychosocial

models involving stigma in chronic pain (Scott et al., 2019). Further study is required to

understand the role which stigma may play in predicting outcomes of psychological distress for

people experiencing chronic pain.

Compassion and chronic pain

Psychobiological and neurobiological systems have evolved for humans within a social

context, and psychologists have argued that the social rank system is one such example (Liotti

and Gilbert, 2011; Gilbert et al., 2003; Lucre and Clapton, 2020). For individuals with social

rank systems that are challenged either during childhood or by subsequent significant life events,

the ability to access innate affiliative self-soothing systems, seek appropriate care or feel socially

safe can be significantly comprimised (Gilbert et al., 2017; Gilbert et al., 2003; Lucre and

Clapton, 2020). The ability to accept compassion from oneself or others is becoming an

increasingly important factor within chronic pain research. A positive correlation between

increased pain intensity and depression has been observed in populations of people with chronic

pain, while higher levels of self-compassion were seen to reduce outcomes of psychological

distress for this cohort (Carvalho et al., 2019b). These results mirror those seen in other

populations, where increased levels of self-compassion significantly correlate with reduced rates

of anxiety and depression (Gilbert et al., 2011). Importantly, while the capacity to show

compassion to oneself is psychologically protective for individuals, there is growing evidence

that for many (particularly those who demonstrate high levels of self-criticism), being

compassionate towards oneself or receiving compassion from others is difficult to the point that

one can be fearful of it (Matos et al., 2017). An aversive response to compassion is often rooted

in early experiences of shame (Matos et al., 2017; Gilbert et al., 2011). Individuals with high

levels of a 'fear of compassion' (FOC) can experience increases in symptoms related to

depression, anxiety and stress (Gilbert et al., 2012; Gilbert et al., 2011). Both shame and FOC,

have been shown to mediate the relationship between 'major life events' and depressive

symptoms (Coelho et al., 2019). Specifically, and importantly for individuals experiencing

chronic pain, FOC is also correlated with increased physiological markers of a stress response,

and stress responses can exacerbate experiences of pain (Duarte et al., 2015).

The ability for an individual with chronic pain to engage with affiliative emotional states,

such as compassion from others or self-compassion, is likely to affects their general well-being

and activities of daily living (Lucre and Clapton, 2020). The ability to direct compassion to

oneself has been shown to predict levels of depression and illness intrusiveness for individuals

with chronic pain (Ziemer et al., 2015; Costa and Pinto-Gouveia, 2011), as well moderate

cognitive responses to pain experiences (Purdie and Morley, 2015). Thus, FOC may moderate

the relationship between an individual's pain experience and their levels of psychological

distress, with high levels of FOC potentially becoming a significant barrier in accessing flows of

compassion from others and oneself (Gilbert et al., 2011). Gilbert et al. (2011) conceptualised

and developed scales for the measurement of three principle fears of compassion depending on

their direction of flow – fear of compassion from others (FOCO), fear of compassion towards

self (FOCS), and fear of giving compassion to others. FOCO can potentially develop after

experiencing shame or criticism when seeking the affiliative soothing of others (Gilbert et al., 2011). FOCS may become prominent due to a lack of compassion from others during development making it difficult to scaffold and direct compassion towards oneself (Gilbert et al., 2012; Gilbert et al., 2011). To date and to the best of my knowledge, only three studies have investigated the role of FOC in chronic illness, and only one of these in chronic pain (Trindade et al., 2018a; Trindade et al., 2018b; Carvalho et al., 2019a). FOCO mediated the relationship between self-compassion and social safeness (the ability of women with chronic pain to feel safe and connected within their social environment) (Carvalho et al., 2019a). As one would expect, having increased fears of receiving soothing and affiliative responses from others reduced women's ability to experience social situations in a safe and connected way. One might expect therefore, for stigmatizing social experiences to also be modulated by an individual's ability to access compassion from themselves and others while experiencing chronic pain.

Aims

Pain intensity has been demonstrated to predict psychological distress in individuals experiencing persistent pain. However, currently, the roles that stigma and FOC have as predictors for psychological (symptoms of anxiety and depression) and daily living outcomes when controlling for pain intensity have not been well characterised. Here, the roles of stigma, FOCO and FOCS in people with chronic pain were investigated.

This study used regression based approaches to understand firstly, if stigma and FOC predicted anxiety, depression and pain interference in activities of daily living, above pain intensity and other demographics. It was hypothesised that both stigma and FOCO and FOCS would predict additional variance in this distress, beyond that accounted for by pain intensity and demographics. Secondly, this study aimed to understand if FOCO or FOCS moderated the

relationship between pain intensity (predictor) or stigma (predictor) and psychological and daily living outcomes. Based upon recent literature (Carvalho et al., 2019a), it was hypothesised that low levels of either FOCO or FOCS would reduce the impact of pain intensity or stigma on psychological distress.

Methods

Study Design

This cross-sectional, online survey, single group, observational study utilised quantitative outcome measures to collate self-reported data relating to participants' experiences of pain intensity, stigma, fears of compassion, pain related anxiety, low mood and pain interference in activities of daily living.

A hierarchal multiple linear regression analysis was then used to determine significant predictors of psychological distress and daily living outcomes. In these models, demographic variables found to correlate with outcome variables were added first, followed by the known predictor variable (pain intensity), and subsequently stigma, then FOCO and FOCS. Finally, moderation analyses were undertaken using the Hayes PROCESS tool within SPSS (Hayes, 2012). In the first models tested, pain intensity was entered as the predictor variable and anxiety, depression and pain interference were the outcome variables. In a second set of models with the same outcome variables, stigma was the predictor variable. In both cases moderator variables of FOCO and FOCS were tested.

Participants

Inclusion criteria

Inclusion criteria were participants who self-reported being 18 years of age or over and currently experiencing persistent pain (pain lasting 3 months or more). No specific diagnosis or

type of pain was requisite for inclusion and all genders were welcome to participate. Participants

needed to be able to answer the questionnaires in English but could be based in any country.

Exclusion criteria

Participants were excluded if they reported presence of acute pain secondary to the usual

site(s) of persistent pain. For example, if a participant recently noticed a toothache, but this pain

was not considered by them to be part of their normal pain profile, then they would not be able to

take part on that day.

Sample size calculation

For the regression analyses, an *a priori* power analysis using Gpower*(Dusseldorf,

Germany) (Faul et al., 2009) using a multiple regression with 4 predictors at an alpha level of

0.05 (p<0.05) and a power of 0.80 was predicted to require a sample size of N=84 to identify a

medium effect size (f^2=0.15).

For a moderation analyses, a reported average for the effect size across studies is

f^2=0.009 (Aguinis et al., 2005). As a consequence, standards for effect sizes in such analyses are

considered to be 0.005, 0.01, and 0.025 for small, medium, and large, respectively (Kenny, 2018)

and sample sizes of more than 200 are considered to be required for detecting moderating effects

that are medium in size (Whisman and McClelland, 2005). An *a priori* power analysis using

Gpower*, testing a linear multiple regression R^2 increase with 3 predictors at an alpha level of

0.05 (p<0.05) and a power of 0.80, predicted a sample size of N=316 would be required to

identify a large effect size (f^2=0.025). Conditional process analyses can be performed using the

Hayes PROCESS tool (Hayes, 2012). Studies which have utilised this tool to perform

moderation analyses to understand psychological factors involved in individuals experiences of

chronic pain or other serious health conditions have previously been able to identify significant

moderating interactions with between 231 and 286 participants (McAteer and Gillanders, 2019; Carvalho et al., 2019b). As such, a target of enrolling 275 participants was set in order to undertake a moderation analysis using Hayes PROCESS tool.

Ultimately, a total of 330 participants started the online survey, with 262 being included in the final analysis.

Procedure

Online survey

The survey completed by participants was developed in consultation with the study field supervisor (Consultant Clinical Psychologist working in a NHS pain service in the North West of England) and the *Pain Away* support group. Members of *Pain Away* are all experts by experience of chronic pain and provided consultation on the clarity of the information participants received prior to enrolling, the experience of completing the survey online, and the usefulness of debriefing materials. Feedback from *Pain Away* was obtained via email and during focus group discussions.

The online survey was designed and powered using the Qualtrics software (Qualtrics Labs, Inc). Outcome measures were reproduced using the online platform as they were presented in their original paper format. Licences and permissions were obtained for any outcome measures requiring prior approvals of use by the copyright holders.

Recruitment

Participants were recruited online using Facebook, Instagram, Twitter and Reddit social media platforms. Recruitment posts included a media advertisement comprising a short talking head video/infographic describing the study, with a link to the online survey. Participants were provided with a webpage containing full "Information for Participants" (Section 4: Ethics

submission) and invited to complete the online survey. Recruitment began on 19th February 2020

and closed on 22nd May 2020.

Outcome Measures

Demographic data regarding age, gender, duration of pain, partnership status,

employment status, current location (country), ethnicity and medical diagnosis was requested

from participants.

Predictor variables

Pain intensity - Brief Pain Inventory (BPI) – pain items only (Cleeland and Ryan, 1994)

The BPI pain inventory assesses pain at its "worst," "least," "average," and "now"

(current pain). For each item pain was rated by participants between 0 (No pain) and 10 (Pain as

bad as you can imagine). The pain inventory has been used extensively during studies relating to

chronic pain and is a well validated measure (Cleeland, 2009). The measure of pain can be

created as a composite of the four items (mean pain severity score), or, single items for "worst"

or "average" pain have been used for some trials. This study used the composite measure (mean

of all four items) when quantifying participants' experience of their pain intensity, as this was the

approach that was validated during the measure's development and is recommended in the test

manual (Cleeland, 2009). The subscale has been validated for delivery in isolation as well as part

of the full BPI questionnaire (Cleeland, 2009), here it is delivered alongside the pain interference

subscale.

Stigma - The Stigma Scale for Chronic Illness 8-item version (SSCI-8) (Rao et al., 2009;

Scott et al., 2019)

The SSCI-8 has 8 items and measures components of stigma that are both enacted and

internalized. Items were rated by participants as being experienced as 1 = Never, 2 = Rarely, 3 =

Sometimes, 4 = Often, and 5 = Always. The total score (minimum 5, maximum 40) was used during analyses, with higher total scores reflecting a greater experience of stigma. The scale has previously been validated in a population of individuals with diagnosed neurological conditions; and was recently validated in a chronic pain population and has shown good internal consistency (Cronbach's alpha = 0.89) (Scott et al., 2019).

Outcome variables

Pain related anxiety - Pain Anxiety Symptom Scale (PASS-20) (McCracken, Zayfert et al. 1992, McCracken and Dhingra 2002)

The Pain Anxiety Symptoms Scale (PASS) short form consists of 20 items. This form of the measure has been validated and demonstrated psychometric characteristics that are comparable to the long form of the measure (McCracken and Dhingra, 2002; McCracken et al., 1992). The measure comprises 20 questions, and participants were required to rate statements relating to various aspects of pain related anxiety as being experienced between 0 (Never) and 5 (Always). The PASS can be used to predict the severity of disability, pain interference and emotional distress and comprises of a composite score (minimum=0, maximum=100) and four subscales (5 items each) which measure somatic anxiety, cognitive anxiety (catastrophizing), fear of pain and escape avoidance. This study used the composite score when modelling participant's pain experience, with higher total score reflecting greater experiences of pain related anxiety. Cronbach's alpha for the composite score in a previous pain study was 0.91 (McCracken and Dhingra, 2002).

Depression - Depression, Anxiety and Stress Scale-21 (DASS-21) (Lovibond and Lovibond, 1995)

The DASS-21 is a 21-item measure of depression, anxiety and stress symptoms. Each item is rated on a 4-point scale (0 Did not apply to me at all; 3 Applied to me very much or most of the time). In this study, all 21 items were delivered to participants to maintain clinical validity of the scale, but the 7-item depression subscale was used exclusively here as a measure for depressive symptoms in the data analysis (minimum=0, maximum=21). Previous studies have described good internal consistency (Cronbach's alpha=0.93) for the depression subscale when used online with people experiencing persistent pain (Carvalho et al., 2019b).

Activities of daily living - Brief Pain Inventory (BPI) – pain interference items (Cleeland and Ryan, 1994)

The BPI has been widely used and validated in a range of chronic pain settings to quantify the impact of chronic pain on activities of daily living (Cleeland, 2009). The BPI pain interference subscale consists of seven items that measure of the effect an individual's pain has on their daily functioning (Cleeland and Ryan, 1994). Ratings regarding pain interferences are given in seven domains: general activity, mood, walking ability, normal work, relationships with other people, sleep, and enjoyment of life. Each item was rated by participants between 0 (does not interfere) to 10 (completely interferes). A mean total score is used here, which has previously demonstrated good internal consistency in several studies (Cronbach's alpha= 0.89-0.92) (Cleeland, 2009). The subscale has been validated for delivery in isolation as well as part of the full BPI questionnaire, (Cleeland, 2009) here it is delivered alongside the pain intensity subscale.

Moderator variables

Fear of compassion - Fear of compassion scale (Gilbert et al., 2011)

Items for all subscales were rated by participants on a 5-point scale from 1 (Don't agree at all) to 5 (Completely agree). The Fear of Compassion scale comprises three subscales: FOCS (15 items; total score: minimum 15, maximum 75), FOCO (13 items; total score: minimum 13, maximum 65), and fear of giving compassion to others (10 items; minimum 15, maximum 50). This study utilised the first two of these subscales during regression and moderation analyses. Cronbach's alpha values obtained from a validation study in participants with depression were 0.90 (FOCS) and 0.91 (FOCO) (Gilbert et al., 2014).

Ethical Considerations

Ethical approval was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (ref: FHMREC19018; Section 4: Ethics submission).

No personal identifiable data (e.g. name, date of birth, contact details) were collected from participants. Data were protected and stored in line with ethics submission requirements.

Consent to participate was obtained in the form of a forced choice question at the beginning of the online survey (Section 4: Ethics submission). Issues of participant distress were considered, and debrief materials were presented at the end of the survey (Section 4: Ethics submission).

Data Analysis

Data were extracted, tabulated and analyzed using IBM SPSS Statistics (Version 26.0). A total of 330 participants started the online survey. Overall, 260 participants answered all items for all outcome measures. Two participants were missing one item from a single subscale of one outcome measure. In both cases, the missing data was imputed by pro-rating the score as a mean of that individual's completed answers for the subscale in question. All other participants (n=68)

had significant amounts of missing data (>5%) and were therefore excluded from the analyses. Consequently, 262 participants were included in the analysis presented here.

Demographic data entered by participants using free text responses were consolidated. Duration of pain was converted to be measured in months (total). Due to the small sample size of the non-binary and trans groups these were combined. Outcome measure score means for each gender group were compared using a one-way analysis of variance (ANOVA).

Descriptions relating to ethnicity where participants stated a country rather than an ethnicity, 'Did Not State' was recorded. Data entered as 'Caucasian' was replaced with 'White' throughout. For data relating to diagnosis, the first diagnosis entered in cases where multiple diagnoses were given was considered to be the primary diagnosis. The *post hoc* categorisation of the diagnoses provided by participants are shown in Appendix 1.

Outcome measure scores were calculated as totals or means as previously described. Cronbach's alpha scores were calculated for each outcome measure to test for internal validity. Data were inspected visually and statistically (using box plot and z-score calculations). Data points greater than 3.29 standard deviations from the mean were considered to be outliers (Field, 2018), however none were identified. Data were then inspected to consider issues of normality of distribution using histograms, P-P plots, and measures of skewness and kurtosis (Field, 2018). All data appeared to be normally distributed.

For hierarchical regressions, linearity and homoscedasticity of residuals were subsequently tested by visual inspection of linear regression scatterplots as described by Field (2018). Q-Q plots were used to assess assumptions of normality of error distributions (Field, 2018). Assumptions of linearity, homoscedasticity of residuals and normality of error distributions were met for all relationships.

Hierarchical multiple regression analyses were undertaken. Any demographic variables that significantly correlated with the outcome variables were entered into each model first. Subsequently, the most well-established predictors were then entered into the model. Pain intensity is a known predictor of psychological distress for individuals with persistent pain and was entered into the model second. Subsequently, measures for stigma, FOCO and FOCS were added sequentially in steps. For the regression analyses with depression and pain related anxiety, casewise diagnostics indicated that less than 5% of cases fell outside of ±2 standardised residuals, and the maximum Cook's distance was 0.096, indicating that none of these cases had an undue influence on the model. For pain interference, less than 5% of cases fell outside of ±2 standardised residuals. However, one of these cases had a standardised residual of 3.429. The Cook's distance for this case was 0.06, indicating no undue influence on the model. This case was therefore not Winsorized and was retained in the model.

Finally, moderation analyses were undertaken using the Hayes PROCESS Tool (Hayes, 2018). Predictor variables of pain intensity and stigma were tested. Outcome variables were depression, pain-related anxiety and pain interferences. Moderator variables were FOCO and FOCS.

Results

Demographics and clinical characteristics

In total, 262 participants were included in the final analysis. Of these, 209 self-identified as female in gender, 49 as male, 9 as non-binary and 2 as trans-men. The most frequent location was the United States (n= 148), with the second highest being the UK (n=76). A total of 213 participants were White, 13 were of mixed ethnic origin, and 5 reported being of Hispanic or

Latino ethnicity. Only 1 participant reported being Black. The most common primary diagnosis

reported was fibromyalgia (n=61), while back pain was the second most frequent (n=36).

Regarding employment status, 29.8% (n=78) of participants reported being in full time

employment, 17.9% (n=47) reported being unable to work and in receipt of disability benefits,

and 12.6% (n=33) were students. Overall, 70.3% of participants reported being in a relationship

(either 'married', 'civil partnership' or in a 'relationship'). All demographic and clinical

characteristics are presented in full in Tables 2.1 and 2.2

Insert Table 2.1

Insert Table 2.2

Outcome measure scores: descriptive statistics and tests of internal consistency

The mean scores, SD, range and Cronbach's alphas for all outcome measures are shown

in Table 2.3. The mean (SD) pain intensity score was 5.91 (1.45), while the mean pain

interference score was 7.33 (2.07), (both out of a maximum score of 10). The mean depression

score (DASS-21 depression subscale) reported by participants was in the moderate range (mean

(SD) DASS-21 score; 17.76 [5.34]), which was similar to mean DASS-21 depression scale score

seen for some studies of chronic pain populations (15.0, [12.22] (Wood et al., 2010) but higher

than others utilizing online survey methodology (8.05 [5.84]) (Carvalho et al., 2019b).

The mean level of pain related anxiety reported by participants was in the 'moderate'

range (mean [SD]; 54.25 [17.33]), which was higher than that seen in the normative sample

(mean; 38.62 [20.38]) (McCracken and Dhingra, 2002). Mean scores for stigma (22.72 [5.96]),

FOCO (32.00 [10.20]) and FOCS (39.30 [15.00]) were all similar to those seen in previous

validation studies of these measures (stigma, men: 21.24 [5.95], women: 21.88 [6.89]; FOCO, 31.69 [11.69]; FOCS, 36.69 [12.34]) (Gilbert et al., 2014; Scott et al., 2019).

Cronbach's alpha scores indicated that the FOCS subscale and PASS scale demonstrated excellent internal consistency (Cronbach's alpha > 0.9). All other scales demonstrated good internal consistency (Cronbach's alpha > 0.8).

Insert Table 2.3

One-way ANOVA

Outcome variables were tested for significant differences in mean scores depending upon the categorical variable of participant gender (female vs. male vs. other [Non-binary or transgender]). No significant difference was observed in mean participant scores for depression (F[2,259]=.048, p =.953), pain related anxiety (F[2,259]=2.235, p=.109), or pain interference (F[2,259]=0.15, p=.985) depending upon participant gender.

Tests of correlation

Demographic variables of age and duration of pain were tested for correlation with outcome variables and are shown in Table 2.4. A correlation matrix of predictor variables and outcome variables can be seen in Table 2.5.

Insert Table 2.4

Insert Table 2.5

Demographic characteristics

Age ($r =.175$, $p< 0.01$) and pain duration ($r =.177$, $p< 0.01$) significantly positively correlated with pain interference scores (BPI). No other demographic variables demonstrated significant correlation with any outcome variables.

Pain intensity

Pain intensity was significantly correlated with all other outcome variables in the expected (positive) direction. A strong correlation was observed with levels of pain interference ($r=.613$, $p< 0.01$); as participants' pain intensity increased, an increase in pain interference was also observed. Weak correlations between pain intensity and depression ($r=.231$, $p< 0.01$) and anxiety ($r=.275$, $p< 0.01$) were also observed; again, as pain intensity increased, increases in participant's reporting of depression and anxiety also occurred.

Stigma

Stigma moderately correlated with pain interference ($r=.576$, $p<0.01$), anxiety ($r=.488$, $p<0.01$), and to a lesser extent depression ($r=.375$, $p<0.01$). That is to say, as participants reported increased experiences of stigma related to their chronic illness, they also reported increases in pain interfering in their daily activity, alongside increased feelings of anxiety and depression.

FOCO and FOCS

FOCO showed a moderate positive correlation with depression ($r=.518$, $p<0.01$) and anxiety ($r=.342$, $p<0.01$) and a weak correlation with pain interference ($r=.260$, $p<0.01$). FOCS showed a moderate correlation with depression ($r=.457$, $p< 0.01$), but only weak correlations with anxiety ($r=.259$, $p< 0.01$) and pain interference ($r=.236$, $p< 0.01$). Thus, as participants'

feelings of fearing compassion from either others or self increased, increases in feelings of depression, anxiety and pain interference also occurred.

Hierarchical linear regressions

Hierarchical linear regression analyses are presented in Tables 2.6–2.8. For all models, demographic variables that were significantly correlated with the independent variable under investigation were included at step one (with the exception of the depression model, where no demographic variables correlated significantly). Pain intensity, stigma, FOCO and FOCS were then each added sequentially in separate steps.

The first model which included DASS-21 depression scores as the independent variable found that pain intensity accounted for 5.3% of the variance, stigma accounted for an additional 10.3% ($p<0.01$), FOCO an additional 15.0% ($p<0.01$) and FOCS an additional 1.4% ($p=0.02$). In total, this model accounted for 32.1% of the variance in DASS-21 depression scores (Adj R^2 = .311). Stigma (β=.111, p=.042), FOCO (β=.172, $p<.01$) and FOCS (β=.059, p=.02) were significant independent predictors in the final model.

Insert Table 2.6

The second model included PASS scores as the independent variable and found that pain intensity accounted for 7.5% ($p<0.01$) of the variance, stigma accounted for an additional 18.2% ($p<0.01$), FOCO an additional 1.6% ($p=0.018$). FOCS accounted for no additional variance in this model. In total, this model accounted for 27.4% of the variance in PASS scores (Adj R^2 = .2634). Pain intensity (β=1.735, p=.01) and stigma (β=1.102, $p<0.001$) were significant independent predictors in the final model.

Insert Table 2.7

The third model included pain interference scores as the independent variable, following demographic variables, pain intensity accounted for an additional 39.6% ($p<0.01$) and stigma an additional 16.8% ($p<0.01$). Notably FOCO and FOCS accounted for no additional variance to the variables included in steps 1-3. In total, this model accounted for 56.4% of the variance in pain interference (BPI) scores (Adj R^2 = .554). Age (β=.020, $p<0.01$), Pain intensity (β=.684, $p<0.01$), and stigma (β=.149, $p<0.01$) were significant independent predictors in the final model.

Insert Table 2.8

Moderation analyses

Moderation analyses were undertaken with pain intensity (BPI) as the predictor variable. Outcome variables modelled were measures of psychological distress (DASS-21 depression score, PASS, BPI pain interference). Moderating variables investigated were FOCO and FOCS. No significant moderating relationships between variables in any of these models were identified ($p>.05$ for all interactions, Appendix 2).

Moderation analyses were undertaken to investigate any moderating relationship of FOCO or FOCS on the relationship between stigma (SSCI-8 score; predictor variable) and depression, anxiety and pain interference. Results of analyses involving anxiety and pain interference were not significant ($p>.05$ for all interactions, Appendix 2).

The interaction term between stigma and FOCO was found to explain a significant increase in variance of depression scores and the interaction term was significant (ΔR^2 = .0172, F= 6.410, p=.0119). Therefore, FOCO was a significant moderator of the relationship between stigma and depression (Table 2.9). The equivalent model in which FOCS was the moderating variable found that this interaction was not significant (ΔR^2 = .0054, F= 1.9071, p=.1685).

Insert Table 2.9

The interaction plot (Figure 2.1) demonstrates that when FOCO is low (1 SD below the mean) there is a significant positive relationship between stigma and depression (b=.2549, SE=.0671, t = 3.7995, p=.0002). At the mean value for FOCO, there remains a significant positive relationship between stigma and depression, however, the size of this relationship is reduced compared to low FOCO (b=.1412, SE=.0528, t = 2.6757, p=.0079). When FOCO is high (1 SD above the mean) a non-significant relationship between stigma and depression is observed (b=.0275, SE=.0714, t = .3854, p=.7003). Thus, at high FOCO there is no relationship between stigma and depression; depression levels are consistently high, regardless of levels of stigma.

Insert Figure 2.1

Discussion

This observational, cross-sectional online study aimed to understand how outcomes of psychological distress for individuals experiencing chronic pain related to pain intensity, stigma and FOC. Here, two principle research questions were asked, firstly, do stigma, FOCO and FOCS independently predict psychological distress (pain related anxiety, depression, pain

interference) in chronic pain, in addition to pain intensity and demographic variables. Secondly, do FOCO and FOCS moderate the relationship between known predictors of psychological distress (pain intensity and stigma) and outcomes.

Pain intensity significantly correlated with, and remained, a strong and significant independent predictor of depression, pain related anxiety and pain interference in all three models in the presence of other factors (stigma and FOC). The mean stigma score reported here (22.72) was similar to those reported previously for men (21.24) and women (21.88) (Scott et al., 2019). The results of this study broadly replicate those of Scott (2019) as regards the utility of the SSCI-8 as a reliable measure of stigma in a population of people with chronic pain (Cronbach's alpha=.86). Increased stigma significantly correlated with increases in measures of depression and anxiety, but was most strongly correlated with increases in pain interference, in agreement with strong correlations observed in previous studies (Kool et al., 2010; Waugh et al., 2014). Based on the results of some quantitative (Waugh et al., 2014; Scott et al., 2019) and several qualitative reports that stigma is encountered and felt by individuals with chronic pain (De Ruddere and Craig, 2016), the first hypothesis of this study was stigma, FOCO and FOCS would predict additional variance in this distress, beyond that accounted for by pain intensity and demographics. This hypothesis was supported by the findings. Stigma independently predicted increased levels of depression and anxiety, a result which is in line with observed positive correlations between stigma and psychological distress across a range of chronic illnesses (Molina et al., 2013; Rao et al., 2009). This result is understandable when the impact of the stigmatizing or invalidating responses of others in response to one's pain is considered (Gilbert et al., 2011; Link and Phelan, 2001; Link and Phelan, 2006). One could suggest that the stigmatising responses of others to one's pain are likely to increase feelings of isolation, social

exclusion and an assault on one's social rank system (Gilbert, 2003; Gilbert et al., 2003).

Consequent increases in internal experiences of self-criticism and shame would then be likely

(Gilbert, 2003; Goesling et al., 2013), potentially fuelling worries related to one's pain and

increasing feelings of low mood (Goesling et al., 2013). The fact that stigma remains a

significant predictor of increased psychological distress in addition to the established predictors

(demographic variables and pain intensity) justifies the hypothesis that stigma should be

considered as an important psychological factor that is impacting the psychological well-being of

those experiencing chronic pain.

The second hypothesis predicted that FOCO would predict additional variance in this

distress, beyond that accounted for by pain intensity and demographics. This was the case in all

but one instance (as independent predictor of pain interference) for FOCO. The degree of

variance added by FOCO was ten times higher in the regression model for depression (~15%),

than for anxiety (~1.5%), with no additional variance seen for pain interference. Previous studies

have demonstrated that fear of receiving compassion from others while chronically ill

significantly predicted feelings of depression (Trindade et al., 2018c). Self-compassion is related

to a motivational drive to increased behavioural activation and reduced demobilisation (Gilbert et

al., 2017; Carvalho et al., 2019a; Gilbert, 2015). Moreover, seeking compassion from others

promotes feelings of social safeness and is associated with neurobiological responses that may

alleviate experiences of pain (Gilbert, 2015). Intuitively, a high FOCO in combination with

experiencing chronic pain is likely to result in feelings of isolation and low mood. The reason

that it does not predict pain-related anxiety to the same level in this study is unclear, given the

influence that activating affiliative and social soothing psychobiological systems through social

connections can have in producing feelings of calmness and safeness (Gilbert et al., 2017;

Gilbert et al., 2003; Lucre and Clapton, 2020; Porges, 2007). Further investigation may be required to understand if this difference is related to the fact that here it is pain-related anxiety that is measured, rather than generalised anxiety.

FOCS correlated with pain-related anxiety and pain interference more-weakly than FOCO. For depression, FOCS correlated less than FOCO, however it still demonstrated a relationship with a medium effect size. The theory driven stepwise nature of the hierarchical regression meant that FOCS was added as the final predictor in each model based upon previous study results (Carvalho et al., 2019a). FOCS added little (1.4%, p=.020) additional variance to the model of depression, and no significant additional variance for outcomes of anxiety or pain interference. This result may indicate that FOCS in chronic pain may not be as important as the potentially stronger impacts of experiencing enacted stigma and internalized stigma whilst also being fearful of seeking the support of others. One might expect that if a person is experiencing a high level of FOCO alongside chronic pain and high levels of stigma, that being fearful of self-compassion is unlikely to add additional levels of distress in an already distressing situation.

The final hypothesis suggested that FOCO and FOCS would moderate the relationship between the predictors of pain intensity and stigma and outcomes of depression, anxiety and pain interference. The lack of significant moderating effect of FOCO/FOCS on the relationships between pain intensity and outcomes means that potentially (1) the relationships between pain intensity and depression, anxiety or pain interference was the same irrespective of levels of FOC, or, (2) a high FOC may mean individuals also experience high levels of depression or anxiety, but the relationship between these outcomes and pain intensity are not changed by FOC.

The moderating effect of FOCO on the relationship between stigma and depression was not as expected i.e. the relationship between stigma and depression was stronger for low FOCO.

Intuitively, an individual who has a low fear of receiving compassion from others when experiencing a painful and stigmatized condition is more likely to actively seek these soothing and affiliative experiences. Such affiliative experiences are likely to reduce feelings of threat and isolation (key contributors to depression) (Lucre and Clapton, 2020; Gilbert, 2015). In the moderating relationship observed here, when a person experiences low stigma in the context of low FOCO, they report low levels of depression. As stigma levels increase, depression levels increase at a faster rate for those with a low FOCO. Once high levels of stigma are reported, individuals also display higher levels of depression. However, for high FOCO there is no relationship between stigma and depression. One explanation may be that those who have a low FOCO may be less guarded than those with high FOCO in social situations with others. Consequently, they may notice more, or be more affected by, enacted stigma when it occurs. Thus, feelings of depression increase at a faster rate following stigmatisation compared to individuals with high FOCO. Individuals with a high FOCO may make assumptions of others based on previous experiences of social exclusion (Gilbert et al., 2003; Gilbert et al., 2011), and therefore have already interpreted the actions of others as threatening/stigmatising, thus stigma is less relevant to their experiences of depression than other psychological and physical factors. A second, simpler and perhaps more likely explanation relates to the observation that individuals with heightened levels of FOCO are highly likely to also experience increased symptoms of low mood (Gilbert et al., 2011). Thus, this is likely to continue in the context of chronic pain and therefore individuals with FOCO report feeling low in mood irrespective of the level of stigma they experience (i.e. the stigma has no additional impact as mood is already low).

This result points to the complexity of the internal psychological processes involved, and indicates that further analysis is needed beyond the simple moderation model tested here. Of

note, FOCS did not significantly moderate the relationship between stigma and depression.

Factors not measured in this study such as self-compassion, self-criticism, guilt and shame and

their interactions with feelings of stigma and depression are likely to be important.

Limitations

This is a cross-sectional study and as such causal relationships cannot be inferred. This

was a study from a heterogenous population with a range of diagnoses relating to chronic pain.

Moreover, this was an online sample of participants who self-reported their pain and diagnoses,

so it is impossible to validate independently that participants were experiencing chronic pain.

Demographic limitations exist; only 1 participant (0.38%) reported being Black, which is

a significant under representation in the sample population of people from this ethnic

background compared to the general populations of the countries listed by participants (e.g. UK

[3%] and United States [14%]) (Office of National Statistics, 2011; United States Census

Bureau, 2010). In general, the demographic make-up of the population self-identified as white.

These data suggest that this sample cannot be considered as representative of the chronic pain

population as a whole.

The majority of participants identified as female. Evidence suggests that the

physiological and psychological responses of individuals to chronic pain are gendered (Keogh,

2015), as such, this study may be gender-biased towards the experiences of women. Indeed, self-

identifying as male was negatively correlated with pain-related anxiety (i.e. being male was

correlated with better outcomes in this domain), and this result may warrant further investigation.

Importantly, the recruitment process for this study utilized online platforms, which likely

selected for a younger population of individuals who readily engage with information through

social media. Moreover, the majority of participants appear to have engaged with the study

following a post on a platform that is popular in the United States, skewing the population

towards a U.S.-based sample. As such, differing social attitudes towards chronic pain, disability

and workplace absence may have influenced the type and frequency of enacted stigma that was

reported.

Perhaps most importantly, this study took place during the COVID-19 pandemic. A

lockdown in participants' activities occurred approximately 3-4 weeks following study launch.

Both the lockdown and the immediate threat of a highly contagious and potentially deadly virus

circulating had the immediate effect of shifting the usual focus of people's attention online and

severely limiting engagement with online posts about this study. Thus it is likely that measures of

psychological distress are confounded. A brief comparison demonstrates that depression levels

reported here were comparable with previous studies, but mean pain-related anxiety was higher.

To what extent the global lockdown during COVID-19 impacted the results presented here

cannot be fully elucidated. However, initial data regarding psychological distress experienced by

individuals from the U.K. with chronic pain during the COVID-19 pandemic lockdown has

demonstrated that, compared to pain-free individuals, they experienced greater increases in

anxiety, low mood, feelings of loneliness and reductions in physical activity (Fallon et al., 2020).

The impact of the global pandemic on this study are considered in greater detail in Section 3.

Clinical implications

This is a quantitative study that cannot derive causative relationships. However, it is

possible to use the findings presented to consider potential avenues for testing clinical

interventions for people in chronic pain who are reporting feeling stigmatised. Stigma, FOCO,

and FOCS all independently predicted depression in this population of people with chronic pain.

Interventions which seek to reduce fears of compassion, and self-critical or shame-based

responses to enacted stigma can be considered. Factors relating to affiliative emotional states are

recognised as playing a role in chronic pain, therefore early attempts to use of Compassion

Focused Therapy are already justifiably emerging (Penlington, 2018). Clinicians may wish to

consider that given that here FOCO appears to strongly predict depression, and previous study

results showed FOCO (but not FOCS) independently predicted increased levels of depression

and pain-related anxiety, as well as mediating the relationship between self-compassion and

social safeness (Carvalho et al., 2019a), that a compassion focused approach may address how

clients seek to engage with others when reporting stigmatising experiences. One might

hypothesise that such work could aim to help clients seek support and social connectedness when

engaging in activities that are experienced as stigmatising, with the aim of reducing FOCO. Yet

to be published data support this hypothesis, demonstrating that the sharing of trauma histories

by clients taking part in a CFT-based pain management programme lead to an understanding of

striving to avoid rejection, reduced feelings of isolation and increased feelings of common

humanity on self-compassion scales (Malpus, 2020).

     Importantly, the work of Scott et al. (2019) demonstrated that a 1:1 ACT-based

intervention aimed at reducing the stigma felt by individuals did not observe this result, despite

improvements in other outcomes related to psychological distress. Reducing enacted and felt

stigma is clearly an important factor for people experiencing chronic pain, however, focusing on

individual interventions is not likely to be successful (Williams, 2016). Clinicians should

consider the prosocial and affiliative processes, including those of validation and normalisation,

that clients with chronic pain may encounter during group and pain management programme

interventions. A review of a several interventions that aimed to reduce stigma relating to health

conditions concluded that they needed to take place at multiple levels – interpersonally (with the

person on an individual level), within organisations and communities, as well as a governmental and structural levels (Heijnders and Van Der Meij, 2006). Organisational change in healthcare may be most effective when training future healthcare professionals, with training bodies seeking to emphasise compassionate medicine approaches in their communications training. Reducing stigma at the societal level requires systemic approaches, such as those already undertaken in other stigmatised health conditions (e.g. HIV) that have been successful by ensuring stakeholder involvement in policies, and the co-production of social interventions (Li et al., 2018).

Future research

Further theoretical work is required to elucidate the complex relationships between psychological factors involved in chronic pain experience. A quantitative study utilizing the full SSCI-20 in order to delineate the role of enacted and felt stigmas within the complex interactions already identified here and elsewhere (Carvalho et al., 2019a; Scott et al., 2019) may further inform future clinical investigations. Theoretical pre-clinical work which utilise less prescriptive modelling processes such as path analysis may allow for the measurement of a greater number of variables (e.g. shame, self-criticism, self-compassion).

Clinical trials able to assess the effectiveness of interventions that aim to reduce participants' reported levels of FOCO may be warranted. In particular, a controlled trial comparing CFT-based interventions with the established treatments for chronic pain, (e.g. CBT or ACT) for outcomes related to low mood, pain efficacy, and pain interference may be justified. Outcome measures in such trials may seek to understand if CFT-based approaches can effectively reduce FOCO, and, if this has a causal relationship with outcomes of psychological distress.

Considering the established role of stigma as a predictor of psychological distress for individuals with chronic pain, and the significant global burden of the condition, clinical studies investigating systemic and local level interventions that destigmatize, alleviate individual distress, and reduce the social impact of chronic pain are urgently needed.

Conclusions

The results of this study demonstrate that stigma, FOCO and FOCS are significant independent predictors of psychological distress for people experiencing chronic pain. Moreover, FOCO has a moderating effect on the relationship between stigma and depression. Clinicians should now consider FOC as an important factor when working with individuals with chronic pain, and when designing and testing both individualized and group-based interventions that rely on affiliative social processes to facilitate therapeutic change. Future research should focus on understanding if compassion-based approaches can improve psychosocial well-being for people experiencing chronic pain.

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Tables and Figures

Tables

Table 2.1 Demographic characteristics: continuous variables

	N	Mean (SD)	Range
Age (years)	262	34.19 (11.58)	18.00-73.00
Duration of pain (months)	262	131.68 (106.61)	6.00-744.00

All variables rounded to 2 decimal places. N, Number; SD, Standard Deviation.

Table 2.2 Demographic characteristics: Categorical variables

Characteristic	Frequency (N=262)	Percentage
Gender		
Female	209	79.8
Male	42	16.0
Non-Binary	9	3.4
Trans Man	2	0.8
Country of Residence		
Australia	4	1.5
Belgium	2	0.8
Canada	22	8.4
Germany	1	0.4
Guatemala	1	0.4
India	1	0.4
Israel	1	0.4
Netherlands	1	0.4
New Zealand	1	0.4
Poland	1	0.4
Sweden	2	0.8

Characteristic	Frequency (N=262)	Percentage
United Kingdom	76	29.0
United States	148	56.5
Did Not State	1	0.4
Ethnicity		
Aboriginal Australian	1	0.4
Asian	1	0.4
Asian - British Indian	1	0.4
Asian – Filipino	2	0.8
Black	1	0.4
Hispanic or Latino	5	1.9
Mixed ethnic group		
White Asian	5	1.9
White Hispanic or Latino	2	0.8
White Middle Eastern	1	0.4
Did Not State	5	1.9
Native American	4	1.5
White	213	81.3
Did not state	21	8.0
Diagnosis (Primary, secondary)		
Ankylosing Spondylitis	3	1.1
Arthritis	1	0.4
Psoriatic	2	0.8
Rheumatoid	3	1.1
Back Pain	17	6.5
Chronic	2	0.8
Degenerative disc disease	6	2.3
Osteoarthritis	4	1.5
Scoliosis	6	2.3
Other	2	0.8

Characteristic	Frequency (N=262)	Percentage
Chronic Pain Syndrome	3	1.1
Chronic Pelvic Pain Syndrome	1	0.4
Complex Regional Pain Syndrome	6	2.2
Ehlers Danlos syndrome	11	4.2
Hypermobile	8	3.1
Other	2	0.8
Endometriosis	9	3.4
Fibromyalgia	2	0.8
Other	10	3.8
Fibromyalgia	38	14.5
Arthritis	3	1.1
Back Pain	5	1.9
CFS	5	1.9
IBS	1	0.4
Migraine	2	0.8
Other	7	2.6
Interstitial Cystitis	2	0.8
Knee pain	1	0.4
Lupus	2	0.8
Migraine	11	4.2
Neck pain - Cervical myelopathy	5	1.9
Neuropathic pain	3	1.1
Peripheral Neuropathy	4	1.5
Sacroiliac (SI) joint pain	2	0.8
Other	25	9.5
Did Not State	48	18.3
Employment status		
Employed Full Time	78	29.8
Employed Part Time	24	9.2

Characteristic	Frequency (N=262)	Percentage
Full time unpaid parent or carer	7	2.7
On maternity, paternity or adoption leave	1	0.4
Retired	4	1.5
Student	33	12.6
Unable to work – receiving disability benefits	47	17.9
Unemployed looking for work	15	5.7
Unemployed not looking for work	16	6.1
Other	37	14.1
Partnership status		
Married	96	36.6
Civil Partnership	7	2.7
In a relationship	30	11.5
In a relationship (co-habiting)	51	19.5
Divorced	9	3.4
Widowed	1	0.4
Single	64	24.4
Prefer not to say	1	0.4
Other	3	1.1

Table 2.3 Descriptive statistics and measure of internal consistency: outcome measures

	Mean (SD)	Range	C α
BPI Pain intensity scale	5.91 (1.45)	2.25-10	0.88
BPI Pain interference scale	7.33 (2.07)	0.57-10	0.89
SSCI-8 total stigma score	22.72 (5.96)	8.00-39.00	0.86
FOCO subscale	32.00 (10.20)	13.00-57.00	0.90
FOCS subscale	39.30 (15.00)	16.00-76.00	0.93
PASS	54.25 (17.33)	5.00-95.00	0.92
DASS-21 depression subscale	17.76 (5.34)	7.00-28.00	0.88

BPI, Brief Pain Inventory; Depression - Depression, Anxiety and Stress Scale-21; FOCO, fear of compassion from others; FOCS, fear of compassion from self; SSCI-8, Stigma Scale for Chronic Illness 8-item version
All variables rounded to 2 decimal places. N, Number; SD, Standard Deviation.

Table 2.4 Pearson correlations: Demographic variables

Demographic characteristic	BPI Pain interference scale	PASS	DASS-21 depression subscale
Age (years)	.175**	-.082	-.053
Pain Duration (months total)	.177**	-.060	-.065

BPI, Brief Pain Inventory; Depression - Depression, Anxiety and Stress Scale-21; PASS, Pain Anxiety Symptoms Scale; Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed)*

Table 2.5 Correlation matrix of predictor and outcome variables

	1	2	3	4	5	6	7
1. BPI Pain intensity scale	1	.613**	.290**	.137*	.163**	.275**	.231**
2. BPI Pain interference scale		1	.576**	.260**	.236**	.426**	.407**
3. SSCI-8 total stigma score			1	.473**	.361**	.488**	.375**
4. FOCO subscale				1	.687**	.342**	.518**
5. FOCS subscale					1	.259**	.457**
6. PASS						1	.364**
7. DASS-21 depression subscale							1

BPI, Brief Pain Inventory; Depression - Depression, Anxiety and Stress Scale-21; FOCO, fear of compassion from others; FOCS, fear of compassion from self; SSCI-8, Stigma Scale for Chronic Illness 8-item version. * p<0.05 level (2-tailed); ** p< 0.01 level (2-tailed).

Table 2.6 Hierarchical regression models for depression (DASS-21)

Step	Independent variable	B	SE	Beta	t	P	R Square	Adjusted R Square	R Square Change	F Change	Sig. F Change
1 Pain intensity							.053	.050	.053	14.665**	<.001
	BPI - pain scale	.849	.222	.231	3.829	<.001					
2 Stigma							.157	.150	.103	31.761**	<.001
	BPI - pain scale	.491	.219	.134	2.242	.026					
	SSCI-8	.301	.053	.336	5.636	<.001					
3 FOCO							.307	.299	.150	55.817**	<.001
	BPI - pain scale	.492	.199	.134	2.472	.014					
	SSCI-8	.115	.055	.128	2.106	.036					
	FOCO	.230	.031	.439	7.471	<.001					
4. FOCS							.321	.311	.014	5.450*	.020
	BPI - pain scale	.453	.198	.123	2.287	.023					
	SSCI-8	.111	.054	.124	2.046	.042					
	FOCO	.172	.039	.329	4.387	<.001					
	FOCS	.059	.025	.166	2.335	.020					

*Durbin-Watson=2.009; *p≤0.05; ** p≤0.01*
BPI, Brief Pain Inventory; FOCO, fear of compassion from others; FOCS, fear of compassion from self; SSCI-8, Stigma Scale for Chronic Illness 8-item version

Table 2.7 Hierarchical regression models for pain related anxiety (PASS)

Step	Independent variable	B	SE	Beta	t	P	R Square	Adjusted R Square	R Square Change	F Change	Sig. F Change
1 Pain intensity							.075	.072	.075	21.217**	<.001
	BPI - pain scale	3.279	.712	.275	4.606	<.001					
2 Stigma							.258	.252	.182	63.684**	<.001
	BPI - pain scale	1.734	.668	.145	2.597	.010					
	SSCI-8	1.299	.163	.446	7.980	<.001					
3 FOCO							.274	.265	.016	5.678*	.018
	BPI - pain scale	1.735	.662	.145	2.622	. <.01					
	SSCI-8	1.102	.181	.379	6.075	<.01					
	FOCO	.244	.102	.143	2.383	.018					
4. FOCS							.274	.263	.000	.000	.997
	BPI - pain scale	1.735	.665	.145	2.608	.010					
	SSCI-8	1.102	.182	.379	6.060	<.001					
	FOCO	.244	.132	.144	1.851	.065					
	FOCS	.000	.085	.000	-.004	.999					

Durbin-Watson=1.808; *p≤0.05; ** p≤0.01; Gender variables dummy coded as described by Fields (2018) pp. 665.
BPI, Brief Pain Inventory; FOCO, fear of compassion from others; FOCS, fear of compassion from self; SSCI-8, Stigma Scale for Chronic Illness 8-item version

Table 2.8 Hierarchical regression models for pain interference (BPI)

Step	Independent variable	*B*	SE	*Beta*	*t*	*P*	R Square	Adjusted R Square	R Square Change	F Change	Sig. F Change
1 Demographic							.041	.033	.041	5.509	.005
	Age	.020	.013	.115	1.612	.108					
	Pain duration	.002	.001	.117	1.648	.101					
2 Pain intensity							.396	.389	.355	151.86	<.001
	Age	.008	.010	.045	.792	.429					
	Pain duration	.002	.001	.117	2.062	.040					
	BPI - pain scale	.855	.069	.600	12.323	<.001					
3 Stigma							.564	.557	.168	98.694	<.001
	Age	.018	.009	.100	2.056	.041					
	Pain duration	.001	.001	.036	.747	.456					
	BPI - pain scale	.674	.062	.473	10.892	<.001					
	SSCI-8	.151	.015	.434	9.934	<.001					
3 FOCO							.564	.555	.000	.033	.857
	Age	.018	.009	.102	2.045	.042					
	Pain duration	.001	.001	.036	.729	.467					
	BPI - pain scale	.673	.062	.473	10.862	<.001					
	SSCI-8	.149	.017	.430	8.795	<.001					
	FOCO	.002	.010	.009	.181	.857					
4. FOCS							.564	.554	.000	.136	.712
	Age	.018	.009	.101	2.027	.044					
	Pain duration	.001	.001	.037	.759	.449					
	BPI - pain scale	.671	.062	.471	10.778	<.001					
	SSCI-8	.149	.017	.429	8.755	<.001					
	FOCO	-.001	.012	-.005	-.089	.929					
	FOCS	.003	.008	.021	.369	.712					

*Durbin-Watson=1.991; *p≤0.05; ** p≤0.01*
BPI, Brief Pain Inventory; FOCO, fear of compassion from others; FOCS, fear of compassion from self; SSCI-8, Stigma Scale for Chronic Illness 8-item version

Table 2.9 Linear model of predictors of depression

Step	b	SE	t	P
Constant	-1.0276	3.3818	-.3039	.7615
Stigma (centered)	.4976	.1472	3.3812	.0008
FOCO (centered)	.4968	.1099	4.5214	.0000
Stigma x FOCO	-.0111	.004	-2.5319	.0119

FOCO, Fear of compassion from others
Total R^2 = .3076

Figures

Figure 2.1 (a) Schematic representation of the moderating effect of FOCO on the relationship

between stigma and depression, (b) the simple slopes equations of the regression of stigma on

depression at three levels of FOCO

(a)
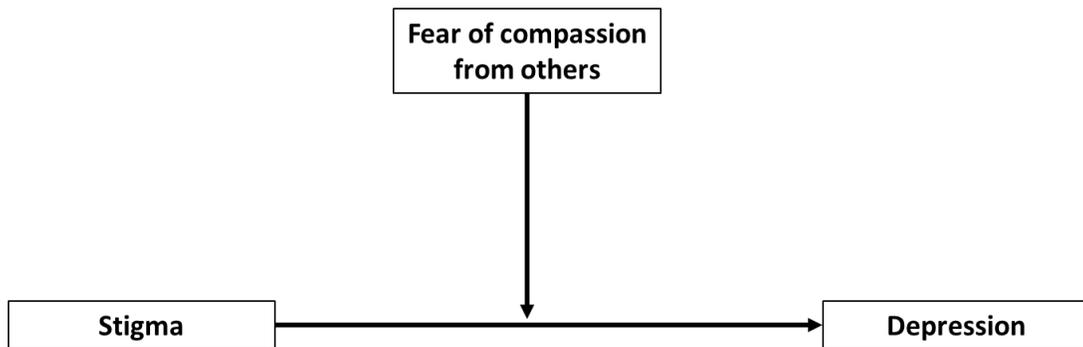
(b)
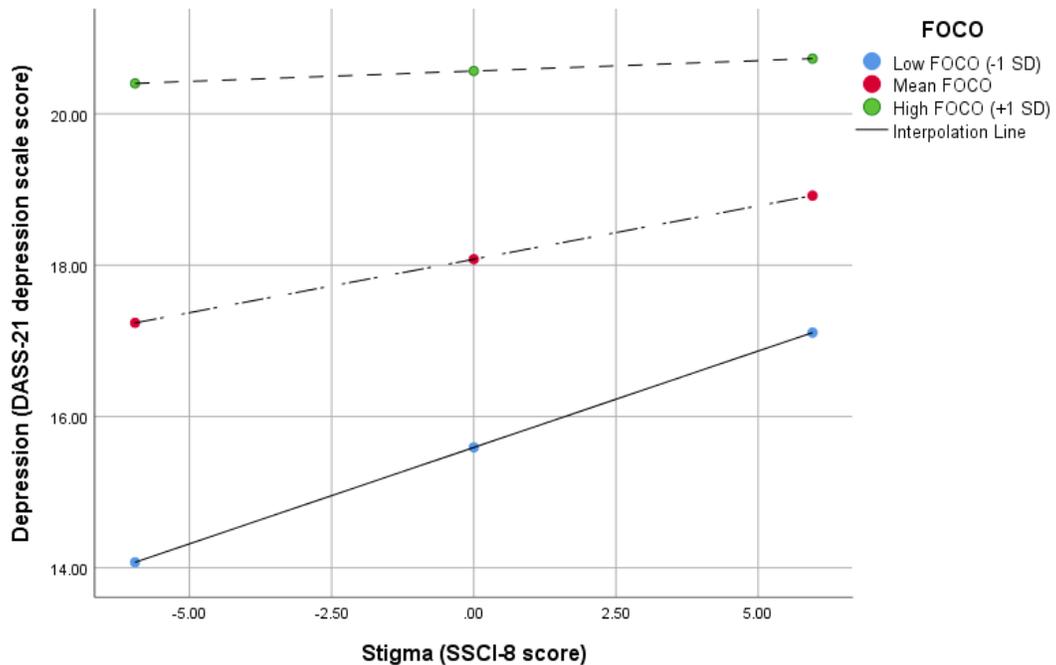
(a) ***p<0.01; (b) Stigma values presented are mean centred values. Depression - Depression, Anxiety and Stress Scale-21; FOCO, Fear of compassion from others; SSCI-8, Stigma Scale for Chronic Illness 8-item version, SD, standard deviation*

Appendices

Appendix 1 – Participant diagnoses

Table 2.10 Categorisation of diagnoses provided by participants

Categorisation	Participant description of diagnosis
Back pain	Adjacent Segment Syndrome
	Degenerative disc disease
	Failed Fusion Syndrome
	Herniated discs
	Lumbar pain
	Perforated discs
	Postlaminectomy syndrome
	Scoliosis
	Spinal cord nerve damage
Chronic Fatigue Syndrome	Myalgic Encephalomyelitis
Hypermobility Syndrome	Joint hypermobility syndrome
Irritable Bowel Syndrome	Irritable bowel
Knee pain	'Knee replacement'
Neck Pain	Cervical myelopathy
Migraine/chronic headache	Cluster headache
	Idiopathic intracranial hypertension
	Intractable migraine
	Migraine with aura
	Neuralgic migraine
	Status migraineous without aura
Neuropathic Pain	Chronic neuropathic pain syndrome
	Diabetic neuropathy
	Paralysis neuropathy
Pelvic pain	Chronic pelvic pain syndrome

Appendix 2 – Moderation Analyses

Table 2.11 Linear model of predictors of anxiety

Step	b	SE	t	P	Total R²
Fear of compassion from others					
Constant	54.1037	.9903	54.6316	<0.01	
Pain intensity (centered)	2.7899	.6824	4.0881	<0.01	
FOCO (centered)	.5090	.0989	5.1485	<0.01	
Pain intensity x FOCO	.0716	.0727	.9859	.3251	.1732
Constant	53.7856	1.0199	52.7363	<0.01	
Stigma (centered)	1.2367	.1775	6.9684	<0.01	
FOCO (centered)	.2231	.1050	2.1239	.0346	
Stigma x FOCO	.0162	.0148	1.0924	.2757	.2580
Fear of compassion from self					
Constant	54.0884	1.0223	52.9105	<0.01	
Pain intensity (centered)	2.8960	.7062	4.1011	<0.01	
FOCS (centered)	.2410	.0696	3.4621	<0.01	
Pain intensity x FOCS	.0452	.0452	.9202	.3583	.1252
Constant	53.6853	.9838	54.5718	<0.01	
Stigma (centered)	1.3193	.1677	7.8691	<0.01	
FOCS (centered)	.1007	.0668	1.5086	.1326	
Stigma x FOCS	.0175	.0100	1.7480	.0817	.2552

Table 2.12 Linear model of predictors of pain interference

Step	b	SE	t	P	Total R^2
Fear of compassion from others					
Constant	7.3252	.1001	73.2063	<0.01	
Pain intensity (centered)	.8375	.0690	12.1467	<0.01	
FOCO (centered)	.0365	.0100	3.6496	<0.01	
Pain intensity x FOCO	-.0001	.0073	-.0185	.9852	.4070
Constant	7.2862	.1153	63.2015	<0.01	
Stigma (centered)	.2037	.0201	10.1558	<0.01	
FOCO (centered)	-.0049	.0119	-.4154	67.82	
Stigma x FOCO	.0014	.0017	.8109	.4181	.3339
Fear of compassion from self					
Constant	7.3351	.1014	72.3222	<0.01	
Pain intensity (centered)	.8373	.0701	11.9515	<0.01	
FOCS (centered)	.0201	.0069	2.9058	.0040	
Pain intensity x FOCS	-.0029	.0049	-.5873	.5575	.3951
Constant	7.3029	.1110	65.7947	<0.01	
Stigma (centered)	.1959	.0189	10.3585	<0.01	
FOCS (centered)	.0041	.0075	.5435	.5873	
Stigma x FOCS	.007	.0011	.6080	.5437	.3339

FOCS, Fear of compassion from self FOCO, Fear of compassion from others

Table 2.13 Linear model of predictors of depression

Step	b	SE	t	P	Total R²
Fear of compassion from others					
Constant	17.8304	.2799	63.7003	<0.01	
Pain intensity (centered)	.5917	.1929	3.0677	.0024	
FOCO (centered)	.2684	.0279	9.6057	<0.01	
Pain intensity x FOCO	-.0352	.0205	-1.7120	.0881	.3028
Fear of compassion from self					
Constant	17.8063	.2940	60.5640	<0.01	
Pain intensity (centered)	.5785	.2031	2.8485	.0047	
FOCS (centered)	.1568	.0200	7.8333	<0.01	
Pain intensity x FOCS	-.0132	.0141	-.9362	.3500	.2362
Constant	17.8955	.3009	59.4781	<0.01	
Stigma (centered)	.2171	.0513	4.2330	<0.01	
FOCS (centered)	.1335	.0204	6.5394	<0.01	
Stigma x FOCS	-.0042	.0031	-1.3810	.1685	.2646

Appendix 3 - Journal guidelines to authors

- Full guidelines to authors can be found here: https://journals.sagepub.com/author-instructions/HPQ

- The guidelines included below are those relevant to the formatting and presentation of the work included in Section 2 of this thesis.

The Editorial Board of the JOURNAL OF HEALTH PSYCHOLOGY considers for publication:

(a) Reports of empirical studies likely to further our understanding of health psychology

(b) Critical reviews of the literature

(c) Theoretical contributions and commentaries

(d) Intervention studies

(e) Brief reports

(e) Signed editorials (about 1000 words) on significant issues.

INTERVENTION STUDIES

Publication guidelines for intervention studies are published in volume 15, number 1, pages 5-7.The journal normally publishes papers reporting intervention studies of up to 8,000 words allowing 500 words per table and figure.

The Journal of Health Psychology welcomes research reports regardless of the direction or strength of the results. However the JHP will only consider reports of clinical trials that have been pre-registered

at http://www.clinicaltrials.gov/ or http://www.controlled-trials.com/

Please consult the Editorial concerning "Publication Guidelines for Intervention Studies in the Journal of Health Psychology" by David F. Marks J Health Psychol January 2010 vol. 15 no. 1 5-

7: http://www.sagepub.com/content/15/1/5.full.pdf+html The criteria for publication include the application of the CONSORT, TREND and PRISMA statements.

BRIEF REPORTS

The Journal also publishes Brief Reports of up to 3,000 words. Brief Reports

should include an abstract of 100 words, and may include a table or figure in lieu of 500 words of the 3,000-word maximum.

ARTICLE LENGTH AND HOUSE STYLE

Articles should be as short as is consistent with clear presentation of subject matter. There is no absolute limit on length but 6,000 words, including footnotes and reference list, is a useful maximum. This word limit also includes the title, abstract and key words of the article. Longer articles will be considered at the discretion of the Editor. Tables and figures count as 500 words each which should be attached as separate pages at the end. "INSERT HERE" signs should be noted within the text. The title should indicate exactly, but as briefly as possible, the subject of the article. It is essential that your literature review is completely up to date. Please check recent issues of the JOURNAL OF HEALTH PSYCHOLOGY and other key journals to ensure that any relevant papers are cited. Papers that fail to do this will be rejected. An Abstract should be at the start of the manuscript and not exceed 100 WORDS (in spite of what is stated on the ScholarOne website) accompanied by FIVE keywords should be selected from the list provided on the JHP ScholarOne website. References are not numbered but appear in alphabetical order by first author surname.

4. PREPARING YOUR MANUSCRIPT FOR SUBMISSION

Please ensure that your manuscript is suitable for publication and completely free of errors before you submit. Please pay particular attention to SAGE guidelines on Authorship and the SAGE Correction Policy.

4.1 FORMATTING

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 ARTWORK, FIGURES AND OTHER GRAPHICS

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's *Manuscript Submission Guidelines*

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested

colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 SUPPLEMENTAL MATERIAL

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4.4 REFERENCE STYLE

Journal of Health Psychology adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use *EndNote* to manage references, you can download the SAGE Harvard EndNote output file.

4.5 ENGLISH LANGUAGE EDITING SERVICES

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Section 4. Ethics Proposal

Ethics Proposal for the empirical study 'The role of compassion in chronic pain and anxiety, low

mood and activities of daily living

John Timney

Word Count – 4469 excluding Tables, References and Appendices

Lancaster University Doctorate in Clinical Psychology

July 2020

Application form submitted to the Faculty of Health and Medicine Research Ethics

   Committee

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

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Title of Project: The role of compassion in persistent pain and anxiety, low mood and activities of daily living

Name of applicant/researcher: John Timney

ACP ID number (if applicable)*: N/A   **Funding source (if applicable)** N/A

Grant code (if applicable): N/A

*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM   Trainee Clinical Psychologist, DClinPsy (2017 intake)

2. Contact information for applicant:

E-mail: j.timney@lancaster.ac.uk   **Telephone**: 07746143061 (please give a number on which you can be contacted at short notice)

Address: Clinical Psychology, Div. Of Health Research, Lancaster University, Lancaster, LA1 4YG

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

Fiona Eccles (Research supervisor, PhD, DClin Psy); Clinical Psychology, Div. Of Health Research, Lancaster University, Lancaster, LA1 4YG

Jocelyn Armitage (Research supervisor, DClinPsy); Clinical Psychology, Div. Of Health Research, Lancaster University, Lancaster, LA1 4YG

Zoey Malpus (Field Supervisor, DClinPsy); Consultant Clinical Psychologist, Pain Team Manchester Royal Infirmary Oxford Road Manchester M13 9WL

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3. **If this is a student project, please indicate what type of project** by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#)

PG Diploma ☐   Masters by research ☐   PhD Thesis ☐   PhD Pall. Care ☐

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

DClinPsy SRP ☐   [if SRP Service Evaluation, please also indicate here: ☐]   DClinPsy Thesis ☒

4. **Project supervisor(s), if different from applicant**:

Fiona Eccles, Jocelyn Armitage, Zoey Malpus

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

Fiona Eccles: Lecturer
Jocelyn Armitage: Clinical Tutor

Clinical Psychology,
Div. Of Health Research,
Lancaster University,
Lancaster,
LA1 4YG

Zoey Malpus (Consultant Clinical Psychologist)

Pain Team
Manchester Royal Infirmary
Oxford Road
Manchester

M13 9WL

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o
4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? n o
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

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

Persistent pain (often referred to as chronic pain), is pain that lasts for 3 months or more, or, pain that still occurs even after the original injury has healed. The number of people who will experience persistent pain is significant and is estimated to be almost one in four individuals in the UK.
The reasons that persistent pain occurs are complex and interconnected. Persistent pain is influenced by biological, psychological and social factors. The way these factors are connected to each other are of interest to psychologists, as they may provide important avenues for therapeutic intervention. Recent research has suggested that increased self-compassion is important in helping to improve feelings of distress for individuals with persistent pain. Some of the factors that can influence an individual's ability to show compassion towards themselves are their likelihood to (1) have a high fear of compassion (FOC), and (2) to have a high tendency to feel stigmatized.
This study will use online surveys that measure the intensity of a person's experience of their pain, the amount of stigma, and FOC they experience, and, how they feel their pain is affecting them psychologically and in their daily lives. The aim of this study is to identify potentially important roles that stigma and fear of compassion may have in making a person's experience of persistent pain either better or worse. Fear of compassion will be measured as two separate constructs, firstly, fear of the compassion from others to self and secondly, the fear of showing compassion to oneself.

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

Start date: 12/19   End date: 05/20

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

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

• Participants will include any individual who self-reports being over 18 years of age as experiencing persistent pain (pain lasting 3 months or more)

- •   No specific diagnosis or type of pain will be requisite for inclusion
- •   All genders are welcome to participate
- • Exclusion criterium will be the presence of recent acute pain secondary to the usual site(s) of persistent pain e.g. toothache that has recently presented
- • Based on power calculations, the minimum number of participants required will be 275. The recruitment phase is expected to last approximately 4 months. If an upper limit of 1000 participants take part in the study, recruitment will be closed at the earliest opportunity after that number is reached.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

- • Participants will be recruited online using principally, but not exclusively, the Facebook, instagram and Twitter platforms. All recruitment content will be identical across platforms, with the exception of the hashtags that are used to accompany the posts. These will be optimised for maximum exposure on specific platforms.
- • All online recruitment posts will include a media advertisement comprising a short header giving information about the study, a short talking head video describing the study, with a link to the online survey.
- • All online posts will be posted from social media accounts set up specifically for the purposes of disseminating recruitment materials for this study. No pre-existing personal social media accounts belonging to the primary researcher will be used for the initial posting of any materials relating to this study.
- • Advocacy groups for people experiencing persistent pain will be approached directly to seek assistance in recruitment, in the form of asking them to reshare the link to the online survey on their social media platforms. These approaches will principally be in the form of an email to a publicly available email contact address, or, telephone or face-to-face contact if feasible. Any contacts of this nature will focus on requests to reshare online materials and will not take the form of direct recruitment.
- • Once landed on the survey page (https://lancasteruni.eu.qualtrics.com/jfe/form/SV_bqI8UBaebTqIH8p), participants will be provided with all relevant information (Appendix 2) and asked to consent to participate (Appendix 3) and confirm their eligibility to participate (Appendix 4) by checking a box within the online survey prior to answering any questions. Participants will then be guided through the outcome measures chosen to quantify the variables under consideration in our model (Appendix 6). Any participants reporting acute pain in response to an initial forced choice question asked within the online survey will be directed to a page explaining why they do not currently meet eligibility criteria for the study (Appendix 4).
- • **Note:** since the principle recruitment strategy is using social media, the online survey display has been optimised for viewing on mobile and tablet devices, not desktop/laptop computers.
- • Any participants reporting acute pain in response to an initial forced choice question asked within the online survey will be directed to a page explaining why they do not currently meet eligibility criteria for the study.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

This study will aim to use regression-based approaches to understand firstly, if FOC and stigma predict anxiety, depression and interference in activities of daily living. Secondly, whether these variables moderate the relationship between pain intensity and psychological and daily living outcomes.

Tests of assumptions of data for parametric analysis will be carried out. A hierarchal multiple linear regression analysis will be used to determine the predictors of psychological distress and daily living outcomes. Any demographic variables that significantly correlate with the outcome variables will be entered into each model first (eg age or gender). Pain intensity is a known predictor of psychological distress for individuals with persistent pain and so will be entered into each model second. Subsequently, measures for stigma and each of the two FOC constructs of interest will be added together. Final regression models will be tested to confirm that the assumptions of a multiple regression are met by assessing multicollinearity, linearity, homoscedasticity and independence of residuals (Field, 2009).

Finally, we will investigate whether stigma and FOC moderate the relationships between pain intensity and psychological and daily living outcomes. If the data collected are of suitable quality they will undergo a conditional process analyses using the Hayes PROCESS tool within SPSS (Hayes, 2012). In all cases the predictor variable will be the pain intensity score, and the dependent variables considered will be the scores for psychological distress (pain related anxiety and depression) and levels of daily activity. Three separate moderators will be considered. These are shame, fear of compassion from others and fear of compassion for self.

Measures

Demographic data to be collected from participants is shown in full in Appendix 6. Demographic categories will be age, duration of pain, gender, country of residence, ethnicity, employment status, diagnosis, partnership status and previous psychological input. The quantitative measures used to generate the scores used in the models are described below. The outcome measures that have been used to create the online survey are shown in Appendix 6. The online survey that participants will undertake can be found using the following link:
https://lancasteruni.eu.qualtrics.com/jfe/form/SV_bqI8UBaebTqIH8p

Pain intensity
Brief Pain Inventory – pain items only (Cleeland & Ryan, 1994)

The BPI pain inventory assesses pain at its "worst," "least," "average," and "now" (current pain). For each item pain is rated between 0 (No pain) and 10 (Pain as bad as you can imagine). The pain inventory has been used extensively during studies relating to chronic pain and is a well validated measure (Cleeland, 2009). The measure of pain can be created as a composite of the four items (mean pain severity score), or, single items for "worst" or "average" pain have been used for some trials. This study intends to use the composite measure when quantifying participants' experience of their pain.

Fear of compassion
Fear of compassion scale (Gilbert et al., 2011)
The Fear of Compassion scale comprises three subscales: fear of compassion for self (17 items), fear of compassion from others (15 items), and fear of giving compassion to others (10 items). It is anticipated this study will only utilize the first two of these subscales as moderators in our moderation models, although the whole measure will be administered. Items for all subscales are rated on a 5 point scale from 1 (Don't agree at all) to 5 (Completely agree).

Stigma
The Stigma Scale for Chronic Illness 8-item version (SSCI-8) (Rao et al., 2009; Scott et al., 2019)

The SSCI-8 measures components of stigma that are both enacted and internalized. Items are rated as being experienced as 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, and 5 = Always. Higher total scores reflect greater experience of stigma. The scale has previously been validated in a population of individuals with diagnosed neurological conditions, it was recently validated in a chronic pain population (Scott et al., 2019) and has shown good internal consistency.

Pain related anxiety
Pain and Anxiety severity scale (PASS-20) (McCracken, Zayfert et al. 1992, McCracken and Dhingra 2002)
The Pain Anxiety Symptoms Scale (PASS) short form consists of 20 items. This form of the measure has been validated and demonstrated psychometric characteristics that are comparable to the long form of the measure (McCracken & Dhingra, 2002; McCracken, Zayfert, & Gross, 1992). The measure comprises of 20 questions, with participants required to rate statements relating to various aspects of pain related anxiety as being experienced between 0 (Never) and 5 (Always) The PASS can be used to predict the severity of disability, pain interference and emotional distress and comprises of a composite score (0-100) and four subscales (5 items each) which measure somatic anxiety, cognitive anxiety (catastrophizing), fear of pain and escape avoidance. This study will use the composite score when modelling participant's pain experience.

Depression
Depression, Anxiety and Stress Scale-21 (DASS-21) (Lovibond & Lovibond, 1995)
The DASS-21 is a 21-item measure depression, anxiety and stress symptoms. Each item is rated on a 4-point scale (0 Did not apply to me at all; 3 Applied to me very much or most of the time). In this study, all 21 items will be delivered to maintain clinical validity of the scale, but the depression subscale will be used exclusively as a measure for depressive symptoms in the data analysis. Previous studies have described good internal consistency (Cronbach's alpha=0.93) for the depression subscale (Carvalho et al., 2019).

Daily living
Brief Pain Inventory (BPI) – pain interference items (Cleeland & Ryan, 1994)
The BPI pain interference subscale consists of 7 items that measure of the effect an individual's pain has on their daily functioning (Cleeland & Ryan, 1994). Ratings regarding pain interferences are given in 7 domains: general activity, mood, walking ability, normal work, relationships with other people, sleep, and enjoyment of life. Each of the 7 items is rated from 0 (does not interfere) to 10 (completely interferes). The BPI has been widely used and validated in a range of chronic pain settings to quantify the impact of chronic pain on activities of daily living (Cleeland, 2009).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

During the project
• No identifiable data will be collected from participants.
  o   Participants will not be required to provide their name or any contact information.
  o   Age data will be required in the form of 'Age (years)' only. Date of birth will not be collected.
• All anonymized survey data will be analyzed and stored electronically under password protection on the primary researcher's secure storage space on Lancaster University servers (or an equivalently Lancaster University secure place e.g. Box or OneDrive).

Upon project completion
• Raw survey data will be saved as an SPSS file and stored by the DClinPsy Research Coordinator who will store the files in password-protected file space on the university server (or equivalently secure location e.g. Box or OneDrive) for 10 years.
• Data will be documented and described in the form of an abstract that is saved as a 'Readme' file within the folder containing the stored data. Data file names and version numbers will be listed within the ReadMe file to facilitate easy navigation of the stored data.
• All electronic project data will be destroyed 10 years following completion of final examination of the project. This process will be overseen by the project supervisor (Fiona Eccles) and undertaken by the DClinPsy research coordinator.

7. Will audio or video recording take place? ☒ no ☐ audio ☐ video
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.
   N/A

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

   N/A

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder
8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

• Raw survey data will be saved as an SPSS file and stored by the DClinPsy Research Coordinator who will store the files in password-protected file space on the university server (or equivalently secure location e.g. Box or OneDrive) for 10 years.
• Data will be documented and described in the form of an abstract that is saved as a 'Readme' file within the folder containing the stored data. Data file names and version numbers will be listed within the ReadMe file to facilitate easy navigation of the stored data.
• All electronic project data will be destroyed 10 years following completion of final examination of the project. This process will be overseen by the project supervisor (Fiona Eccles) and undertaken by the DClinPsy research coordinator.
There will be no public access to these data.
8b. Are there any restrictions on sharing your data?
• Due to the personal nature of the data being divulged, participants may be reticent to take part if their data is made publicly available without limitations (despite the guarantee of anonymity). Therefore, access for other researchers to data will be granted on a case by case basis by the research supervisor (Fiona Eccles) who will oversee storage of the data.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

• Consent to participate will be obtained in the form of a forced choice question at the beginning of the online survey. This will require participants to check a box to confirm that they have read and understood the 'Information for participants', that they confirm that they are 18 years of age or older, and that they confirm they are happy for the information they provide to be used for research purposes (Appendix 3). Participants will not be able to undertake the outcome measures section of the survey, or submit their responses, if they do not first indicate informed consent to participate.

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

• As it will not be possible to identify participants from the data that they submit, they will be informed that they will not be able to withdraw their data/contribution once they have started the survey (Appendix 2). However, participants will be informed that they are able to stop doing the survey at any point. In order to minimize the risk of data loss, data will be captured by the survey software as it is entered.
• Risk issues relating to individuals reporting high levels of personal distress will be considered as far as is possible within the anonymous survey study design. Debrief materials will include information relating to appropriate helplines or other sources of support if a person is experiencing significant distress.
   o   Participants will be directed to appropriate websites that provide downloadable materials that might support in issues relating to shame and self-compassion (e.g. CompassionateMind.org)
• The primary researcher is a trainee clinical psychologist, and he is supervised by three qualified clinical psychologists who are experienced in conducting psychological research. Thus, the study has been designed to minimise the potential psychological distress for participants and any time burden due to the questionnaires chosen.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).
• No risks to the researcher identified

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.
• There may be no direct benefit to participation in this study. However, participants may find it a positive experience to take part in the research because of the potential for the results to contribute to the wider understanding of the psychological factors involved in persistent pain.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
• None

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.
• No identifiable data will be collected from participants.
  o   Participants will not be required to provide their name or any contact information.
  o   Age data will be required in the form of 'Age (years)' only. Date of birth will not be collected.

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

• Anonymous focus group feedback was collected from experts by experience who are members of a third sector pain advocacy group based in the north west of England. This group was contacted via email and none of the members are currently under the clinical care of any individual involved in this study. Their feedback was used to refine the accessibility of the information provided to participants and understand the potential time burden of completing the online survey.

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

• Publication in Thesis
• Publication in relevant academic journal.
• Participation and presentation at the Lancaster DClinPsy's thesis presentation day
• Potential to share results at other conferences, meetings or training events relevant to clinical psychology or the field of persistent pain.

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

• No additional concerns identified beyond those listed above

SECTION FOUR: signature
Applicant electronic signature: John Timney   Date 15 October 2019

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review   ☒

Project Supervisor name (if applicable): Fiona Eccles and Jo Armitage   Date application discussed 14.10.19

Submission Guidance
  1. Submit your FHMREC application <u>by email</u> to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:

      i.   **FHMREC application form.**
            Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*

ii.   **Supporting materials.**
       Collate the following materials for your study, if relevant, into a single word document:

      a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
      b. Advertising materials (posters, e-mails)
      c. Letters/emails of invitation to participate
      d. Participant information sheets
      e. Consent forms
      f. Questionnaires, surveys, demographic sheets
      g. Interview schedules, interview question guides, focus group scripts
      h. Debriefing sheets, resource lists

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

2. Submission deadlines:

   i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to [Becky Case](#) **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

   ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

      a. existing documents/data only;
      b. the evaluation of an existing project with no direct contact with human participants;
      c. service evaluations.

3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

Ethics approval letter

Lancaster University

Applicant: John Timney
Supervisor: Fiona Eccles and Jocelyn Armitage
Department: Health Research
FHMREC Reference: FHMREC19018

22 November 2019

Dear John

Re: The role of compassion in persistent pain and anxiety, low mood and activities of daily living

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

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Becky Case
Research Ethics Officer, Secretary to FHMREC.

Section 4 Appendix

Research protocol

The role of compassion in chronic pain and anxiety, low mood and activities of daily living

Version 2

Date: 15/11/2019

Researcher: John Timney (Trainee Clinical Psychologist, Lancaster University)

Supervised by:

Fiona Eccles (Research supervisor, PhD, DClin Psy); Clinical Psychology, Div. Of Health Research, Lancaster University, Lancaster, LA1 4YG

Jocelyn Armitage (Research supervisor, DClinPsy); Clinical Psychology, Div. Of Health Research, Lancaster University, Lancaster, LA1 4YG

Zoey Malpus (Field Supervisor, DClinPsy); Consultant Clinical Psychologist, Pain Team Manchester Royal Infirmary Oxford Road Manchester M13 9WL

Introduction

Persistent pain (often referred to as chronic pain), is pain that lasts for 3 months or more, or, pain that persists beyond the time of tissue healing (Fine, 2011). The burden of persistent pain globally is significant; it is now considered a public health priority with some estimates suggesting up to 10% of adults receive a diagnosis of 'chronic pain' annually (Goldberg & McGee, 2011). In the UK, persistent pain is an issue for approximately 14 million people (British Pain Society, 2015). Individuals with persistent pain are significantly more likely to experience low mood or anxiety compared to the general population (Poole, White, Blake, Murphy, & Bramwell, 2009), and report experiencing reductions in quality of life and feelings of fear and isolation (Thomas & Johnson, 2000).

Persistent pain is now well established as multi-dimensional, and is influenced by biological, psychological and social factors (Darnall, Carr, & Schatman, 2016; Melzack, 1999; Moseley, 2017). Several psychological factors have been identified as important factors in the relationships between pain and physical disability, as well as low mood and anxiety (Lee et al., 2015; Marshall, Schabrun, & Knox, 2017). These factors include psychological flexibility, catastrophizing, cognitive fusion, and prosocial affiliative states, such as self-compassion and adult attachment style (Carvalho, Pinto-Gouveia, Gillanders, & Castilho, 2019; Lee et al., 2015; Meredith, Ownsworth, & Strong, 2008). As such, psychological therapeutic approaches have often targeted these factors to try and reduce distress for individuals experiencing persistent pain, with some success. Cognitive behavioural therapy has focused on several factors, including catastrophic thinking styles (Williams, Eccleston, & Morley, 2012), while Acceptance and Commitment Therapy approaches often focus on factors such as psychological flexibility or cognitive fusion (Scott, Hann, & McCracken, 2016; Scott, Yu, Patel, & McCracken, 2019).

Given factors relating to affiliative emotional states are recognised as playing a role in persistent pain, early attempts to use of Compassion Focused Therapy are emerging (Penlington, 2018).

Prosocial affiliative states evolved in mammals as part of a care giving system that promotes nurture and increases group survival. The human brain has evolved under the pressure of social interaction and the need to process and understand relationships. Therefore, an understanding of early and current social contexts is fundamental for understanding an individual's experience of distress (Gilbert, 2014). Self-to-self relating that is experienced as highly shaming or self-critical underlies a wide range of mental health problems (Gilbert & Irons, 2005; Kannan & Levitt, 2013; Kim, Thibodeau, & Jorgensen, 2011). People experiencing persistant pain often report hypervigilence to the threat of social rejection, due to fears of being disbelieved or a burden to others (Smith & Osborn, 2007). Experiences of embarassment, social exclusion, and humiliation can be encountered and associated changes in physical ability can lead to negative reappraisals of the self within one's social context (Arnold et al., 2008). Negative evaluation of social status can lead to both self-criticism and the precipitation of threat-based responses such as anxiety and shame (Gilbert, 2014). Individuals experiencing persistent pain have reported significantly greater levels of negative emotions, including shame, guilt, and fear of negative evaluation (Turner-Cobb, Michalaki, & Osborn, 2015).

Stigma can be defined as devaluing and discrediting responses towards an individual or group who are understood to have an attribute or attributes that differ from the socially understood norms, resulting in social exclusion or embarrassment (Scott et al., 2019). Stigma has been characterised as comprising two components, enacted stigma, which is experienced due to the negative actions/attitudes of others, and internalised stigma, whereby an individual begins to believe the negative attitudes and direct these inwardly towards the self (Scott et al., 2019). The

psychological pain that is experienced by stigmatised individuals is considered to be rooted in an understanding and recognition that 'others' view the 'self' negatively, impacting therefore on one's social attractiveness and giving rise to feelings of shame (Gilbert, 2003; Matos, Pinto-Gouveia, Gilbert, Duarte, & Figueiredo, 2015). A meta-analysis of 108 studies (N=22, 411) investigating shame, showed it had significant associations with depressive symptoms (Kim et al., 2011). Understanding the roles of stigma as part of the emotional underpinning of shame and mental distress will be important if therapeutic approaches are to be effective in combatting the current healthcare burden presented by persistent pain – a condition where high rates of enacted stigma and shame are commonly reported (Scott et al., 2019). Individuals with persistent pain report feeling misunderstood by friends, romantic partners and family members (Holloway, Sofaer-Bennett, & Walker, 2007; Monsivais, 2013; Toye & Barker, 2010). Significantly in the context of this study, individuals often describe feeling healthcare professionals underestimate their experience of pain, or feel stigmatised by them (Nguyen, Turner, Rydell, Maclehose, & Harlow, 2013; Slade, Molloy, & Keating, 2009). Importantly this can interfere with there willingness to seek care (Slade et al., 2009).

A positive correlation between increased pain intensity and increased severity of symptoms of depression has been observed in populations of people with persistant pain, and higher levels of self-compasion were seen to reduce symptom severity for this cohort (Carvalho et al., 2019). These results mirror those seen in the other client populations, in that increased levels of self-compassion significantly correlate with reduced rates of self-criticism, anxiety and depression (Gilbert, McEwan, Matos, & Rivis, 2011). The ability for an individual with persistent pain to engage with affiliative emotional states affects their general well-being and activities of daily living, since such emotions regulate threat-based affects.

Importantly, while the capacity to show compassion to oneself is psychologically protective for individuals there is growing evidence that for many, in particular those who demonstrate high levels of self-criticism, being compassionate towards themselves or receive compassion from others is difficult to the point that they can be fearful of it (Matos, Duarte, & Pinto-Gouveia, 2017). This aversive response to compassion is often rooted in early experiences of shame (Gilbert et al., 2011; Matos et al., 2017). Individuals with high levels of a 'fear of compassion' (FOC) can experience increases in symptoms related to depression, anxiety and stress (Gilbert et al., 2012; Gilbert et al., 2011). Both shame and FOC, have been shown by some to mediate the relationship between 'major life events' and depressive symptoms (Coelho, Trindade, Mendes, & Ferreira, 2019). Specifically, and importantly for individuals experiencing persistent pain, FOC is also correlated with increased physiological markers of a stress response (Duarte, McEwan, Barnes, Gilbert, & Maratos, 2015). However, to date the role of the FOC in persistent pain has not been well characterized. Understanding whether and how FOC, either from from self or others, is important for people with persistent pain could help in the development and targeting of interventions and is therefore of important therapeutic interest for clinical psychologists.

Aims

Pain intensity has been demonstrated to predict psychological distress in individuals experiencing persistent pain. Currently, the roles that stigma and FOC have as predictors for psychological (symptoms of anxiety and depression) and daily living outcomes, or as moderators of the relationships between pain intensity and these outcomes, have not been well characterised quantitatively. Here, the roles of stigma and FOC in people with persistent pain will be investigated.

This study will aim to use regression based approaches to understand firstly, if FOC and stigma predict anxiety, depression and interference in activities of daily living. Secondly, whether each of these variables (stigma and FOC) moderates the relationship between pain intensity and psychological and daily living outcomes.

Research questions

1. Do stigma and FOC predict psychological and daily living outcomes in people experiencing persistent pain?

2. Do stigma and FOC moderate the relationship between pain and psychological and daily living outcomes in people experiencing persistent pain?

In both cases two constructs of FOC will be investigated, (1) Fear of compassion from others and (2) Fear of compassion for self.

Method

This study is being conducted with supervision from a clinical psychologist from an adult pain service situated in the North West of England.

Participants

For the regression analyses, an a priori power analysis using Gpower*(Dusseldorf, Germany) (Faul, Erdfelder, Buchner, & Lang, 2009) using a multiple regression with 4 predictors at an alpha level of 0.05 ($p<0.05$) and a power of 0.80 is predicted to require a sample size of N=84 to will be required to identify a medium effect size ($f^2=0.15$).

For moderation analyses, a reported average for the effect size across studies is $f^2=0.009$ (Aguinis, Beaty, Boik, & Pierce, 2005). As a consequence, standards for effect sizes in such

analyses are considered to be 0.005, 0.01, and 0.025 for small, medium, and large, respectively (Kenny, 2018) and sample sizes of more than 200 are considered to be required for detecting moderating effects that are medium in size (Whisman & McClelland, 2005). An a priori power analysis using Gpower*, testing a linear multiple regression R^2 increase with 3 predictors at an alpha level of 0.05 (p<0.05) and a power of 0.80, predicts that a sample size of N=316 will be required to identify a large effect size (f^2=0.025). Conditional process analyses using the Hayes PROCESS tool utilizes bootstrapping methodology to reduce the sample sizes required to perform moderation analyses (Hayes, 2012). Studies which have utilised this tool to perform moderation analyses to understand psychological factors involved in individuals experiences of chronic pain or other serious health conditions have previously been able to identify significant moderating interactions with between 231 and 286 participants (Carvalho et al., 2019; McAteer & Gillanders, 2019). This study will use the Hayes PROCESS tool and the in built bootstrapping methodology it employs in order to reduce sample size requirements.

As such it is estimated the minimum number of participants required to take part in order to perform this analysis will be 275.

Inclusion criteria

Inclusion criteria are participants who self-report being 18 years of age or over and currently experiencing persistent pain (pain lasting 3 months or more). No specific diagnosis or type of pain will be requisite for inclusion and all genders are welcome to participate.

Exclusion criteria

Participants will be excluded if they report presence of acute pain secondary to the usual site(s) of persistent pain. For example, if a participant recently noticed a toothache, but this pain

is not considered by them to be part of their normal pain profile, then they would not be able to take part on that day.

Design

This online survey study will adopt a single group, observational, cross-sectional design utilizing quantitative outcome measures.

Analysis plan

Tests of assumptions of data for parametric analysis will be carried out. A hierarchal multiple linear regression analysis will be used to determine the predictors of psychological distress and daily living outcomes. Any demographic variables that significantly correlate with the outcome variables will be entered into each model first (eg age or gender). Pain intensity is a known predictor of psychological distress for individuals with persistent pain and so will be entered into each model second. Subsequently, measures for stigma and each of the two FOC constructs of interest will be added together. Final regression models will be tested to confirm that the assumptions of a multiple regression are met by assessing multicollinearity, linearity, homoscedasticity and independence of residuals (Field, 2009).

Finally, we will investigate whether stigma and FOC moderate the relationships between pain intensity and psychological and daily living outcomes. If the data collected are of suitable quality they will undergo a conditional process analyses using the Hayes PROCESS tool within SPSS (Hayes, 2012). In all cases the predictor variable will be the pain intensity score, and the dependent variables considered will be the scores for psychological distress (pain related anxiety and depression) and levels of daily activity. Three separate moderators will be considered. These are shame, fear of compassion from others and fear of compassion for self.

Measures

Demographic data to be collected from participants is shown in Appendix 6. The

quantitative measures used to generate the scores used in the models are described below. The

full surveys that will be presented to participants are shown in Appendix 6:

Pain intensity

1. **Brief Pain Inventory – pain items only (Cleeland & Ryan, 1994)**

The BPI pain inventory assesses pain at its "worst," "least," "average," and "now"

(current pain). For each item pain is rated between 0 (No pain) and 10 (Pain as bad as you can

imagine). The pain inventory has been used extensively during studies relating to chronic pain

and is a well validated measure (Cleeland, 2009). The measure of pain can be created as a

composite of the four items (mean pain severity score), or, single items for "worst" or "average"

pain have been used for some trials. This study intends to use the composite measure when

quantifying participants' experience of their pain.

Fear of compassion

2. **Fear of compassion scale (Gilbert et al., 2011)**

The Fear of Compassion scale comprises three subscales: fear of compassion for self (17

items), fear of compassion from others (15 items), and fear of giving compassion to others (10

items). It is anticipated this study will only utilize the first two of these subscales as moderators

in our moderation models, although the whole measure will be administered. Items for all

subscales are rated on a 5 point scale from 1 (Don't agree at all) to 5 (Completely agree).

Stigma

3. **The Stigma Scale for Chronic Illness 8-item version (SSCI-8) (Rao et al., 2009; Scott**
   et al., 2019)

The SSCI-8 measures components of stigma that are both enacted and internalized. Items are rated as being experienced as 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, and 5 = Always. Higher total scores reflect greater experience of stigma. The scale has previously been validated in a population of individuals with diagnosed neurological conditions, it was recently validated in a chronic pain population (Scott et al., 2019) and has shown good internal consistency.

Pain related anxiety

4. **Pain and Anxiety severity scale (PASS-20) (McCracken, Zayfert et al. 1992, McCracken and Dhingra 2002)**

The Pain Anxiety Symptoms Scale (PASS) short form consists of 20 items. This form of the measure has been validated and demonstrated psychometric characteristics that are comparable to the long form of the measure (McCracken & Dhingra, 2002; McCracken, Zayfert, & Gross, 1992). The measure comprises of 20 questions, with participants required to rate statements relating to various aspects of pain related anxiety as being experienced between 0 (Never) and 5 (Always) The PASS can be used to predict the severity of disability, pain interference and emotional distress and comprises of a composite score (0-100) and four subscales (5 items each) which measure somatic anxiety, cognitive anxiety (catastrophizing), fear of pain and escape avoidance. This study will use the composite score when modelling participant's pain experience.

Depression

5. **Depression, Anxiety and Stress Scale-21 (DASS-21) (Lovibond & Lovibond, 1995)**

The DASS-21 is a 21-item measure depression, anxiety and stress symptoms. Each item is rated on a 4-point scale (0 Did not apply to me at all; 3 Applied to me very much or most of

the time). In this study, all 21 items will be delivered to maintain clinical validity of the scale, but the depression subscale will be used exclusively as a measure for depressive symptoms in the data analysis. Previous studies have described good internal consistency (Cronbach's α=0.93) for the depression subscale (Carvalho et al., 2019).

Daily living

6. Brief Pain Inventory (BPI) – pain interference items (Cleeland & Ryan, 1994)

The BPI pain interference subscale consists of 7 items that measure of the effect an individual's pain has on their daily functioning (Cleeland & Ryan, 1994). Ratings regarding pain interferences are given in 7 domains: general activity, mood, walking ability, normal work, relationships with other people, sleep, and enjoyment of life. Each of the 7 items is rated from 0 (does not interfere) to 10 (completely interferes). The BPI has been widely used and validated in a range of chronic pain settings to quantify the impact of chronic pain on activities of daily living (Cleeland, 2009).

Procedure

Recruitment

Participants will be recruited online using principally, but not exclusively, the Facebook, Instagram and Twitter social media platforms. All recruitment content will be identical across platforms, with the exception of the hashtags that are used to accompany the posts. These will be optimized for maximum exposure on specific platforms. All online recruitment posts will include a media advertisement comprising a short header giving information about the study, a short talking head video/infographic describing the study, with a link to the online survey (Appendix 1). All online posts will be posted from social media accounts set up specifically for the purposes of disseminating recruitment materials for this study. No pre-existing personal social media

accounts belonging to the primary researcher will be used for the initial posting of any materials relating to this study.

Advocacy groups for people experiencing persistent pain will be approached directly to seek assistance in recruitment, in the form of asking them to reshare the link to the online survey on their social media platforms. These approaches will principally be in the form of an email to a publicly available email contact address, or, telephone or face-to-face contact if feasible. Any contacts of this nature will focus on requests to reshare online materials and will not take the form of direct recruitment.

Online survey

Once participants click on the link embedded in the recruitment posts, they will be directed to the online survey, designed and powered using the Qualtrics software (Qualtrics Labs, Inc).

Once landed on the survey page, participants will be provided with all relevant information (Appendix 2) and asked to consent to participate (Appendix 3) and confirm their eligibility to participate (Appendix 4) by checking a box within the online survey prior to answering any questions. Participants will then be guided through the outcome measures chosen to quantify the variables under consideration in our model (Appendix 6).

Any participants reporting acute pain in response to an initial forced choice question asked within the online survey will be directed to a page explaining why they do not currently meet eligibility criteria for the study (Appendix 4).

Data storage

During the project

All anonymized survey data will be analyzed and stored electronically under password protection on the primary researcher's secure storage space on Lancaster University servers (or an equivalently Lancaster University secure place e.g. Box or OneDrive).

Upon completion of final examination of the project

Raw survey data will be saved as an SPSS file and stored by the DClinPsy Research Coordinator who will store the files in password-protected file space on the university server (or equivalently secure location e.g. Box or OneDrive) for 10 years.

Data will be documented and described in the form of an abstract that is saved as a 'Readme' file within the folder containing the stored data. Data file names and version numbers will be listed within the ReadMe file to facilitate easy navigation of the stored data.

All electronic project data will be destroyed 10 years following completion of final examination of the project. This process will be overseen by the project supervisor (Fiona Eccles) and undertaken by the DClinPsy research coordinator.

There is the potential for future publication of this study in a peer-reviewed journal. Journal requirements for publication may require data to be made available to other researchers upon request. Due to the personal nature of the data being divulged, participants may be reticent to take part if their data is made publicly available without limitations (despite the guarantee of anonymity). Therefore, access to data will be granted on a case by case basis by Fiona Eccles, research supervisor (who will oversee the storage of data).

Practical issues

No expenses are anticipated to be incurred for postage of materials as electronic copies of all materials will be provided to participants via the online portal.

Ethical concerns

Anonymity

No identifiable data will be collected from participants. Participants will not be required to provide their name or any contact information in order to take part in the survey. Age data will be required in the form of 'Age (years)' only. Dates of birth will not be collected. The participants will provide their responses to the survey questions in a wholly anonymous way. This is outlined to participants in the information for participants section of the online survey (Appendix 2).

Informed consent

Consent to participate will be obtained in the form of a forced choice question at the beginning of the online survey. This will require participants to check a box to confirm that they have read and understood the 'Information for participants', that they confirm that they are 18 years of age or older, and that they confirm they are happy for the information they provide to be used for research purposes (Appendix 3). Participants will not be able to undertake the outcome measures section of the survey, or submit their responses, if they do not first indicate informed consent to participate.

As it will not be possible to identify participants from the data that they submit, they will be informed that they will not be able to withdraw their data/contribution once they have started the survey (Appendix 2). However, participants will be informed that they are able to stop doing

the survey at any point. In order to minimize the risk of data loss, data will be captured by the survey software as it is entered.

Participant well-being

The issues raised in this research are considered to be straightforward and can be managed within the frameworks of standard research practice and guidelines (Good Clinical Practice guidelines [NIHR] and the Declaration of Helsinki [WHO]). The primary researcher is a trainee clinical psychologist, and he is supervised by three qualified clinical psychologists who are experienced in conducting psychological research. Thus, the study has been designed with an aim to minimize the potential psychological distress for participants and any time burden due to the questionnaires chosen.

While it is not anticipated that completing the questionnaires will cause distress, debrief materials presented at the end of the survey (Appendix 5) will include information relating to appropriate helplines or other sources of support if a person is experiencing significant distress. Participants will be directed to appropriate websites that provide downloadable materials that might support in issues relating to shame and self-compassion (e.g. CompassionateMind.org)

Service User Involvement

Anonymous focus group feedback was collected from experts by experience who are members of a third sector pain advocacy group based in the north west of England. This group was contacted via email and none of the members are currently under the clinical care of any individual involved in this study. Their feedback was used to refine the accessibility of the information provided to participants and understand the potential time burden of completing the online survey.

Dissemination Strategy

The results of this study will be published in the thesis of the primary researcher. Attempts to publish the research in a relevant academic journal will also be undertaken.

The primary researcher will also undertake the oral presentation of results at the Lancaster DClinPsy training courses thesis presentation day, and at a regional Health Psychology Special Interest Group (SIG) meeting and may also be presented at other relevant conferences and meetings. Once the study is complete, the findings will be shared on the social media accounts used for recruitment, so that participants have the opportunity to see the results.

Timescale (2019-20)

Ethical review	October - November 2019
Data collection	Estimated start date Dec 1st 2019 – Estimated end date February 1st 2020
Analysis	February – March 2020
Write up	March – April 2020

Thesis hand in deadline : May 8th 2020

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Appendix 1

Recruitment materials to be distributed online

Account logo to be used on all social media accounts

Social media post contents

Do you experience chronic pain? Can you spare 20 minutes to take part in some research to help us understand chronic pain better?

Click here to find out more and take part:

https://lancasteruni.eu.qualtrics.com/jfe/form/SV_bqI8UBaebTqIH8p

#[insert optimised hashtag]
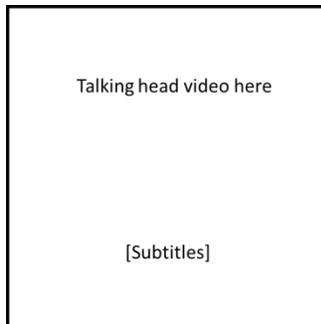
Video script

"Are you currently experiencing chronic pain that has lasted for more than 3 months? If you are, I need your help. My name is John, I'm a trainee clinical psychologist in the UK and I'm doing a research project that hopes to help us better understand how we experience chronic pain. We want to understand the psychological factors that might make the impact of the pain worse, and what might reduce that impact. We want to do this so that in the future we can explore what types of psychological support will best help individuals who experience chronic pain. If you would like to help, click on the link in this post, read more about the study, and take part. Thank you."

Appendix 2

Doctorate in Clinical Psychology | Lancaster University

Participant Information Sheet

The role of compassion in chronic pain and anxiety, low mood and activities of daily living

For further information about how Lancaster University processes personal data for research

purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is John Timney and I am conducting this research as part of the Doctorate of Clinical Psychology programme at Lancaster University.

What is the study about?

The reason I am performing this study is to try and better understand the psychological mechanisms that are involved when you experience persistent pain (or as it's more commonly known, chronic pain). We are hoping that this will help us learn more about the psychological factors which contribute to chronic pain, what might make the impact of the pain worse, and what might reduce that impact. We want to do this so that in the future we can explore what types of psychological support will best help individuals who experience chronic pain.

Why have I been approached?

You have been approached because the study requires information from people aged 18 years and older who have experienced chronic pain for a period of 3 months or more.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to complete an online questionnaire, which will ask about how you experience your pain, how you manage your pain and your emotions, the impact pain has on your daily life and some demographic information. It will take approximately 15-20 minutes to complete the online questionnaire. This survey has been formatted to look best on a mobile or tablet, but it will work on any device or computer.

Will my data be identifiable?

No one will know the information is yours, as the information you provide will be anonymous.

At the end of the study, data will be kept securely on the university's secure server for ten years. At the end of this period, they will be destroyed.

A synthesis of the data may be published. The full dataset will not be publicly available; however, it may be provided to other researchers upon request on a case by case basis. At all times all data will be anonymous, and no identifiable elements will be included.

Once you begin to enter the anonymous data it will not be possible to withdraw this contribution as it is captured by the survey software automatically. However, you are able to stop doing the survey at any point.

What will happen to the results?

The results will be submitted for publication as a thesis as part of the Lancaster University Doctorate in Clinical Psychology programme. Following this, the report may be submitted for publication in an academic journal. I will also be sharing a summary of the results in oral presentations to other healthcare professionals and at conferences. I will also post a summary of the study using the social media accounts that I have used for recruitment, so that you can see the results that you have contributed to creating. The summary will never have specific information about you or any other individual participant.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress whilst completing the questionnaire please stop immediately and contact the organisations included in the resources provided at the end of this sheet. In addition, please contact these organisations if you experience distress following participating in this study.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

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

Where can I obtain further information about the study if I need it?

Researcher & Trainee Clinical Psychologist

Name: John Timney

Lancaster Doctorate in Clinical Psychology,

Lancaster University, Lancaster,

LA1 4YG

Email: j.timney@lancaster.ac.uk

Phone: [insert research mobile number]

Alternatively, you can speak to the Research Supervisors from the Lancaster Clinical Psychology training programme on:

Name: Dr Fiona Eccles   Name: Dr Jocelyn Armitage

Email: f.eccles@lancaster.ac.uk   Email: j.armitage@lancaster.ac.uk

Contact Number: 01524 592807   Contact Number: 01524 594939

Postal Address: C34 Furness College, Lancaster University, Lancaster, LA1 4YG

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith

Email: I.smith@lancaster.ac.uk

Research Director

Doctorate in Clinical Psychology,

Lancaster University, Lancaster

LA1 4YG

If you wish to speak to someone outside of the DClinPsy Doctorate Programme, you may also contact the Associate Dean for Research:

Professor Roger Pickup Tel: +44 (0)1524 593746

Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

Lancaster University, Lancaster

LA1 4YG

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, please contact your GP for support. In addition, the following resources may be of assistance

The Compassionate Mind organization   Website: http://www.CompassionateMind.org

Mind for better mental health   Website: http://www.mind.org.uk

Pain self-management   Website: https://www.paintoolkit.org/

Appendix 3

Consent

We are asking if you would like to take part in a research project that explores the psychological

principles of chronic pain. Before you consent to participating in the study please read the information

provided. If you have any questions or queries before taking part, please contact to the principal

investigator, John Timney at J.Timney @lancaster.ac.uk.

Please read the following statements and click on the option below to indicate that you

are happy to take part in the study.

1. I confirm that I have read the participant information sheet and fully understand what is

expected of me.

2. I understand that the questionnaire will include questions about how I deal with emotional

situations and that although every care has been taken for these questions to be asked in a

sensitive manner, they may be upsetting at times. I understand that I do not have to complete

the questionnaire and that I am free to stop at any time, for any reason.

3. I understand that once I have submitted my anonymous responses it will not be possible to

remove them.

4. I understand that my anonymous responses will be added to other participants' responses

and may be published as part of an anonymous dataset and written up as a research report,

which may be published.

5. I consent to Lancaster University keeping the anonymous data from the study for 10 years

after the study has finished.

☐ I agree with the above statements and consent to participate in the current study

Appendix 4

Eligibility

Before you continue, please read and confirm the following statements.

To be eligible to participate in this study you must be 18 years of age and currently experiencing chronic pain (pain lasting 3 months or more).

Please do not complete the survey if you are currently experiencing any short-term pain that is not normally present alongside your usual chronic pain. For example, if a you recently noticed a toothache, but this pain is not part of the chronic pain you normally experience. If this is the case, please do complete the survey on a day when you are not experiencing any short-term pain.

To be able to continue please check each box to confirm you are eligible to participate in this study.

☐ I am 18 years of age or older

☐ I am currently experiencing chronic pain (pain lasting 3 months or more)

☐ I am not currently experiencing any short-term pain alongside my chronic pain

If you are younger than 18 years old or do not experience chronic pain (pain lasting 3 months or more) unfortunately you are not eligible to participate in the current study. Thank you for your interest in this study.

Appendix 5

Debrief

The role of compassion in chronic pain and anxiety, low mood and activities of daily living

Thank you for your time

Thank you for participating in this study. The information you have provided will be pooled with other peoples' responses and written up as a research report.

If you are feeling upset

Should you feel distressed either as a result of taking part, or in the future, please contact your GP for support. In addition, the following resources may be of assistance

The Compassionate Mind organization   Website: http://www.CompassionateMind.org

Mind for better mental health   Website: http://www.mind.org.uk

Pain self-management   Website: https://www.paintoolkit.org/

If you wish to discuss an aspect of the study

Please contact:

John Timney

Lancaster Doctorate in Clinical Psychology,

Lancaster University, Lancaster,

LA1 4YG

Email: j.timney@lancaster.ac.uk

Phone: [insert research mobile number]

If you have a complaint

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith

Email: I.smith@lancaster.ac.uk

Research Director

Doctorate in Clinical Psychology,

Lancaster University, Lancaster

LA1 4YG

If you wish to speak to someone outside of the DClinPsy Doctorate Programme, you may also contact

the Associate Dean for Research:

Professor Roger Pickup Tel: +44 (0)1524 593746

Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

Lancaster University, Lancaster

LA1 4YG

Appendix 6: Outcome measures

The outcome measures in the format shown here are provided here for information and will not be distributed to participants. The final format of the questions and precise nature of the rubric is on the online version can be viewed at:

https://lancasteruni.eu.qualtrics.com/jfe/form/SV_9n0ujOAIUbvr2gR

Demographic information

Age (years)	[free text response]
How long have you experienced your pain (approximately)	[free text response] **Years** [free text response] **Months**
Gender	[free text response]
Country of residence	[free text response]
Ethnicity	[free text response]
Employment status	□ Student □ Employed Full time □ Employed Part time □ Unable to work - receiving disability benefits □ Full time unpaid parent or carer □ Retired □ Unemployed - looking for work □ Unemployed - not looking for work □ Currently on maternity, paternity or adoption leave □ Prefer not to say Other [free text box]
Have you been given a diagnosis for your chronic pain?	□ No Yes: please indicate [free text box]
Partnership status	□ Married □ Civil Partnership □ In a relationship □ In a relationship (co-habiting) □ Widowed □ Single Other [free text box]
Have you previously accessed psychological support from professional psychological services or a pain service related to your chronic pain?	□ No □ Yes

Brief Pain Inventory – Short form

3. Please rate your pain by marking the box beside the number that best describes your pain at its `worst` **in the last 24 hours.**

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
No   Pain As Bad As
Pain   You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its `least` **in the last 24 hours.**

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
No   Pain As Bad As
Pain   You Can Imagine

5. Please rate your pain by marking the box beside the number that best describes your pain on the `average.`

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
No   Pain As Bad As
Pain   You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have `right now.`

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
No   Pain As Bad As
Pain   You Can Imagine

9. Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

B. Mood

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

C. Walking ability

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

D. Normal Work (includes both work outside the home and housework)

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

E. Relations with other people

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

F. Sleep

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

G. Enjoyment of life

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10
Does Not   Completely
Interfere   Interferes

The Stigma Scale for Chronic Illness 8-item version (SSCI-8)

Below you will find a number of statements. Please rate how true the statements are for you by selecting the most accurate rating." Response options next to each item: (1) Never, (2) Rarely, (3) Sometimes, (4) Often, (5) Always

1. Because of my illness, some people seemed uncomfortable with me

2. Because of my illness, some people avoided me

3. Because of my illness, I felt left out of things

4. Because of my illness, people were unkind to me

5. Because of my illness, people avoided looking at me

6. I felt embarrassed about my illness

7. I felt embarrassed because of my physical limitations

8. Some people acted as though it was my fault I have this illness

Fear of compassion

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FEARS OF COMPASSION SCALE

Different people have different views of compassion and kindness. While some people believe that it is important to show compassion and kindness in all situations and contexts, others believe we should be more cautious and can worry about showing it too much to ourselves and to others. We are interested in your thoughts and beliefs in regard to kindness and compassion in three areas of your life:

1.   Expressing compassion for others
2.   Responding to compassion from others
3.   Expressing kindness and compassion towards yourself

Below are a series of statements that we would like you to think carefully about and then circle the number that best describes how each statement fits you.

SCALE

Please use this scale to rate the extent that you agree with each statement

Don't agree at   0   1   2   3   4   Completely
all   agree
                                Somewhat
                                  agree

Scale 1: Expressing compassion for others

1.   People will take advantage of me if they see me as too compassionate   0   1   2   3   4

2.   Being compassionate towards people who have done bad things is   0   1   2   3   4
      letting them off the hook

3.   There are some people in life who don't deserve compassion   0   1   2   3   4

4.   I fear that being too compassionate makes people an easy target   0   1   2   3   4

5.   People will take advantage of you if you are too forgiving and   0   1   2   3   4
      compassionate

6.   I worry that if I am compassionate, vulnerable people can be drawn to   0   1   2   3   4
      me and drain my emotional resources

7.   People need to help themselves rather than waiting for others to help   0   1   2   3   4
      them

8.   I fear that if I am compassionate, some people will become too   0   1   2   3   4
      dependent upon me

9.   Being too compassionate makes people soft and easy to take   0   1   2   3   4
      advantage of

10. For some people, I think discipline and proper punishments are more   0   1   2   3   4
      helpful than being compassionate to them

1

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Scale 2: Responding to the expression of compassion from others

1. Wanting others to be kind to oneself is a weakness   0 1 2 3 4

2. I fear that when I need people to be kind and understanding they won't be   0 1 2 3 4

3. I'm fearful of becoming dependent on the care from others because they might not always be available or willing to give it   0 1 2 3 4

4. I often wonder whether displays of warmth and kindness from others are genuine   0 1 2 3 4

5. Feelings of kindness from others are somehow frightening   0 1 2 3 4

6. When people are kind and compassionate towards me I feel anxious or embarrassed   0 1 2 3 4

7. If people are friendly and kind I worry they will find out something bad about me that will change their mind   0 1 2 3 4

8. I worry that people are only kind and compassionate if they want something from me   0 1 2 3 4

9. When people are kind and compassionate towards me I feel empty and sad   0 1 2 3 4

10. If people are kind I feel they are getting too close   0 1 2 3 4

11. Even though other people are kind to me, I have rarely felt warmth from my relationships with others   0 1 2 3 4

12. I try to keep my distance from others even if I know they are kind   0 1 2 3 4

13. If I think someone is being kind and caring towards me, I 'put up a barrier'   0 1 2 3 4

2

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Scale 3: Expressing kindness and compassion towards yourself

1. I feel that I don't deserve to be kind and forgiving to myself — 0 1 2 3 4

2. If I really think about being kind and gentle with myself it makes me sad — 0 1 2 3 4

3. Getting on in life is about being tough rather than compassionate — 0 1 2 3 4

4. I would rather not know what being 'kind and compassionate to myself' feels like — 0 1 2 3 4

5. When I try and feel kind and warm to myself I just feel kind of empty — 0 1 2 3 4

6. I fear that if I start to feel compassion and warmth for myself, I will feel overcome with a sense of loss/grief — 0 1 2 3 4

7. I fear that if I become kinder and less self-critical to myself then my standards will drop — 0 1 2 3 4

8. I fear that if I am more self compassionate I will become a weak person — 0 1 2 3 4

9. I have never felt compassion for myself, so I would not know where to begin to develop these feelings — 0 1 2 3 4

10. I worry that if I start to develop compassion for myself I will become dependent on it — 0 1 2 3 4

11. I fear that if I become too compassionate to myself I will lose my self-criticism and my flaws will show — 0 1 2 3 4

12. I fear that if I develop compassion for myself, I will become someone I do not want to be — 0 1 2 3 4

13. I fear that if I become too compassionate to myself others will reject me — 0 1 2 3 4

14. I find it easier to be critical towards myself rather than compassionate — 0 1 2 3 4

15. I fear that if I am too compassionate towards myself, bad things will happen — 0 1 2 3 4

3

Pain Anxiety Symptom Scale Short Form 20

Please rate each item in terms of frequency, from 0 (Never) to 5 (Always).

Item Numbers	Never					Always
1. I can't think straight when in pain	0	1	2	3	4	5
2. During painful episodes it is difficult for me to think of anything besides the pain	0	1	2	3	4	5
3. When I hurt I think about pain constantly	0	1	2	3	4	5
4. I find it hard to concentrate when I hurt	0	1	2	3	4	5
5. I worry when I am in pain	0	1	2	3	4	5
6. I go immediately to bed when I feel severe pain	0	1	2	3	4	5
7. I will stop any activity as soon as I sense pain coming on	0	1	2	3	4	5
8. As soon as pain comes on I take medication to reduce it	0	1	2	3	4	5
9. I avoid important activities when I hurt	0	1	2	3	4	5
10. I try to avoid activities that cause pain	0	1	2	3	4	5
11. I think that if my pain gets too severe it will never decrease	0	1	2	3	4	5
12. When I feel pain I am afraid that something terrible will happen	0	1	2	3	4	5
13. When I feel pain I think I might be seriously ill	0	1	2	3	4	5
14. Pain sensations are terrifying	0	1	2	3	4	5
15. When pain comes on strong I think that I might become paralyzed or more disabled	0	1	2	3	4	5
16. I begin trembling when engaged in activity that increases pain	0	1	2	3	4	5
17. Pain seems to cause my heart to pound or race	0	1	2	3	4	5
18. When I sense pain I feel dizzy or faint	0	1	2	3	4	5
19. Pain makes me nauseous	0	1	2	3	4	5
20. I find it difficult to calm my body down after periods of pain	0	1	2	3	4	5

Total Score _____

DASS21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0   Did not apply to me at all
1   Applied to me to some degree, or some of the time
2   Applied to me to a considerable degree or a good part of time
3   Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3