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Abstracts

Systematic Review of the Literature (SRL)

Title: Mental Defeat in Chronic Pain: A Systematic Review of the Concept

Objectives: Mental defeat is a form of self-catastrophising that has been theorised as a possible psychological response to living with chronic pain. This review aims to provide a narrative synthesis of existing quantitative research on mental defeat among those living with chronic forms of pain in order to explore the evidence of its relationships and associations.

Methods: A systematic review was conducted based on PRISMA guidelines. Searches were performed across six databases (CINAHL, EMBASE, MEDLINE, PsychINFO, PubMED, Scopus) for articles containing mental defeat within populations with a chronic form of pain. Two independent reviewers screened articles and performed a quality assessment of the included articles. Results were narratively synthesised using Synthesis without Meta-Analyses (SWIM) reporting guidelines.

Results: Twelve articles were included in the review with eleven meeting criteria for good scientific evidence on the quality appraisal. Results showed that levels of mental defeat were consistently elevated in those with chronic pain when compared to acute pain or pain-free controls. Relationships between mental defeat and constructs within pain related, cognitive, behavioural, psychological and treatment domains demonstrated medium to large associations with mental defeat.

Discussion: Mental defeat is strongly associated with the experience of chronic pain. Theorised associations such as the links between pain intensity, pain catastrophising, adverse psychological outcomes and links to suicide have been demonstrated in the literature. Future research into the cognitive or affective processing associated with mental defeat are required to explore its mechanisms and interactions with self and identity.

Key words: chronic pain; mental defeat; systematic review; catastrophising; psychological.

Service Improvement Project (SIP)

Title: Perspectives on using the Service User Network (SUN): A qualitative framework analysis of service user and staff experiences

Purpose: The Service User Network (SUN) Team in Berkshire Healthcare NHS Foundation Trust wanted to improve their service through gaining feedback and perspectives from service users and staff. SUN is designed to provide an open access community support group based on the principles of a Therapeutic Community for those who may struggle with interpersonal difficulties or emotional dysregulation associated with personality disorders.

Methodology: A review of collected quantitative service data and qualitative focus groups and interviews with service users (*n*=11) and staff (*n*=4) was undertaken. Haigh's (2013) theoretical principles of a therapeutic community was used as the basis for a framework analysis approach. Service user attendance profiles were analysed to understand differential aspects of themes and sub-themes in order to make improvement recommendations.

Findings: Review of service data found that over the 32 months since the service inception, 598 referrals had been made and 52% of those referred had attended at least one group. Framework analysis identified various areas for improvement across the five thematic areas of *Attachment*, *Containment*, *Communication*, *Involvement,* and *Agency*.

Originality: The framework analysis identified service user and staff perspectives on key aspects of the SUN service which contributed to the service and community. A number of aspects were identified to act as barriers to engagement for some users.

Practical Implications: Recommendations for the service have been made based on findings and in relation to the stated service aims.

Key words: Therapeutic Community; Service User Network; SUN; Personality Disorder; Framework analysis; Qualitative.

Theoretically Driven Research Project (TDRP)

Title: The impact of health anxiety after curative treatment for prostate cancer: Quality of life, fear of cancer recurrence, cognitive maintenance processes and mental defeat.

Objectives: This study aimed to determine the association between health anxiety (HA) and quality of life (QoL) among individuals who had been diagnosed with and received a successful curative treatment for prostate cancer (PC). It also aimed to determine whether HA was linked to theorised cognitive biases and appraisals.

Design: A cross-sectional between subjects design with three criterion groups; PC survivors with high levels of HA and low levels of HA were compared alongside a healthy benchmark group of men aged 50-85 with no prior cancer diagnosis and below clinical thresholds of HA.

Methods: A mixed model ANCOVA was run to determine whether there were significant main effects of group and subscale measure of QoL and an interaction effect after controlling for age as a covariate. One way-ANOVAs were used to compare group differences on mean scores of demographic and descriptive variables and other dependent variables; fear of cancer recurrence; mental defeat; dysfunctional health cognitions; responsibility beliefs. A hierarchical regression was used to analyse potential predictors of QoL.

Results: PC Survivors with high HA reported significantly lower levels of QoL than PC survivors who had lower levels of HA across all subscales. There were also significantly higher levels of fears of cancer recurrence, mental defeat, inflated responsibility beliefs and dysfunctional health cognitions among those with high-HA. HA and mental defeat were the only significant predictors of QoL in regression model which also included age, prostate cancer side effect symptoms and fear of cancer recurrence.

Conclusions: HA may provide a more nuanced interpretation of the psychological impacts of being treated for PC and is associated with impaired QoL and theorised cognitive biases and beliefs.

Keywords: Health Anxiety; Prostate Cancer; Quality of Life; Fear of Cancer Recurrence; Mental Defeat

Systematic Review of the Literature

Mental Defeat in Chronic Pain: A Systematic Review of the Concept

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Abstract

Objectives: Mental defeat is a form of self-catastrophising that has been theorised as a possible psychological response to living with chronic pain. This review aims to provide a narrative synthesis of existing quantitative research on mental defeat among those living with chronic forms of pain in order to explore the evidence of its relationships and associations.

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Discussion: Mental defeat is strongly associated with the experience of chronic pain. Theorised associations such as the links between pain intensity, pain catastrophising, adverse psychological outcomes and links to suicide have been demonstrated in the literature. Future research into the cognitive or affective processing associated with mental defeat are required to explore its mechanisms and interactions with self and identity.

Key words: chronic pain; mental defeat; systematic review; catastrophising; psychological.

Introduction

It is estimated that around 20% of the global population experience at least one form of pain and that 10% are diagnosed with a chronic form of pain each year.[1,2] Calculating prevalence estimates for chronic pain is complicated by difficulties in standardising both its definition and in how it should be measured in empirical studies.[3] The most widely accepted definition of chronic pain is pain that occurs on most days for three months or more.[4] Pain can be experienced for a number of reasons such as tissue damage following an injury (nociceptive pain), sensations associated with issues with the nervous system such as neurodegenerative, autoimmune or inflammatory diseases (neuropathic pain), or alterations which impact pain processing and modulation in the absence of tissue or nerve damage (nociplastic pain).[5] Acute physical pain that persists beyond an expected healing period to become chronic may be better understood as a form of disease which is maintained by an interplay of biological, psychological and social factors.[5] Such factors can influence the way an individual experiences chronic pain and impact upon its duration, intensity and impacts.[6] While chronic pain can be experienced by anyone, those who are older, of lower socioeconomic status or female tend to report higher rates of chronic pain.[7] Those living with chronic pain have been demonstrated to have a range of adverse physical, social and psychological problems. Work attendance, productivity, physical functioning, quality of life, social engagement and reliance on medical services and medications are just a few of the impacts of living with chronic pain.[7,8]

The psychological correlates of living with chronic pain include experiencing heightened levels of anxiety and depression, impaired emotional functioning and reductions in self-esteem.[8] These psychological issues may be caused by experiencing chronic forms of pain, or may be associated with the catastrophic interpretations of somatic pain resulting in such individuals being more likely to report and seek treatment.[9] Other factors likely to be involved in the maintenance of pain problems include the coping styles that an individual employs

either in response to the pain experienced or to manage their psychological responses.[10] Pain catastrophising, acceptance and self-efficacy have also been identified as important variables which influence the impact of pain on mental wellbeing.[8,10,11] Other studies have demonstrated that people who live with chronic pain are more likely to have experienced trauma, injury, a history of abuse or experiencing interpersonal violence.[7] It may be that the longstanding psychological impacts of experiencing a history of abuse or violence interacts with the etiology and interpretation of chronic pain to increase psychological distress.

Many of the psychological implications of experiencing pain have been linked to the concept of catastrophising where the immediate appraisal of experiencing pain is believed to be extremely and globally catastrophic for the individual.[12] Pain catastrophising is a disproportionally negative interpretation of pain that occurs during a pain experience or about an anticipated pain experience which serves to exaggerate the threat appraisal associated with pain symptoms.[13,14] Empirical research has consistently demonstrated that pain catastrophising is an important psychological factor in the experience of pain leading to pain being rated as more intense and to cause increased emotional distress.[15] One of the theoretical explanations to understand pain catastrophising has included understanding it as activating a cognitive schema that is linked to emotional functioning which increases the likelihood of cognitive and emotional biases in the processing of pain.[13] Similar to this, Tang et al., (2007) introduced the concept of mental defeat to understand a particular cognitive and emotional response to experiences of chronic pain which represents a catastrophising in terms of social functioning, identity, agency or status due to pain.[17]

The concept of mental defeat was originally introduced in the study of depression and was linked to social defeat in the social rank theory of depression. Here, it was conceptualised as a psychological and physiological response to a situation involving entrapment which demonstrated strong associations with depressive symptoms.[18,19] The concept was also applied to the formation and maintenance of symptoms of Post-Traumatic Stress Disorder

(PTSD) where it was demonstrated to be associated with chronic PTSD symptoms.[20] This was in the context of people who had experienced a form of entrapment torture and was therefore linked to situations where individuals felt hopeless and completely out of control and was defined as 'the perceived loss of all autonomy, a state of giving up in one's own mind all efforts to retain one's identity as a human being with a will of one's own'.[21] In both depression and PTSD, mental defeat can be conceptualised as catastrophising at the level of social and personal identity.

Tang et al., (2007) suggested that there may be similarities between the impact of persistent and repeated episodes of pain in the absence of any ability to control it and the experience of degrading, painful and humiliating torture.[17] Their 'initial exploration of the concept' of mental defeat in chronic pain followed from qualitative research which identified individual's reactions to chronic pain as a sense of 'mental defeat' where pain was an 'enemy' encroaching on autonomy and personal integrity.[17(p222)] When applied to chronic pain, mental defeat was defined as 'a disabling type of "self-processing" where repeated episodes of persistent and debilitating pain trigger negative beliefs about the self in relation to pain'.[17(p222)] The authors suggest that based on the cognitive behavioural conceptualisation of emotional disorders that 'the activation of negative beliefs about the self in relation to pain enhances information processing bias and interferes with coping'.[17(p222)] They hypothesize that the 'pain patient with a strong sense of mental defeat would experience loss of autonomy and give up efforts to retain identity and agency'.[17(p222)]

These authors noted that mental defeat was seen as related to moment-to-moment pain catastrophising in that it is 'focused not on the experience and meaning of pain per se, but rather catastrophising focused on the effects of pain as an assault on the person's life and sense of identity'.[17(p222)] It is suggested that mental defeat is 'likely to be both triggered by catastrophising and contribute to it in terms of negative beliefs about the way fundamental elements of the person's basic humanity have been eroded or destroyed'.[17(p223)] As a

concept, they suggest that the utility of mental defeat is that it offers the ability to analyse the impacts of chronic pain with a focus on self and identity.[17(p223)]

Theoretically, the original authors suggested that mental defeat can be incorporated into cognitive-behavioural theories of chronic pain which use appraisal based interpretations of the meaning of pain.[17] They suggest that it parallels with the pain-self enmeshment theory, which links pain, self and schemas to account for the cognitive biases and emotional distress evident in some individuals with chronic pain.[17] In this initial paper, the authors also developed, validated and assessed the reliability of a measure of mental defeat in chronic pain, the Pain Self Perception Scale (PSPS). This scale was adapted from measures of mental defeat in PTSD and depression populations. The clinical relevance of understanding mental defeat in those with chronic pain is that Cognitive Behavioural Therapy (CBT) has shown to be effective in reducing cognitions associated with mental defeat in a number of different psychological disorders.[22,23]

Since this original paper, there have been a number of studies which have measured mental defeat in populations with chronic pain alongside other pain related, cognitive, behavioural and psychological variables. There has been no known attempt to synthesize these findings to determine what we know about this cognitive phenomenon in populations with chronic pain, and its links with other psychological, cognitive, or behavioural responses. The present systematic review aims to provide a detailed narrative synthesis of the concept of mental defeat as it has been studied in populations who live with chronic pain. It aims to understand what demographic, cognitive, behavioural or other psychological variables have demonstrated empirical relationships with mental defeat in populations living with pain/ chronic pain. It also aims to appraise the quality of evidence and identify any gaps in the literature surrounding mental defeat among those with chronic pain.

Methods

A systematic review of the literature on mental defeat within chronic pain populations was performed according to the Preferred Reporting for Systematic Review and Meta-Analyses (PRISMA) guidelines for systematic reviews and Synthesis without Meta-Analyses (SWiM) reporting guideline.[24] A protocol was registered on PROSPERO (CRD42024475148) in January 2024. A narrative synthesis of the available research on mental defeat within populations with pain was conducted because after initial scoping searches it appeared that many papers would be observational studies and there would likely be high levels of heterogeneity between study samples with different types of pain, pain durations and severity and demographic differences.

Searches were performed across six databases (CINAHL, EMBASE, MEDLINE, PsychINFO, PubMED, Scopus) in May 2024. The search included full free-text articles, published materials, subjects and fields relevant to pain and chronic pain. Search terms included "Defeat (within 3 words of mental or feeling or sense of)" and "Pain" or "Chronic Pain" (see Appendix A.3 for full search terms used).

Procedure

All searches were retained and duplicate articles screened out. Forward and backward citation searching was performed on identified studies. The titles and abstracts of remaining articles were screened by two independent researchers (GM & HR) and excluded if they met any of the following exclusion criteria: 1) Not written in English; 2) Having no quantitative analysis (theoretical or comment paper only); 3) Animal study only (non-human participants); 4) Studies of populations aged under 18 (only or not having adult population clearly identified); 5) Qualitative papers; 6) Does not include a measure of defeat or mental defeat; 7) Does not include participants with pain/ chronic pain (no measure of pain included or participants not seeking treatment for pain management or pain is not the primary presenting

problem for treatment); 8) The study was irrelevant to the population or mental defeat. Cohen's Kappa between the two-raters was 0.95 for titles and abstracts. Remaining papers that were not excluded at title and abstract screen were screened in full by the same two researchers. Any differences were discussed and a third independent researcher (PS) was used to settle any disagreements. The criteria upon which searched items were excluded is presented in Figure 1.1 but were the same criteria used at the abstract and title stage. Kappa for full text screening between the two researchers was rated as 0.87. One study over which the raters differed was discussed with all researchers and agreement was reached to exclude as the sample did not include those with pain or chronic pain.[25]

Data extraction and organisation of studies

Data was extracted from papers meeting eligibility criteria using a protocol created before the search. This allowed for information about the study design, population, measures, statistical tests, results and conclusions to be extracted. Results were organised based on the associations with mental defeat which included demographic, pain-related, cognitive, behavioural, psychological and treatment domains.

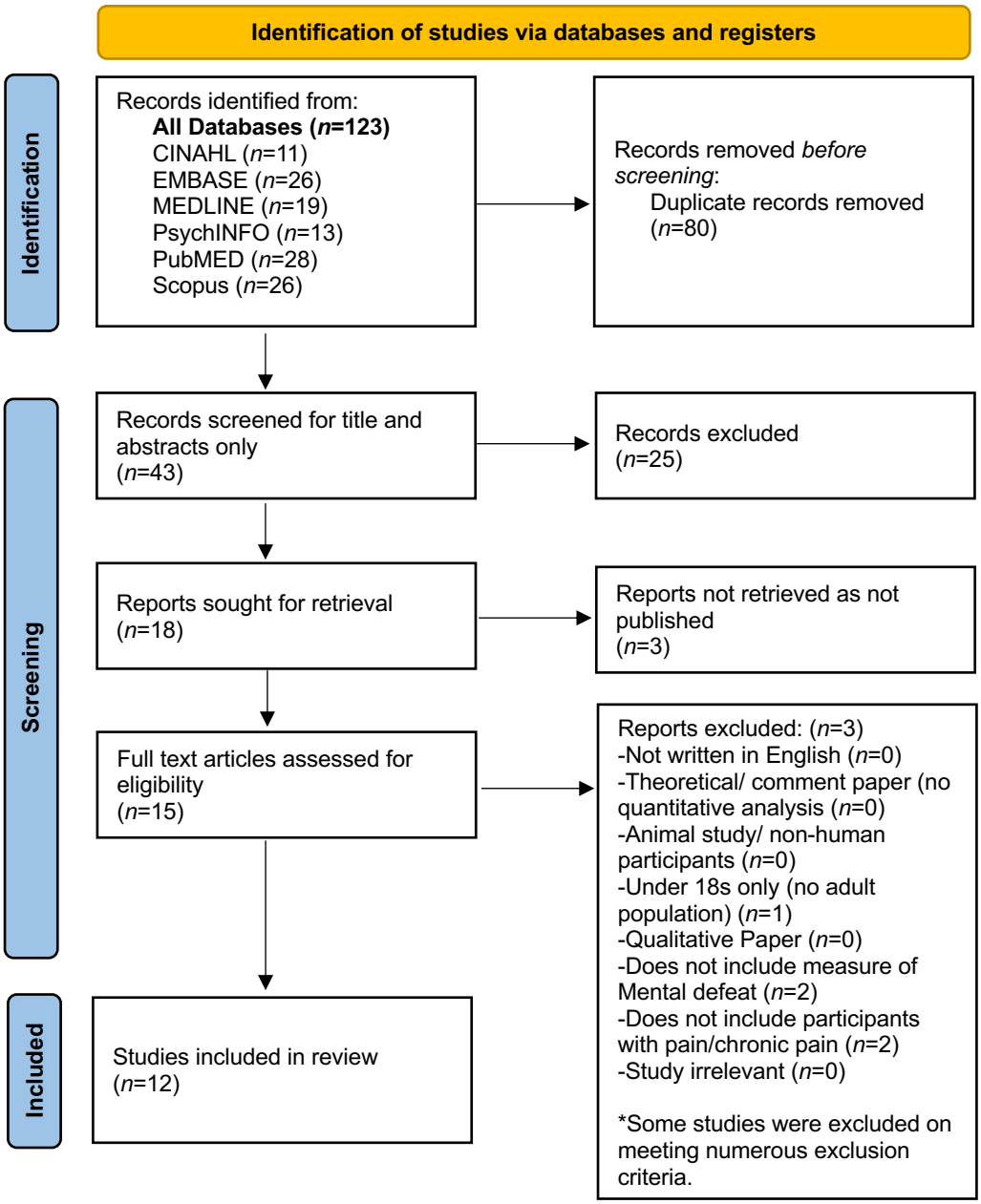
When grouping studies for synthesis, the following considerations were taken into account. As eleven of twelve included papers were observational studies, the primary grouping criteria used was the study population and chronic pain definition, demographic information as well as mean scores on mental defeat. Secondary grouping criteria was based on outcomes (cognitive, behavioural, pain, psychological, treatment) and demonstrated effect sizes of associations with mental defeat. The quality appraisal scores were also used to determine summary presentation of results. Data were extracted and presented based on the statistical analyses used in included study papers. Cohen's *F* and *t* statistics were extracted for analysis which compared group differences. Effect sizes were included for partial eta squared (η_p^2), Pearson's correlation coefficients (*r*), Cohen's *d* and Cohen's f^2. Standardised Beta coefficients were extracted for regression analyses where mental defeat was used as

an independent variable and R^2 values where it was a dependent variable. Significance (p) values were extracted for all studies and statistical tests.

Quality assessment

The Downs and Black Checklist is a tool that can assess the quality and risk of bias and quality in both experimental and observational studies.[26] The original checklist includes 27 items which are used to assess the quality of non-randomised intervention studies but as only one study identified had an experimental design, items used in the checklist only relevant to assessing intervention studies were removed and the remaining 18 items were used to assess the observational studies in this review (see Appendix A.4 for a list of the included and excluded items). The item measuring study power was adapted for this review and rated as 0 for no power calculation and 1 for a power calculation instead of 1-5. The total available score was 28 for the experimental study design and 19 for observational studies. Studies scoring over 50% were considered of good scientific evidence based on criteria set by checklist authors and used in other systematic reviews of observational studies.[26–30] Two raters reviewed 33% of included papers and kappa was rated at 0.88, which meant that one reviewer completed the quality appraisal.

Figure 1.1 – PRISMA flow diagram for the selection of studies



Results

The systematic search identified a total of 123 papers from the six searched databases (Figure 1.1). After removal of duplicates 43 papers were screened for titles and abstracts. Twenty-five were excluded at this stage for not meeting eligibility criteria. Eighteen full text papers were screened and a further six were excluded at this point for not meeting eligibility criteria of publication, not including samples with chronic pain or not including a measure of mental defeat, leaving twelve papers in the final review. Eleven of the twelve studies which

were included for data extraction were observational studies with cross-sectional designs with only one study having an experimental design. Following data extraction, studies were quality assessed using the Downs and Black Checklist with the first reviewer (GM) reviewing all papers and the second reviewer (HR) reviewing 33%. Ten of the eleven observational studies were rated as being of good scientific evidence with scores above 50% on the checklist (scores of 10 or more), with one study not meeting this threshold. The only experimental study included was also rated of good scientific evidence with a score of 20 from a possible 28 meeting the 50% criteria. The quality assessment total scores can be found in Tables 1.1 and 1.2 below. As the findings were generally consistent across studies with 11 of 12 studies meeting criteria for good scientific evidence, in the text that follows there is no further reference to quality aside from a reference to the paper that fell short of quality standards.

Mental defeat in Chronic Pain samples and associations with demographic variables

Nine papers measured the levels of mental defeat in chronic pain samples[16,31–38] with one paper having a sample of those in pain[39] and two recruiting a sample who had Fibromyalgia.[40,41] All studies measured mental defeat using the Pain Self-Perception Scale (PSPS). Details of all included studies are found in Table 1.1 and all synthesized relationships, associations and effect sizes are included in Appendix A.2.

Table 1.1 – Details of included studies

Author	Design	Pain Type/ definition	Number (total)	Analysis Groups (N)	Mean PSPS Score (SD)	Quality Score (D&B)	Measure of mental defeat	Variables with associations to MD
Izquierdo-Alventosa et al., 2024	Experimental design; Randomized clinical trial	Fibromyalgia patients with diagnosis	33	Pre intervention (*n*=17) group	53.47 (24.99)	20†	PSPS	Treatment - Hyperbaric Oxygen Therapy treatment (8 weeks, 5 sessions per week)
				Post intervention group (*n*=17)	35.47 (23.62)			
				Pre (*n*=16) control group	45.31 (25.38)			
				Post control group (*n*=16)	50.44 (24.72)			
Ayache et al., 2021	Observational; cross-sectional design	Recruited from social media for those with chronic pain. No specific definition for inclusion criteria for pain.	1577	Chronic pain patients. Nondisrupted cluster (Low PTG, Low PTD)	31.72	13	PSPS	Posttraumatic Growth and Depreciation
				Chronic pain patients. Growing Cluster (High PTG; Low PTD)	44.64			
				Chronic pain patients. Ambivalent Cluster (High PTG, High PTD)	60.31			
				Chronic pain patients. Distressed cluster (Low PTG, High PTD)	69.41			
Cheatle et al., 2023	Observational; cross-sectional design	Chronic non-cancer pain for at least 6 months (without substance use disorder) before undertaking Long Term Opioid Therapy	609	No/Lower Risk of suicidal behaviour (n=499)	29.1 (26.3)	14	PSPS	Suicidal Behaviours Pain Catastrophising
				Higher Risk of suicidal behaviour - (n=110)	58.8 (28.4)			
Garcia-Campayo et al., 2010	Observational; cross-sectional design	Fibromyalgia patients with diagnosis	250	All Fibromyalgia patients	33.4 (26.7)	14	PSPS (Spanish Translation)	Fibromyalgia (Global function) Depression Anxiety Pain Pain Catastrophising Demographics
Hazeldine-Baker et al., 2018	Observational; cross-sectional design	Chronic pain patients reporting pain for 6 months or more	59	All chronic pain patients	44.2 (28.2)	14	PSPS	Pain Level/ intensity Pain self-efficacy Sensory Pain Affective Pain
Philips, 2015	Observational; cross-sectional design	Pain (no definition) among participants seeking treatment for pain at a rehabilitation centre.	44			8	PSPS	The likelihood of Cognitive Bias associated with pain images
Tang et al., 2016	Observational; cross-sectional design	Chronic non-malignant pain for 6 months or more	57	All chronic pain	33.4 (24.9)	14	PSPS	Pain Duration Pain Self-Efficacy Pain Intensity Pain Catastrophising Hopelessness Anxiety Depression Suicidal Ideation
Tang et al., 2010	Observational; cross-sectional design	Pain for 6 months or more	133	All with Chronic pain		11	PSPS	Pain interference Sleep interference Anxiety Depression

								Psychosocial disability Functional disability
Tang et al., 2007	Observational; cross-sectional design	Chronic pain patients reporting chronic pain for 6 months or more. Acute pain patients who reported pain for less than 6 months.	304	Chronic Pain Patients (*n*=94)	36.2 (28.9)	15	PSPS	Sensory Pain Affective Pain Pain Intensity Anxiety Depression
				Acute Pain Patients (*n*=38)	14.6 (17.4)			
				Pain Free Volunteers (*n*=79)	7.2 (9.3)			
				Acute Pain Volunteers (*n*=30)	6.9 (9.2)			
				Chronic Pain Volunteers (*n*=32)	16.7 (19.3)			
				Anxious Controls (*n*=31)	13.4 (18.9)			
Tang et al., 2013	Observational; cross-sectional design	Chronic pain group - persistent (non-cancerous) pain for 6 months or more. Acute pain group – reporting pain for less than 3 months and no history of Chronic pain.	107	Chronic pain patients (n=43)	49 (25.9)	15	PSPS	Pain interference Pain Duration Pain Severity Anxiety Depression Demographics
				Chronic pain volunteers (n=41)	33.1 (28.9)			
				Acute Pain Volunteers (n=23)	17.5 (19.3)			
Themelis et al., 2023	Observational; cross-sectional design	Chronic non-cancer pain for at least 3 months and on a stable treatment regimen.	524	All	35.53 (25.01)	10	PSPS	Suicidal Behaviour
				Chronic pain volunteers who reported low/no risk of suicide intent (n=319)	28.01 (21.40)			
				Chronic pain volunteers who reported higher risk of suicide intent (n=202)	47.49 (25.71)			
Turner-Cobb et al., 2015	Observational; cross-sectional design	Chronic pain patients reporting chronic pain for 6 months or more.	127	chronic musculoskeletal pain patients (n=64)	46.38 (26.35)	13	PSPS	Functional Disability
				pain free control group (*n*=63)	9.37 (9.04)			

†Quality assessment using full 27 item Downs & Black Checklist (see Appendix A.4) max score=28
PSPS – Pain Self Perception Scale; PTG – Post Traumatic Growth; PTD – Post Traumatic Depreciation; SD – Standard Deviation; MD – Mental defeat

Table 1.2 – Quality Appraisal and Risk of Bias ratings using Downs & Black Checklist

Observational Studies

Author	Reporting Score (Max=8)	External validity score (max=3)	Internal Validity – Bias Score (Max=3)	Internal Validity confounding (selection bias) score (Max=4)	Power Score (Max=1)	TOTAL Score (max=19)
Tang et al., 2007	8	2	3	1	1	15
Tang, 2013	8	2	3	2	0	15
Cheatle et al., 2023	8	1	3	1	1	14
Garcia-Campayo et al., 2010	8	2	3	1	0	14
Hazeldine-Baker et al., 2018	8	1	3	1	1	14
Tang et al., 2016	6	3	3	2	0	14
Ayache et al., 2021	7	0	3	2	1	13
Turner-Cobb et al., 2015	7	2	3	1	0	13
Tang et al., 2010	7	1	3	0	0	11
Themelis et al., 2023	7	0	3	0	0	10
Philips, 2015	5	0	3	0	0	8
Experimental Studies	**Reporting Score (Max 11)**	**External validity score (max=3)**	**Internal Validity - Bias Score (Max=7)**	**Internal Validity confounding (selection bias) score (Max=6)**	**Power Score (Max=1)**	**TOTAL Score (max=28)**
Izquierdo-Alventosa et al., 2024	8	1	6	4	1	20

The reviewed studies included a number of categories of individuals who had pain/ chronic pain. This included individuals who were seeking treatment for chronic pain such as attending sessions at a specialist pain clinic, pain management or rehabilitation centres. Mean scores for those who were identified as seeking treatment for chronic pain ranged from 33.4 to 49 on the PSPS in studies by Tang et al., (2007, 2013, 2016), Turner-Cobb et al., (2015), Garcia-Campayo et al., (2010), Izquierdo-Alventosa et al., (2024) and Hazeldine-Baker et al., (2018).[14,32,33,36,38,39,40] Three studies recruited groups of chronic pain volunteers (individuals living in the community who were not seeking treatment for chronic pain but who had reported elevated levels of pain in questionnaires) with mean scores being 33.1 and 35.5 in studies by Tang et al., (2013) and Themelis et al., (2023).[34,37] The chronic pain volunteers in the third study by Tang et al., (2007) registered a lower mean score with 16.7.[17] Mean PSPS scores for groups of pain free volunteers were identified in two studies by Tang et al., (2007) and Turner-Cobb et al., (2015) and were 7.2 and 9.37.[16,38] One study by Tang et al., (2007) used a control group of people with anxiety who had a mean PSPS score of 13.4.[16]

Three studies analysed whether there were significant differences between groups of different types or levels of pain and mean scores of mental defeat. Tang et al., (2007) found significant differences across 5 groups on mental defeat scores – chronic pain patients demonstrated higher levels of mental defeat compared to chronic pain volunteers, acute pain patients, acute pain volunteers and anxious controls ($F_{(5,298)}$=22.29, p<0.001).[17] A 2013 study by Tang et al., replicated this and found significant differences between group means of chronic pain patients, chronic pain volunteers and acute pain volunteers ($F_{(2,102)}$=11.24, p<0.001).[34] Turner-Cobb et al., (2015) also tested differences on mental defeat scores between a group with chronic pain patients and a pain free control group ($F_{(1,125)}$=111.34, p<0.001) finding significant differences with a large effect size, which explained 47% of the variance between groups.[38]

One study analysed the relationships between demographic variables and mental defeat within a chronic pain sample. There were no significant correlations between mental defeat and age, body mass index (BMI), sex, marital status or employment.[34] A significant positive medium size correlation was identified between mental defeat and those with higher educational attainment (r=0.34, p<0.001).[34] In a sample of Fibromyalgia patients there were no significant associations between gender, age, marital status, education or work status.[40]

Mental defeat and associations with pain

Seven studies analysed the relationships between mental defeat and different aspects of experiencing pain finding medium effect sizes with pain intensity/ severity, pain interference and sensory pain and with large effect sizes to affective pain. In three studies by Hazeldine-Baker et al., (2018) and Tang et al., (2007, 2018) mental defeat had medium sized positive correlations with measures of pain levels, intensity or severity among chronic pain patients (r=0.41-0.53, p<0.001).[16,34,42] In one study, Tang et al., (2016) found that measures of present pain intensity were not significantly correlated with mental defeat (r=0.25, p<0.10).[35] In a study with Fibromyalgia patients by García-Campayo et al., mental defeat was significantly

correlated with pain intensity/ levels at a medium size (r=0.42, p<0.001).[40] One study conducted a stepwise regression to predict pain levels but found that mental defeat was not a significant predictor when entered alongside age, anxiety, depression, hopelessness, and pain catastrophising.[42]

Two studies included analysis of the relationship between pain interference and mental defeat in chronic pain patients.[34,36] In both, pain interference was significantly associated with mental defeat with medium positive correlations (r=0.44-0.65, p<0.001). Tang et al., (2010) found that mental defeat was the strongest predictor of pain interference when entered into a linear regression along with catastophizing, pain intensity, health anxiety, rumination and worry in a model which predicted 26% (Adjusted R^2=0.26, p<0.08).[43] In a stepwise regression model, mental defeat was a significant independent predictor of pain interference alongside pain intensity and catastrophising ($F_{(3,129)}$=25.2, p<0.001). Together these accounted for 37% of the variance in pain interference of which mental defeat contributed 26%, pain intensity 9%, and catastrophising 2%.[36] Tang et al., (2013) used a hierarchical linear regression to test the independent impact of mental defeat above the effect of pain and a person's functioning on pain interference.[34] Education and pain severity were entered first as these had demonstrated significant correlations with pain interference. When mental defeat was added the model predicted 47% of the variance (R^2=0.47) with an R^2 Change of 0.16 above education and pain severity with mental defeat contributing a standardised B of 0.49 (F change=23.01, p<0.001). Finally, pain interference scores were significantly different between chronic pain groups with high and low levels of mental defeat with a large effect size (d=0.88, p<0.001).[36]

Mental defeat was linked to the intensity of both sensory pain and affective pain in the same two studies.[16,42] In both studies, sensory pain among those living with chronic pain had medium size positive correlations with mental defeat (r=0.38–0.40, p<0.001). However, a stepwise regression analysis found that mental defeat was not a significant predictor of

sensory pain when entered alongside age, anxiety, depression, hopelessness, and pain catastrophising. Pain catastrophising was the only significant predictor to this model which accounted for 16% of the variance of sensory pain.[42] Affective pain had large positive correlations with mental defeat in two studies with chronic pain patients (r=0.53–0.62, p<0.001).[16,42] A stepwise regression analysis demonstrated that mental defeat was the only significant predictor of affective pain when entered alongside age, anxiety, depression, hopelessness, and pain catastrophising in a model which accounted for 39% of the variance of affective pain.[42]

Finally, one paper analysed the relationship between global functioning in Fibromyalgia and mental defeat in a sample of Fibromyalgia patients.[40] A significant medium size positive correlation was found(r=0.41, p<0.001). Three studies investigated the relationship between pain duration and mental defeat in chronic pain or fibromyalgia samples.[34,35,40] There were no significant associations found in any of these studies.

Mental defeat and associations with cognitive processing

Five studies analysed the relationships between mental defeat and cognitive processes finding large associations with pain catastrophizing and post-traumatic growth and depreciation.[31,35,39,40] This included two studies which analysed the relationships between mental defeat and pain catastrophising. Mental defeat had a significant large positive correlation with pain catastrophising in a sample of chronic pain patients in a study by Tang et al., (2016) (r=0.67, p<0.01).[35] In a sample of Fibromyalgia patients by Garcia-Campayo et al., (2010), the correlation was a medium size (r=0.40, p<0.01).[40] In a study by Tang et al., (2010) which analysed the relationships between a range of pain related by-products such as pain interference, sleep interference, anxiety, depression, functional disability and psychosocial disability, mental defeat and catastrophising were selected into a number of models as significant predictors.[43] This led the authors to conclude that mental defeat and catastrophising are related but separate constructs.

Mental defeat also demonstrated large effect sizes between group means of 4 groups of chronic pain participants who were segregated on scores of post-traumatic growth (PTG) and post-traumatic depreciation (PTD) in a study by Ayache et al., (2022).[31] Those who had lower levels of PTD had lower PSPS mean scores.

The likelihood of cognitive bias associated with pain images had a medium size positive correlation with mental defeat (r=0.327, p<0.01) in a sample of pain patients with physical disabilities, however this study by Philips (2015) was the only study of the eleven reviewed which fell below criteria for meeting good scientific evidence on the quality appraisal.[39] Mental defeat was not significantly correlated with hopelessness appraisals in chronic pain patients (r=0.07, not significant).[35]

Mental defeat and associations with behavioural responses

Six studies included an analysis of mental defeat with behaviours or behavioural responses or impacts of living with chronic pain.[32,35–38,42] These included links between mental defeat and suicide with medium to large effect sizes, sleep interference, pain self-efficacy and functional disability with medium effect sizes and psychosocial disability with large effect sizes.

The links between chronic pain, experiences of mental defeat and suicidal intent, risks, or behaviours were explored in three of these studies. One study analysed the relationships between mental defeat and worst ever suicide attempt and found a medium positive correlation among chronic pain patients (r=0.45, p<0.001).[35] The same study analysed the relationship between mental defeat and present suicidal intent with those who rated themselves as suicidal (n=22) but did not find a significant correlation (r=0.13, not significant). The same study used mental defeat as an independent variable to determine whether it was a significant predictor of worst ever suicide intent in a hierarchical multiple

regression. Mental defeat was demonstrated to be a significant predictor of worst-ever suicide intent in two regression models. In total, alongside pain intensity, anxiety, depression and pain catastrophising, mental defeat explained 24% of the variance of worst ever suicide attempt (R^2=0.24, p<0.05).[35] In the final model, only pain intensity and mental defeat were significant predictors as anxiety, depression and pain catastrophising only added a combined 1% of variance. Mental defeat was a better predictor of worst ever suicidality than depression, anxiety and pain catastrophising both individually and alongside these predictors.

Two other studies analysed the relationship between mental defeat and suicidal behaviours using mental defeat as an independent variable to determine the predictors of suicidal behaviour thresholds among chronic pain patients.[32,37] In a univariate logistic regression, mental defeat significantly increased the odds of reporting higher suicidality scores (CI: 1.02–1.05, p<0.001) in a sample of 609 chronic pain patients.[32] Similarly, Themelis et al., conducted a similar analysis and found that elevated mental defeat scores increased the odds of reporting higher suicidality scores (CI: 1.035–1.045, p<0.001).[37] In multivariate models, mental defeat was also found to be a significant contributor to increasing the odds of reporting higher suicidality scores on the SBQ-R, alongside pain catastrophising, lifetime major depression and Opiod Use Disorder (OUD) (OR=1.02, 95% CI: 1.01–1.03, p<0.001).[32] Similarly, Themelis et al., found that mental defeat was a significant contributor to increasing the odds of someone scoring higher suicidality scores alongside depression, perceived stress, head pain and smoking status (95% CI: 1.00–1.04, p=0.37).[37]

Cheatle et al., conducted a ROC curve analysis to determine threshold levels of mental defeat and pain catastrophising which predicted scores of 8 or more on SBQ-R[32]. They found that a PSPS score of 40 provided a sensitivity value of 0.69 and a specificity value of 0.70 with an acceptable ability to predict participant SBQ-R scores of 8 or over, with the area under the curve (AUC) of 0.77 (95% CI: 0.72–0.82, p<0.001). In a similar analysis by

Themelis et al., a mental defeat score of 36.5 demonstrated acceptable ability to predict participants with SBQ-R scores of 8 or more.[37] Here a mental defeat score of 36.5 provided a sensitivity value of 0.707 and a specificity value of 0.307 with the AOC=0.74 (95% CI: 0.688–0.792, p<0.001). The same two studies also compared group means of mental defeat scores while using scores of 8 or more on the suicidal behaviour questionnaire (SBQ-R) as an independent variable to determine groups using a t-test. Cheatle et al., found a large effect size between the mean levels of mental defeat in their sample, (d=1.11, p<0.001).[32] When comparing their sample of chronic pain patients, Themelis et al., also found a large effect size between groups with those with no/ lower risk of suicide having significantly lower mean scores of mental defeat compared to those with higher suicide risk (SBQ>7) (d=-0.84, p<0.001).[37]

Tang et al., (2010) analysed the relationship between chronic pain, mental defeat and sleep interference. In their sample of chronic pain patients sleep interference was positively correlated with mental defeat at a medium effect size (r=0.35, p<0.001).[43] Sleep interference and mental defeat were still significantly positively correlated when pain intensity, age and Body Mass Index were accounted for (r=0.29, p<0.01). The same study used a t-test to determine whether sleep interference mean scores were different in groups of those with high mental defeat scores and those with low mental defeat scores and found a medium effect size (d=0.53, p<0.001). When entered as a predictor into a linear regression model to predict sleep interference among chronic pain patients, mental defeat was a significant predictor alongside catastrophising, pain intensity, health anxiety, rumination and worry accounting for 15% of the variance and 12% when catastrophising was removed (R^2=0.12, p<0.008). In a stepwise regression model, however, mental defeat was not a significant predictor of sleep interference, while both pain intensity and catastrophising accounted for 22% of the variance.

Two studies analysed the relationship between chronic pain, mental defeat and pain self-efficacy. Mental defeat had large negative correlations with pain self-efficacy scores in both Tang et al., (2016) (r=0.52, p<0.001) and Hazeldine-Baker et al., (r=0.69, p<0.001).[35,42] Entered into a stepwise regression to predict pain self-efficacy scores, mental defeat was entered alongside age, anxiety, depression, hopelessness and catastrophising in a stepwise manner and emerged as the only significant predictor (B=-0.69, t(59)=-7.23, p=0.001) explaining 47% of self-efficacy scores (R^2= -0.47, $F_{(1,59)}$=52.26, p=0.001).[35]

Two studies also analysed the relationships between experiences of chronic pain, mental defeat and experiencing functional or psychosocial disability.[36,38] Mental defeat and functional disability were positively correlated with medium effect sizes in two studies by Tang (2010) (r=0.49, p<0.001), and Turner-Cobb (r=0.36, p=0.008).[38,43] After the effects of age, pain intensity and body mass index were accounted for, mental defeat was still significantly correlated with functional disability with a moderate effect size (r=0.41, p<0.001). In a linear regression to predict functional disability, when entered alongside catastrophising, pain intensity, health anxiety, rumination and worry, mental defeat was the second strongest predictor after catastrophising. Without catastrophising, mental defeat with the other mentioned variables accounted for 24% of the variance (R^2=0.24, p<0.008), catastrophising explained an additional 2% of variance.[36] When placed into a stepwise regression model to predict functional disability, mental defeat was not a significant predictor, while pain intensity, catastrophising and rumination tendency were. When comparing mean scores of functional disability between groups with chronic pain and high mental defeat scores and low mental defeat scores, a large effect size was observed (d=0.96, p<0.001).[36]

The relationships between mental defeat and psychosocial disability in those with chronic pain was further explored by Tang et al., (2010).[43] Psychosocial disability was demonstrated to have a large, significant positive correlation with mental defeat (r=0.61, p<0.001).[36] In a linear regression model to predict psychosocial disability, mental defeat was the strongest

predictor in a model predicting 37% of the variance alongside catastrophising, pain intensity, health anxiety, rumination and worry (Adjusted R^2=0.37, p<0.08).[36] In a stepwise regression model, mental defeat was a significant predictor of psychosocial disability alongside catastrophising, rumination tendency and pain intensity ($F_{(4,128)}$=40.2, p<0.001). Together these accounted for 56% of the variance in psychosocial disability. Mental defeat accounted for 37% of the variance, with catastrophising accounting for 2%, rumination tendency for 8%, and pain intensity for 8%.[36] When comparing mean scores of psychosocial disability between groups with chronic pain and high mental defeat scores and those with chronic pain and low mental defeat scores, a large effect size was observed (d=1.35, p<0.001).[36]

Mental defeat was also linked to treatment seeking behaviours as levels of mental defeat were demonstrated to have significant differences between groups of those with chronic pain who were patients and seeking treatment, and those who had chronic pain but were community volunteers and not seeking treatment ($t_{(52)}$=2.20, p<0.032).[16]

Mental defeat and associations with psychological outcomes

Mental defeat demonstrated large associations with psychological and mood variables of anxiety and depression. Five studies incorporated analysis of the relationship between levels of anxiety in those living with chronic pain and experiences of mental defeat. Each of these associations demonstrated large significant positive correlations (r=0.60-0.65, p<0.001).[17,34,35,43] The relationship between anxiety and mental defeat was similar in a population of Fibromyalgia patients (r=0.57, p<0.001).[40]

In a hierarchical linear regression to predict levels of anxiety in those with chronic pain, pain severity and mental defeat were significant predictors of anxiety predicting 38% of the variance.[34] Here, pain severity accounted for 14% of the variance with mental defeat adding 25% of the variance. In a linear regression to predict anxiety scores in a chronic pain population, mental defeat emerged as the 2nd strongest predictor behind catastrophising,

alongside pain intensity, health anxiety, rumination and worry, in a model that predicted 39% of the variance.[36] In a stepwise regression mental defeat was a significant predictor of anxiety alongside catastrophising, worry tendency, health anxiety ($F_{(4,128)}$=37.7, p<0.001). Together these accounted for 54% of the variance in anxiety. Mental defeat accounted for 2% of the variance, with catastrophising accounting for 39%, worry tendency for 10%, health anxiety for 4%.[36]

The same five studies also included measures of depressive symptoms in those with chronic pain and examined the relationship with experiences of mental defeat. All associations between depression and mental defeat in chronic pain samples were large with significant positive correlations (r=0.61–0.66, p<0.001).[16,34–36]

In a hierarchical linear regression to predict levels of depression in those with chronic pain, mental defeat and pain severity with employment status accounted for 38% of the variance, with mental defeat adding 26% of unique variance to the other predictors (R^2=0.38, p<0.001).[34] Mental defeat was entered alongside pain catastrophising, pain intensity, health anxiety, rumination and worry to predict depression scores. Mental defeat emerged as the strongest predictor of depression in a model that accounted for 43% of the variance in depression (Adjusted R^2=0.43, p<0.08).[36] In a stepwise regression to predict depression, mental defeat was a significant predictor of depression alongside health anxiety ($F_{(2,130)}$=59.1, p<0.001). Together these factors accounted for 48% of the variance. Mental defeat accounted for 44% of the variance and health anxiety for 4%.[36]

Mental defeat and associations with treatment outcomes

The only paper that analysed mental defeat as a dependent variable in a treatment intervention study among those with chronic pain found that treatment with hyperbaric oxygen therapy (HBOT) significantly reduced mental defeat with a medium effect size.[41] Izquierdo-Alventosa et al., analysed the effects of an intervention for chronic pain which

randomly allocated 33 diagnosed Fibromyalgia patients to either an intervention group receiving an eight week treatment with five sessions per week of a low-pressure HBOT (n=17) or to a control group receiving no therapy (n=16). They found that the group receiving the HBOT significantly reduced in levels of mental defeat with a medium effect size when compared to baseline (d=0.74, p<0.001) while those in the control group had no significant improvements.[41] The intervention also improved self-perceived pain intensity, pain catastrophising, pain acceptance, pain flexibility and quality of life with no improvements in the control group.

Discussion

This systematic review sought to provide a narrative synthesis of mental defeat based on the evidence from research among samples of people living with pain and chronic pain. Twelve papers were included in the final review and quality was assessed as generally high with eleven studies meeting criteria for good scientific evidence. The review found that mental defeat is consistently elevated in those with chronic pain when compared to those who have acute pain or are pain free. Mental defeat was found to be associated with key aspects of experiencing pain such as pain intensity and sensory pain with medium sized associations, and to pain interference and affective pain with large effect sizes. As theorised, mental defeat was associated with pain catastrophising with large effect sizes as well as with other cognitive and affective responses to experiencing pain such as post-traumatic growth and depreciation. There were also medium to large associations between mental defeat and behavioural responses such as suicidal ideation, pain self-efficacy, psychosocial disability and functional disability. Mental defeat was also linked to the psychological measures of anxiety and depression with large associations. There was less evidence to suggest that mental defeat is linked with demographic factors as there was only one study which found a significant association with educational attainment. There was also only one study which analysed the impacts of a form of pain treatment on reducing mental defeat, which

demonstrated that low-pressure hyperbaric oxygen therapy reduced mental defeat with a medium effect size.

In the original theoretical outline of mental defeat in chronic pain, Tang et al., (2007) described the links between mental defeat and catastrophising.[17] These links were confirmed by the findings of this review where pain catastrophising was linked to mental defeat with large effect sizes in samples of those with chronic pain and with medium effect sizes in those with fibromyalgia.[35,40] Pain catastrophising has previously been linked with the levels or severity of pain that an individual experiences.[15,44,45] Similarly, as theorised, in this review mental defeat demonstrated medium sized associations with the rated levels or intensity of pain, illustrating its overlaps with the construct.[16,34,42] However, there are apparent differences between the two constructs as suggested by Tang et al., (2007) based on their observed associations. For example, this review found that mental defeat was more associated with affective pain while catastrophising was linked to sensory pain.[17,42] This means that while pain catastrophising has closer links to the sensory perception of pain which involves the intensity, location and quality of pain, mental defeat had closer links to the affective aspects of experiencing pain which are linked to the emotional unpleasantness of the experience and the motivation to protect oneself from its harm or anticipated return.[46–48] While the sensory dimensions of pain found within the articles in this review were linked to the sharpness, throbbing, stabbing, aching or burning of the pain experience, the affective components measured pain as being fearful, punishing, cruel or sickening or leading to feelings of tiredness or exhaustion.[17,42] This provides evidence towards the differences between pain catastrophising and mental defeat outlined in the original theoretical article which suggested that mental defeat was based ‘not on the experience and meaning of pain per se, but rather catastrophising focussed on the effects of pain as an assault on the person’s life and sense of identity’.[17]

This conception of mental defeat being a specific form of catastrophising at the level of social or personal identity also provides some context to the links between it and pain interference and pain self-efficacy found in this review. It seems understandable that those who experience more interference with engaging in their everyday lives because of pain, or who rate their confidence in coping with activities due to pain would experience elevated levels of mental defeat.[34,36] Experiencing functional disability was linked with mental defeat but the links between psychosocial disability were stronger which highlights the connection between one's social identity being impacted by pain having a greater relationship with mental defeat than functional impairments. Pain catastrophising had stronger links with functional disability highlighting its focus on the sensory perception of pain, rather than impairments to social functioning. The links between the experience of pain and its perceived catastrophic effects on the self and identity also contextualise the link between mental defeat and suicide found in this review. The strong links between mental defeat and suicidal behaviour or ideation may be understood through Williams' Cry of Pain (COP) model of suicide which links entrapment and social defeat to experiencing suicidal ideation.[35,49]

In addition to the above theorised associations with mental defeat among those with chronic pain, this review also summarised a range of other relationships with the concept. As might be expected, it shared consistent associations with alterations in mood associated with anxiety and depression in a number of studies.[17,34,35,43] Mental defeat was demonstrated to be more associated with the symptoms of depression because pain catastrophising emerged as a stronger predictor of the symptoms of anxiety. This was similar to the links to PTG and PTD where traumatic experiences can alter one's assumptions about oneself and the world and have a negative impact on one's beliefs about oneself or the world (depreciation), or they can otherwise foster a sense of resilience and an ability to cope (growth).[50] Here, those with lower PTG and higher levels of PTD reported higher levels of mental defeat.[31] The links with PTD appear to be theoretically consistent with the prolonged feelings of worthlessness, giving up and defeat associated with the PSPS measure.

However, while the findings of this review point to these associations between the experience of pain and its impacts being catastrophic on self or identity, none of the papers included investigated the mechanisms which underpin this process and result in mental defeat. The original theoretical outline of mental defeat suggested that its specific focus of catastrophising on the self and on identity may be linked to the activation of illness schema to account for the specific cognitive biases and emotional distress associated.[17] However, there are no studies which serve to elaborate on this link. Mental defeat in the PTSD literature has been linked to a specific type of cognitive processing during and after a traumatic experience which contribute to the maintenance of a persistent sense of current threat.[51] However, the sense of current threat is maintained not only by cognitive biases and processing where mental defeat is conceptualised to influence appraisals, but also through processing linked to memory storage such as conceptual processing, integration of experience on self into autobiographical memory and dissociative processes.[51] In PTSD, mental defeat has been identified as being linked to dissociative symptoms.[52] It may be possible that dissociative processes which maintain a lack of integration of competing cognitive and affective schemas on one's sense of self and identity interact with the experience of pain which contribute to the catastrophising of self and identity based on affective responses to somatic pain. Dissociative processes have already been linked to pain catastrophising[53] and as a mediating factor in those with chronic pain who experienced childhood betrayal trauma to physical quality of life.[54] Given the overlaps between chronic pain, childhood traumatic experiences and dissociation, it may be that the ways in which threats to the self were experienced in childhood influence the likelihood of appraisals of threat from pain being interpreted as catastrophic to losing one's self or identity. Research into the self-pain enmeshment theory has shown that living with chronic pain can result in one's self-image becoming enmeshed with the very experience of the pain, a process which has been linked with activating the self-schema that impaired psychological adjustment.[55–57] It is clear that chronic pain has an impact on an individual's sense of self[58] and as a recent review by

Themelis and Tang highlights, future research focusing on the impacts of chronic pain on the self may provide innovative opportunities for psychological approaches for pain management.[59]

Limitations and recommendations

This review focused on the reported levels and associations of mental defeat within populations living with pain or chronic pain. Studies that did not include pain participants or those with other physical health problems were therefore excluded from the analysis. The ways in which pain was operationalised in this review was heterogenous as we included studies which included participants with both acute and chronic pain and a range of different types of pain in different locations of the body. While this review includes all the published literature on mental defeat among populations who experience pain or chronic pain published in English, the breadth of types of pain experienced by the populations within this review limit our understanding of the relationship of mental defeat to the nuanced experience of particular types of pain. The review also focused on studies which included mental defeat only, and while this might be regarded as a strength, other similar concepts which may have considerable overlaps with mental defeat were not included in our search.

Eleven of the twelve studies included in this review were observational and cross-sectional in design. Future studies on the role of mental defeat in those with chronic pain may include more experimental designs among those living with pain and those who are not, or longitudinal studies which track the development and changes in mental defeat and other pain, cognitive and behavioural variables over time. Future reviews might focus on mental defeat in other physical health problems or its links to those living with histories of trauma or PTSD. Within chronic pain populations, future studies may seek to further elaborate on the cognitive, affective or schematic processing associated with mental defeat that links this type of catastrophising to aspects of identity. This might include studying associated cognitive or schematic biases, personality or aspects of dissociation which may contribute to mental

defeat.

Conclusion

This review shows that mental defeat is strongly associated with the experience of chronic pain and that individuals with chronic pain are more likely than those with acute or no-pain to have elevated levels of mental defeat. A number of theorised links with mental defeat were present in the existing literature across pain, cognitive, behavioural and psychological domains. Some of the predicted differences between pain catastrophising and mental defeat were demonstrated with some evidence linking mental defeat with constructs associated with self and identity. Further research into the ways in which mental defeat interacts with cognitive processing, particularly surrounding social identity is suggested.

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Service Improvement Project

Perspectives on using the Service User Network (SUN): A qualitative framework analysis of service user and staff experiences

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Abstract

Purpose The Service User Network (SUN) Team in Berkshire Healthcare NHS Foundation Trust wanted to improve their service through gaining feedback and perspectives from service users and staff. SUN is designed to provide an open access community support group based on the principles of a Therapeutic Community for those who may struggle with interpersonal difficulties or emotional dysregulation associated with personality disorders.

Methodology: A review of collected quantitative service data and qualitative focus groups and interviews with service users (*n*=11) and staff (*n*=4) was undertaken. Haigh's (2013) theoretical principles of a therapeutic community was used as the basis for a framework analysis approach. Service user attendance profiles were analysed to understand differential aspects of themes and sub-themes in order to make improvement recommendations.

Findings: Review of service data found that over the 32 months since the service inception, 598 referrals had been made and 52% of those referred had attended at least one group. Framework analysis identified various areas for improvement across the five thematic areas of *Attachment*; *Containment*; *Communication*; *Involvement* and *Agency*.

Originality: The framework analysis identified service user and staff perspectives on key aspects of the SUN service which contributed to the service and community. A number of aspects were identified to act as barriers to engagement for some users.

Practical Implications: Recommendations for the service have been made based on findings and in relation to the stated service aims.

Key words: Therapeutic Community; Service User Network; SUN; Personality Disorder; Framework analysis; Qualitative

Introduction

Personality disorders are common conditions in the community and those who have them often struggle with interpersonal difficulties, emotional dysregulation and are at greater risk of self-harm and suicide (Coid et al., 2006; Pompili et al., 2005; Reichl & Kaess, 2021). In 2003, the National Institute of Mental Health in England identified the systematic failings of statutory services to meet the needs of those with a Personality Disorder Diagnosis and identified that one quarter of Mental Health Trusts provided no service for this patient group (NIMH(E), 2003). It outlined a range of policy strategies to increase support and engagement for those living with a personality disorder, one of which was developing an informal service user network to provide additional support and reduce demands on emergency services.

In response to this, a community based, open-access support group project was piloted in South-West London and St. George's Trust in 2004, funded by the Department of Health with the aim of improving access to services, increasing empowerment, improving coping skills, and reducing the use of emergency services for its service users (Miller et al., 2011). In order to facilitate the replication of the service model, a paper outlining the Service User Network (SUN) model for community based open-access support groups for people with personality disorders and its theoretical underpinnings was outlined by Miller et al., (2011) and named the SUN Project.

Theoretical underpinnings of SUN Model

The SUN model as outlined by Miller et al. (2011) has its theoretical roots in psychodynamic understandings of personality disorders and cognitive theories of change. The model allows users with or without a diagnosed personality disorder to decide whether they use the service and their frequency of attendance. The cognitive theory underpinning the model is Coping Process Theory which is utilized to structure the parts of the group in order to reduce risks to participants, where primary and secondary appraisals of threat are identified and modified to alter coping responses. Its outcomes are to increase coping efficacy and coping

effectiveness. Membership within the therapeutic community is viewed in the model as offering service users an opportunity to engage in 'referencing' within the group by establishing themselves 'within a context specific narrative' in order to feel a sense of self being accurately perceived and establish a self-identity within the community (Miller et al., 2011).

There is only a small evidence base for the efficacy of the SUN model. Miller & Crawford (2010) conducted an interim study into the SUN service in south-west London 16 months after its implementation. They found improvements in self-reported social functioning, reductions in presentations to emergency services and in-patient admissions. Service users were surveyed about their satisfaction with the service including their opinions on the support, inclusion and improvements in coping strategies. The study found that 83% of members returned to the group on at least one occasion and the median attendance number was seven.

Local Context

A number of NHS Trusts have subsequently adopted this service model in order to provide community based support groups for people with personality disorders in their local contexts. The SUN Service in the Intensive Management of Personality Disorders and Clinical Therapies Team (IMPACTT) in Berkshire Healthcare NHS Foundation Trust (BHFT) was established in September 2020 and is based on the theoretical model outlined by Miller et al. (2011). The service currently offers a number of in-person and online groups throughout the week to those living in Berkshire aged over 18 years who have self-referred. The service was initially intended to run 12 groups per week but due to issues surrounding staffing and capacity, the number of groups was operating at a reduced level in 2023. Each group last 2.5 hours and is run by two facilitators who are trained in the SUN model with one of these usually being a lived-experience facilitator. The maximum group size for each session is 10 service users as well as the two facilitators. The content of each group is decided by group

members within the consistent structure of check-in, main forum, and check-out segments. Those who refer to the service can join as many or few groups as they wish based on the timetable offered.

The services operational aims are outlined in the Local Operating Procedure and include the following:

- To provide long-term, on-going, co-produced and peer-led group therapy along the lines of therapeutic community principles via a network of groups throughout the Trust, across all communities.
- Empower and enable individuals to manage crisis situations and access services appropriately.
- Operate a structure focusing on risk and Crisis Support Planning and individual safety plans.
- Enable easy access to “peer” support when people require it with no defined “end point”.
- Promote peer support and reduce isolation.
- Support and empower individuals by learning new coping strategies and sharing experiences with others.
- Offer a safe and contained environment.

Therapeutic Community Approaches

Research which has aimed to determine the effectiveness of such therapeutic communities (TC) for personality disorders includes a randomized control trial conducted by Pearce et al., (2017). Analysis of outcome measures such as number of inpatient admissions and attendances at emergency departments and GPs over a 24 month period found that the democratic TC group did not reduce in-patient services more than the treatment-as-usual group. Given this quantitative attempt to demonstrate their utility did not show clear results, it is possible that any benefits the group may have for members may be found in qualitative evidence. A theoretical model of the efficacy of therapeutic communities outlined by Haigh

(2013) suggests that there are particular aspects of a TC that are necessary in order to facilitate primary and secondary emotional development (Table 2.1). This model is rooted in attachment theory and suggests that the efficacy of a TC necessitates establishing a range of structures which facilitate the emotional development for those who attend.

Table 2.1 – Facets of emotional development within a therapeutic community (Haigh, 2013)

Developmental need	***Origin in***	***Culture***	***Structures***
Attachment	Primary bond, losses as growth	Belonging	Referral, joining, leaving
Containment	Maternal and paternal holding; intersubjectivity	Safety	Support, rules, boundaries
Communication	Play, speech, others as separate	Openness	Groups, ethos, correspondence
Involvement	Finding place amongst others; interdependence	Living-learning	Community meeting agendas
Agency	Establishing self as seat of action; individuation	Empowerment	Votes, decisions, seniority

Aims and Purpose

The service had been running for over two years and the clinical leads of IMPACTT and SUN wanted to gain more insight into service user perspectives on both positive aspects of service delivery and anything that might act as a barrier to use. This project therefore aimed to explore service user experiences of attending SUN groups to ascertain any potential benefits from using the service and barriers to engagement. It also aimed to incorporate staff perspectives on facilitating and delivering groups to gain a wider systemic perspective on whether the service was meeting its stated aims. It aimed to provide the service with a list of practical recommendations to improve its operations.

Methods

Design

Two phases of data collection and analysis were undertaken. First, a review of current service activities within the SUN service was undertaken by an analysis of quantitative service data collected from service inception in September 2020 to April 2023. This was done to contextualise the qualitative data and to uncover any patterns in service provision and

user attendance over time. The second phase involved collecting qualitative data from service users through a focus group and individual in-depth interviews and a focus group of staff members involved in group delivery.

Research team

The lead researcher (GM) co-designed the study, conducted the interviews and lead data analysis. Three clinical psychologists co-designed and supported the project. Members of the SUN leadership team and service users and were consulted on the design and implementation of the study in order to maximise relevance, recruitment and methods to communicate findings.

Ethics

Ethical approval was provided for this service improvement project by the clinical audit team in BHFT (Ref: Local Project 9815). Participants were made aware of the project and provided time to consider their participation. An information sheet was distributed and they were provided a means to ask any additional questions. Each service user who participated provided their informed consent.

Data Analysis

A framework analysis approach was used to identify themes within the collected data. This strategy followed the steps outlined in Goldsmith (2021). Data familiarisation followed by stages of identifying and selecting a theoretical framework to apply to the data, indexing, charting and mapping of coded data followed by interpretation was used to analyse all of the qualitative data. These steps are outlined in detail with examples in Appendix B.6. to B.10. Initially data was transcribed from recordings of interviews and focus groups which allowed for data familiarisation. Qualitative data analysis was undertaken using software to code individual chunks of data. Transcripts of service user data were coded at the most basic meaningful segment to a new or existing code. Facilitator data was analysed following this and where relevant coded to the same codes as well as creating a number of new facilitator

only codes. Once all data was coded, the selected framework was applied to structure interpretation of the codes at theme and sub-theme levels. The theoretical basis for the final selected framework which guided the analysis of qualitative data was Haigh's (2013) principles of the therapeutic community (Table 2.1). Following this indexing stage, the data was charted and mapped using codes by service user/ facilitator profiles to determine patterns in the data.

Procedures

A semi-structured interview and focus group schedule was developed for service users and staff in consultation with users who engaged with the service to check for comprehension and relevance. The lead researcher carried out interviews and a focus group with service users using remote video-call software. A focus group with staff members was carried out in person at a site delivery venue. All qualitative data collection was undertaken in March and April 2023.

Participants

Participants were recruited from the SUN Service in BHFT. The service stores e-mail addresses for all registered users of the service and, upon project inception, it wrote to users asking for their voluntary participation and informed consent to participate in the qualitative elements of the study. Inclusion criteria involved registration to the service. Service users were asked to volunteer information on how regularly, if at all, they used the service, gender identification, age range and ethnicity. A total of thirty service users responded and provided their consent and contact details. The final sample consisted of eleven service users, three attending a focus group and eight in individual interviews. The attendance profile, gender, age and ethnicity of participants is shown in Table 2.2. Four staff members were also involved in a focus group.

Table 2.2 – Sample Characteristics

Staff (total)	4
Lived experience facilitators	2
Professional facilitators	2
Service Users (total)	11
Focus Group	3
Interviews	8
Attendance Profile	
Never used the service - I have been offered the chance to attend a group but I have never done so	3
Lapsed user - I used to attend SUN groups regularly but I have not for the past 6 months	2
Irregular user - I attend groups every couple of months but there can be long intervals between the times I attend	2
Regular user - I attend groups at least monthly or more frequently	4
Gender	
Female	6
Male	4
Non-Binary	1
Age	
18 – 24	2
25 – 29	2
30 – 39	1
40 - 49	3
50 - 59	3
Ethnicity	
White British	10
Arab	1

Findings

The SUN service in BHFT was established in September 2020 and during this time COVID-19 pandemic social restrictions prohibited face-to-face clinical meetings. For the first eighteen months of service delivery, all SUN groups were conducted online. Since March 2022, groups have been offered both online and at in-person delivery venues across BHFT.

Service Activities Data

Analysis of service data revealed the following information about service activities over the twenty-seven months since the SUN service began activities (September 2020 to April 2023). In total, the service had received 598 referrals to the end of April 2023. A total of 316

individual clients attended appointments across the period which is 52% of those referred. There were a total of 3,416 appointments attended across all areas. Since March 2021, the service had consistently been attended by over 25 people per month. The number of unique monthly appointments elevated between August and December 2022, when over 40 individuals attended groups, and the number of individual appointments was higher. Issues with staffing meant that in 2023 there was a reduction in the number of groups being offered per week which at the time of data collection was four instead of ten (Figure 2.1). The data collected demonstrated that 13 staff members were involved in delivering groups to members since service inception. In April 2023, there were currently six SUN facilitators operating group delivery.

Figure 2.1 – SUN Appointments attended and number of individuals attending at least 1 appointment per month (Sep 2020 – April 2023)

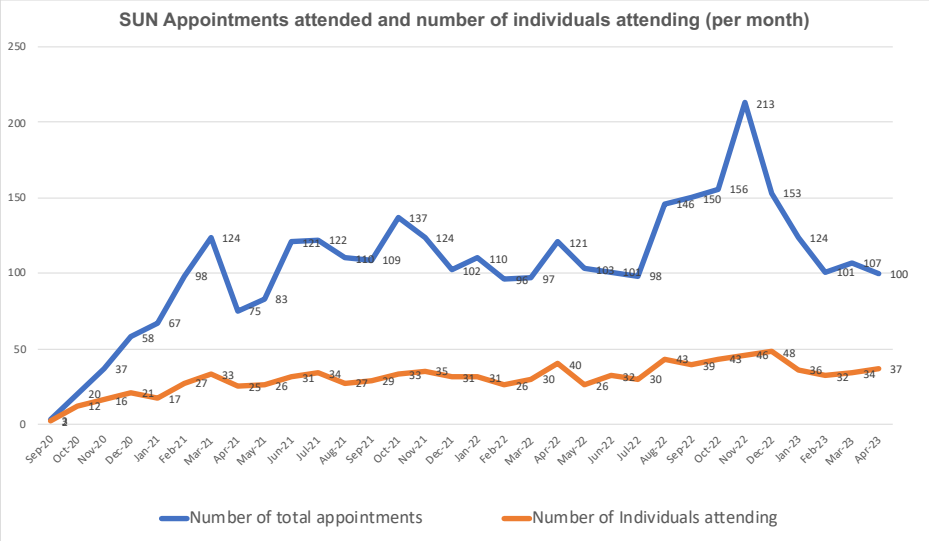

Table 2.3 – Final Thematic Framework adapted from The Five Principles to create emotional development within a therapeutic community (Haigh, 2013)

Theme 1 - Attachment	
The Attachment theme relates to the initial stages of joining the SUN service. Good experiences with attaching to the service lead to a culture of belonging where individuals felt there were able to return to use the service when they needed it. The initial experiences with service communications, expectations and experiences in joining a group are included here. Sub-themes related to aspects of the therapeutic community involved in this theme were *referral* to the service, *joining* the service for the first time, *leaving* the service and *returning* to the service.	
Sub Theme	**Sub-theme description**
Referral	Referral to the service represented service users' first contacts with information about the service. This information was key to shaping perceptions of the service and expectations and goals upon joining.
Joining	Joining the service represented the first step in approaching the SUN community. Service users had to overcome a number of barriers to joining. First experiences in joining were also important to returning to the community. Undertaking Crisis and Support Plans (CASPs) were an important aspect of joining the community.
Leaving	Reasons for leaving the service were an important determinant of service perceptions. These ranged from negative experiences with other service users or facilitators to feeling the environment was not emotionally safe. Leaving (for others) was viewed as temporary and that the service was there if needed.
Returning	Returning was added as a sub-theme as SUN members can attend at any time, and some members had left the service for some time but had chosen to return. Regular members make the decision to return based on a number of factors which encouraged their approaches to the service.
Theme 2 - Containment	
Containment within the therapeutic community relates to the provision of a safe environment which enables users to survive in a world which minimises criticism and rejection. A key component of this theme is the positive and negative experiences of support that members experience within the community. As the service user experiences the community, the development of limits, discipline and rules are important. Other sub-themes therefore relate to the rules and structures that underpin groups and the boundaries that are in place to provide a safe environment. Positive experiences of this theme were more likely to describe a culture of safety within the service.	
Sub Theme	**Sub-theme description**
Rules	Consistent rules surrounding the delivery of the service and the behaviour of other members and facilitators was an important aspect of feeling like there was a safe environment within groups. Having consistent group timetables, structures within groups and the ability to call out unsupportive behaviour was reflected upon by both staff and service users.
Support	Positive support experiences were an important aspect of joining the community. Feeling unsupported by the community was likely to cause disconnection from the service. Finding a role in supporting others was an important aspect of finding identity within the community.
Boundaries	A key component of creating a safe environment was having boundaries that were understood and upheld by both members and facilitators. A range of difficulties in asserting boundaries were identified by both service users and staff.
Theme 3 - Communication	
The Communication theme related to the sharing of problems and ways of understanding experiences within groups in order to find meaning through connection. Communication between members and facilitators and instances of conflict were important components of this theme. Other sub-themes related to how the service communicated with members about group timetables and administrative aspects. The ethos of the community and how it was communicated was an important aspect of how members felt connected to this ethos or felt it reflected their own values and experiences of using the service. This included openness about the service aims and ethos of the community.	
Sub Theme	**Sub-theme description**
Groups	Communication within groups proved an important determining factor in how members engaged with the community. Communication between members and communication between members and facilitators formed an important aspect of joining groups and engaging. How members and facilitators managed and responded to conflict was also an important aspect in community engagement and learning.
Correspondence	Correspondence from the service was an important aspect of how members felt connected to the community when not in a group. Facilitators communicating service ethos and regular updates was an aspect of facilitating connection to the community.
Ethos	Communicating the ethos of the SUN service to both new and existing members emerged as a key theme to ensure that the environment could be both safe and containing. This

	included the perceived service aims and elements which make an ideal group and how to learn from bad experiences.
Theme 4 – Involvement	
Involvement within the therapeutic community continues the developmental sequence through adolescence to adulthood within the context of the therapeutic community. This theme relates to participation within the community, experiences of being seen and connected to others within the culture, and environments provided by the community. Involvement and participation leads to learning and growth as well as experiencing benefits and impacts of attending. If this theme is correctly met, social cohesion creates interdependence and meaningful connection to other members.	
Sub Theme	**Sub-theme description**
Community	The community sub-theme involved service user and staff perceptions of the culture and environments within groups and different experiences with the service. Whether an individual felt connected to others within the community was a key determinant of establishing a group identity.
Participation	This sub-theme includes experiences of participating within groups. This included differential experiences of feeling heard and seen by other group members as well as seeing and supporting other members.
Learning	Learning within groups was linked to service users and staff perspectives on the impacts and benefits of attending groups. Learning was encouraged by facilitators through encouraging involvement and participation within groups.
Interdependence	The ability to have interdependence on the community where service users could come to the group and depend on the support and social opportunities it provided. Interdependence was also linked to helping others to cope within groups.
Theme 5 - Agency	
Agency within the therapeutic community relates to being provided the sense of personal agency within the community in order to establish themselves as the seat of action. This related to taking responsibility both within groups, for the wellbeing of other members and in their own lives. Empowerment over human relationships within the community is created by the ability to manage self and surroundings in groups and make decisions. Community structures which allow this included taking group decisions and votes and members taking responsibility over the wellbeing of others. This leads to a sense of individuation where members form a core identity as part of the group and take on roles of seniority in order to nurture group structures.	
Sub Theme	**Sub-theme description**
Empowerment	The empowerment sub-theme was linked to the impacts or perceived benefits of attending the SUN service. This included learning coping skills and improving one's ability to manage difficult situations. It also incorporated empowering individuals within the community to take on the responsibility of decision making.
Individuation	Achieving individuation was linked to finding one's identity within the context of the group. This was also linked to undertaking roles of individual responsibility as a mark of a members seniority within the community.
Establishing self as seat of action	Taking responsibility for oneself and finding self-agency was linked to taking responsibility inside groups and finding areas where personal responsibility can be exercised outside of groups.

Framework Analysis of Qualitative Data

Five themes were identified in the analysis, alongside a range of sub-themes. The themes and subthemes are outlined below and are based on Haigh's (2013) theoretical framework for the five experiences necessary to create emotional development within a TC. Each theme centres around a developmental need identified by Haigh and subthemes are linked to the culture and structures within the SUN Service. Each of the final five themes and associated sub-themes are described and summarised in Table 2.3. The results below indicate the key findings from the framework analysis with particular reference to aspects of service improvement and differences across service user attendance profiles. Where data did not

obviously fit the framework, additional sub-themes were added. See Appendix B.6. for details of the steps taken in the framework analysis.

Theme 1 – Attachment: a culture of belonging

> "I don't really look at my CASP that much, but the experience of doing it I just thought it was just excellent." – *Regular User*
>
> "There were two new members. So that took up the entire 50 minutes of open forum. I sort of always feel a bit annoyed or frustrated when we've spent a whole group on a CASP and I know that a member is not gonna come back." – *Regular User*

Overall, regular users and some irregular users reported many positive elements of the referral and joining process which facilitated their approach and continued engagement with the SUN Service. Lapsed users were more likely to reflect on negative experiences within groups they attended and cited these as factors for leaving the service and acting as barriers to returning. Upon referral, users who had not yet used the service were largely unaware of what the service was intended for and how it would operate. Barriers to joining a group included not being aware of who the service was for, whether they would fit in or if it could help them, and what joining might entail. There was a lack of clarity among users who had not yet attended a group of the population that the service intended to serve, whether a personality disorder diagnosis or experiencing acute crisis was a requirement, and the types of mental health issues it was designed for.

Undertaking a Crisis and Support Plan (CASP) after joining was seen as a useful experience by service users and staff. Staff referred to the CASP as a working-document that can be updated, but for some irregular users they had not looked at their CASP since they undertook it within a group. Regular users highlighted CASPs for new members can take up considerable time within group sessions. Both staff and regular service users were frustrated by new members who did not return after joining and undertaking a CASP.

Lapsed users cited negative interactions with other members or facilitators to be a key reason why they left the service and did not return. Staff also commented on other staff members leaving and identified team dynamics, relationships with service users, and a lack of career progression opportunities as reasons why others had chosen to leave.

Factors that encouraged returning to the service included experiencing positive support experiences within groups, using the service for social opportunities or as a key part of a weekly routine. The reduction in the number of weekly groups also acted as a barrier to irregular and lapsed members who could not identify a suitable group to join.

Theme 2 – Containment – a culture of safety

> "There's a bit of a structure to the group. However, the way that its structured is varied, with the facilitators, and that was something I struggled with because that's not something that was ever explained to me." – *Lapsed User*
>
> "There are no boundaries." – *Lapsed User*

Positive experiences of containment within the boundaries, structures, and rules of the SUN Service created feelings of support and the ability to offer support to others, which helped to create a culture of safety. Rules that structured groups were more likely to be identified by regular and irregular members who understood the format and length of groups. Lapsed users had less awareness of the structure and felt that facilitators could do more to communicate this and ensure its consistent implementation. The impacts of the recent reduction in group timetables were highlighted across service user and staff groups. This had also impacted the size of groups, with more members attending less frequent groups, which had various impacts on the ability to participate and caused frustration within groups.

Both staff and all types of service users highlighted that there was the risk of unsupportive behaviour within groups from other members and facilitators and this detracted from feeling safe within the environment. Participants identified 'cliquey', 'bullying', 'aggressive' or 'triggering' behaviour which emotionally impacted other service users and staff. Lapsed users

were more likely to comment on the lack of boundaries within groups to call out such behaviour, suggesting that facilitators should do more to enforce boundaries. Staff noted their difficulty in asserting boundaries, suggesting they sometimes felt attacked when they enforced a boundary. Irregular users identified at times not feeling the group was an emotionally safe environment with unsupportive behaviour or members in crisis, which contributed to their perception of groups as sometimes 'volatile' environments.

Theme 3 – Communication – a culture of openness

> "I think definitely the facilitators stepping forward when they can see there's tension and trying to help out with that would be good" – *Regular User*
>
> "I also find it good when there's been a rupture in a group, and then there's a repair." – *Staff Member*

Regular service users were more likely to positively reflect on the communication between members within groups, highlighting the positive social aspects of attending groups. Regular and irregular users identified that other members can give support and speak up on your behalf to ensure that all views are heard. Communicating to help others was viewed as a positive element of attending groups. Facilitators communicating their own supportive responses were also central to positive experiences of support. Lapsed users who had not returned to the service for some time identified a range of factors that impacted on their ability to communicate with other members which had deterred them from returning. Points of frustration in communications included other members being 'strong willed', or having a conflict or bad experience with another member or facilitator. Despite the potential for conflict, staff identified members having and resolving a conflict within a group to be a positive learning experience serving to enhance group communications. All user groups and staff noted that conflict management within groups could be improved. Service users were more likely to look to facilitators to manage and regulate conflicts between members, while staff identified that managing conflict was also the responsibility of the community and that their own attempts to do so could be met with hostility. Regular service users also identified that regulating groups was also their responsibility too and not just that of the facilitators.

Service users identified e-mail as the primary way in which the service itself communicates information to members. Those who had never used the service had mentioned receiving or desiring a phone call or more contact prior to joining their first group in order to better regulate expectations and anxieties. Regular, and irregular users as well as staff were aware of the newsletter and also identified inconvenient late notice cancellations of groups due to recent staff reductions. Regular users were more able to accurately identify service aims, but there was a lack of communication of exactly what the service aims and ethos were and how they were communicated.

Theme 4 – Involvement – a culture of participation and citizenship

> "Generally, the culture is really supportive." – *Regular User*
>
> "My attitude is it's my place to go and, you know, meet my tribe and offload problems. Learn other ways of coping with different situations." – *Regular User*
>
> "I went to group for a reason. And because of not being able to have time to talk. I would have been much better off downstairs with my partner." – *Lapsed User*
>
> "When that member can come back and was told that by the other members your action had this effect on us, it then makes them actually see it from a different perspective." – *Staff Member*

Involvement within the community relied upon feeling that the culture and environments within groups facilitated participation. Regular users identified a range of positive and supportive elements within groups, including being friendly and social environments. All service user groups and staff felt that conflict could be managed better within groups in order to maintain a supportive environment that promoted participation. Feeling connected to others within the community was an important aspect of participation, and finding other people who shared an understanding of similar mental health problems was a positive product of attending. Irregular and regular users were more likely to identify friendship as a factor which encouraged them to use the service. All service user groups identified that groups could be 'cliquey' at times and that relationships with other members could be frustrating.

Positive experiences of participation were linked to feeling heard, seen and supported by the community. Giving support to other members was also considered a positive aspect of participation by regular users. Issues with participation were identified by having too many people within a group, negative experiences with other members or facilitators and in witnessing conflicts or crisis situations which were unresolved.

Learning through participation was linked to the perceived impacts and benefits identified by service users. All user groups identified that attending the service had positive impacts on their life with regular users identifying that it increased their ability to cope through difficult times. Regular users also identified that attending had helped them learn skills, make plans, and manage relationships and conflict better overall. Staff members also identified positive aspects of attending groups, such as providing a sense of routine for members. Lapsed members were less likely to suggest the service had helped them cope better during difficult times, and they felt that its impacts were limited as it was not direct therapy.

Being able to depend on the service and allow others to depend on the group's support to cope was an important aspect of participation. Regular service users and staff identified that one of the positive outcomes of the service was the knowledge that users would not be 'abandoned' by the service at any point. However, staff also noted that some users may become too dependent on attending SUN as a form of ongoing support.

Theme 5 – Agency – a culture of empowerment

> "And if then we're supposed to be encouraged to call out anti social behaviour but when you do, you get pilloried for it." – *Irregular user*
>
> "Then we say, ok who wants to be timekeeper? So somebody takes responsibility for being the timekeeper. And it doesn't become us." – *Staff Member*
>
> "The facilitators are trying to sort of get us to try to resolve our own conflict within the group." – *Irregular user*

Finding personal agency and empowerment was linked to the impacts that members perceived from attending the service. Regular and irregular service users perceived benefits to their ability to cope with difficulties and manage conflicts and relationships. Taking decisions within and as a community is a key component of a culture of empowerment. Staff highlighted that service users are encouraged to facilitate groups and take ownership of their own recovery. Regular service users identified that groups had taken decisions to ban members demonstrating unsupportive behaviour and that it was their responsibility to regulate groups. Irregular users felt that their attempts at calling out unsupportive behaviour was not supported by others.

Finding a sense of identity within the service was identified as a key component of individuation, as users are encouraged to find a sense of identity to be seen and understood within the context of the group. Regular members identified finding identity within the group through seniority and time spent within the community as well as taking on roles and responsibilities within the community. Lapsed users did not report finding any types of identity within the group, illustrating that the developmental needs for this group had not been met to fully achieve aspects of this theme for some users.

Discussion

This project aimed to explore service user and staff perspectives on the Service User Network (SUN) Service in BHFT. The SUN service model was established to provide an innovative and deinstitutionalised approach to helping people with personality disorders develop better ways of coping with crises (S. Miller & Crawford, 2010). The aims of the service in BHFT were to provide on-going community-based support along the lines of TC principles. This project reviewed collected service data and analysed service user and staff perspectives to determine the extent to which they met themes linked to therapeutic community principles. Service improvement recommendations are outlined below.

The review of quantitative data demonstrated that the service had provided a consistent service across BHFT since it began in September 2020. It adapted to the constraints of the COVID-19 pandemic in order to provide online groups. Challenges to retain facilitators and recruit new staff members resulted in reductions in the number of groups offered per week. This impacted the number of appointments offered per month during 2023 and was reflected in the qualitative data.

Framework analysis of the qualitative data utilised the principles for therapeutic communities developed by Haigh (2013). This allowed a framework of five themes to be taken into consideration in determining different aspects of an individual's journey using the SUN service. These themes included experiences of *attachment* to the SUN community and finding a culture of belonging; being *contained* by the community in a culture of safety; *communication* providing a culture of openness; *involvement* and inclusion in a culture of participation and citizenship; and to finding personal *agency* in a culture of empowerment. There were differential experiences of each theme based on the service user attendance profile which was used as a category of analysis in the project.

Regular users were more likely to describe positive experiences in each of the themes and for these users, the SUN community had offered an on going peer-led community based support group which offered support, reduced isolation, improved ability to cope during crisis situations, and provided ongoing opportunities to connect to the community and find an identity of empowering self and others.

However, users who had not yet used the service as well as lapsed users were less likely to have attachment and containment needs met by the service. Neither of these groups had a good understanding of what to expect from joining, or the ethos and structures in place to meet containment needs or encourage continued participation after a bad experience.

Lapsed users identified a range of barriers at the attachment stage and why they had decided to leave the service. They also identified issues with containment and finding a culture of safety within the groups they did attend. The issues identified by service users and staff across each of the themes have been collated in Table 2.4 and recommendations for service improvement have been made.

The findings of this project contribute to wider literature on the efficacy of therapeutic communities for those living with personality disorders. Quantitative research involving analysis of SUN service data from other services and a cross-sectional survey by Miller & Crawford (2010) found that use of the SUN service was associated with improved social functioning, and regular users within this analysis likewise suggested that they had improved social and relational coping. Research conducted by Pearce et al. (2017) on a similar therapeutic community found that self and other directed aggression and satisfaction with care were significantly improved for those who attended the TC. The findings from this qualitative analysis complement our understanding of the processes that underpin service users' engagement with the service and the aspects of the community which promote attachment, containment, and wider engagement with the service as well as those factors which act as barriers to participation and involvement. Similarly, in this study regular service users did report improvement in conflict management and had a positive regard for the support offered within SUN.

Table 2.4 – Summary of Service Improvement Recommendations for SUN Service

Recommendations to improve *Attachment* and promote *a culture of belonging*	
Issues identified	**Recommendations for improvement**
Reductions in the numbers of groups being offered meant that members found it hard to attend available groups. At the time of the project, only four groups per week were conducted due to staffing issues.	Provide strategy to improve recruitment of staff to resolve facilitator capacity for operating groups.
Users who had not yet used the service identified barriers to engagement including confusion over who the service was targeted at (whether for people with personality disorder diagnosis or for other mental health problems), whether it was for people in high levels of distress or crisis only, or what joining would involve. Only 52% of those referred attended a group at the service.	Provide additional literature to prospective members post-referral to communicate: • Who the service is for and the populations of people the SUN community involves. • What joining a group will entail and what to expect. • What joining means in terms of participating such as undertaking CASP and engaging in community. • The structure and ethos of the SUN Service.
New members often do not return after their first session.	Encourage new members to return by providing increased communications following attendance at first group. Provide overview of structure and ethos to empower members to participate.
CASPs were identified to take up a lot of time within groups. This was especially the case if there was more than one new member involved in a group.	Provide CASP to members upon referral and request to consider prior to first group. Place time boundaries around CASP discussions when there is more than one new member.
Limitations of the CASP were identified as having not been used or referred to since first joining the service.	Encourage members to take responsibility for their CASP but to have regular check-ins and to add for learning.
Recommendations to improve *Containment* and promote *a culture of safety*	
Issues identified	**Recommendations for improvement**
Structure of group can vary with facilitators, and it was perceived that there were no structures or rules by some members.	Communicate service ethos, group structure and relevant information on therapeutic communities and SUN model to service users after attending first group. Communicate the potential for conflict within groups and individual reflections on how to manage conflicts.
Some groups were identified to have 'no boundaries' in relation to admitting members, regulating conflict between members or the behaviour of other members when in crisis was not called out as unsupportive.	Encourage senior service users to diffuse conflict and address unsupportive behaviour. Consider integrating democratic ways of communicating and signalling unsupportive behaviour between members and facilitators. Facilitators to address and encourage reflection on challenging episodes or instances of unsupportive behaviour.
More consistency among facilitators when making decisions and calling out unsupportive behaviour.	Improve rules within group and how these are communicated with members both at service level and within individual groups. Facilitators to encourage other members to call out unsupportive behaviour. Facilitators to be active in calling out unsupportive behaviour themselves.
Recommendations to improve *Communication* and promote *a culture of openness*	
Issues identified	**Recommendations for improvement**
Users who had not yet attended groups were unsure what joining would entail and who the groups were for.	Increase communications available to prospective users of the service (see above).
While some understood the ethos of the service and were able to attempt to embody these, other members felt that there was no consistent ethos.	Consider communications of key service ethos at regular intervals. Alterations can be discussed in sessions among members and changes agreed between members and facilitators.
Issues with groups being cancelled at short notice and not replaced.	Communicate cancellations in advance. During periods of reduced groups consider asking members for ideal group times to ensure those who wish to attend can.
Lapsed members not sure of when groups are on or how to attend.	Send out targeted communication to users who have not attended and remind of timetable and service activities. Encourage members

	who have not attended to return to share positive learning experiences in order to promote a sense of community.
Recommendations to improve *Involvement* and promote *a culture of learning*	
Issues identified	**Recommendations for improvement**
Users attend for a short period of time and then do not return.	Encourage users to return to group when not in crisis in order to share experiences and learning with others in order to promote learning and community. Encourage users to return to reflect on bad experiences within groups in order to promote learning.
Groups can be overcrowded and it can be difficult for everyone to feel involved or have time for everyone to be involved.	Facilitators to ensure groups are structured and that every participant can contribute to main forum. Increase number of weekly groups to ensure available groups are not over attended.
Recommendations to improve *Agency* and promote *a culture of empowerment*	
Issues identified	**Recommendations for improvement**
When faced with other members in conflict or crisis moments, members were likely to want facilitators to uphold boundaries of behaviour. Facilitators feeling like they are expected to manage crisis situations in groups.	Encourage members to learn from conflict within groups. Encourage senior members to regulate conflicts or facilitate discussions about how the conflict might be managed in future groups. Facilitators to enact service ethos in setting examples.
Members who may not attend regularly or have lapsed did not identify a group identity or demonstrate taking on a senior role within community.	Encourage members to take on seniority and increased responsibilities as they attend more groups. Promote finding identity within the community as a key component of service ethos.

Strengths and Limitations

This project had the full cooperation of the SUN Service within BHFT and provided access to collected service data from the inception of the service in September 2020 to the time of the analysis in April 2023. Qualitative data therefore represents experiences of the service at a specific period when the service was faced with a reduction in facilitators due to staff leaving and being unable to recruit which had impacted the numbers of groups being offered per week.

All referred individuals who had contact details stored and could be contacted were invited to participate in the project. However, while over 500 people were invited to register to participate, only 30 people enrolled in the project. The sample size is small and therefore limited in scope and not representative. Those who did take part are likely to have an increased bias to recall aspects of the groups that they most recently attended.

The framework analysis that was applied allowed data to be structured and interpreted using the pre-existing theoretical model outlined by Haigh (2013). However, while this is helpful in

assessing the efficacy of the TC to meet emotional development needs, it limits the ability to generate new theoretical insights and may provide an oversimplified interpretation.

Conclusions

This is one of the first qualitative studies to explore perspectives on the therapeutic community offered by a SUN Service. It incorporates the perspectives of quantitative service data, service users of different user status, and staff delivering SUN groups to determine ways in which this therapeutic community might be improved. The SUN Service was analysed through the thematic lens of the five principles of emotional development within a therapeutic community identified by Haigh (2013). Recommendations were made to improve attachment and belonging, containment and safety, communication and openness, involvement and participation, and agency and empowerment.

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Theoretically Driven Research Paper

The impact of health anxiety after curative treatment for prostate cancer: Quality of life, fear of cancer recurrence, cognitive maintenance processes and mental defeat.

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Abstract

Objectives: This study aimed to determine the associations between health anxiety (HA), quality of life (QoL) and theorised cognitive biases and appraisals among individuals who had been diagnosed with and received a successful curative treatment for prostate cancer (PC).

Design: A cross-sectional between subjects design with three criterion groups; PC survivors with high levels of HA and low levels of HA were compared alongside a healthy benchmark group of men aged 50-85 with no prior cancer diagnosis and below clinical thresholds of HA.

Methods: A mixed model ANCOVA was run to determine whether there were significant main effects of group and subscale measure of QoL and an interaction effect after controlling for age as a covariate. One way-ANOVAs were used to compare group differences on mean scores of demographic and descriptive variables and other dependent variables; fear of cancer recurrence; mental defeat; dysfunctional health cognitions; responsibility beliefs. A hierarchical regression was used to analyse potential predictors of QoL.

Results: PC Survivors with high HA reported significantly lower levels of QoL than PC survivors who had lower levels of HA across all subscales. There were also significantly higher levels of fears of cancer recurrence, mental defeat, inflated responsibility beliefs and dysfunctional health cognitions among those with high-HA. HA and mental defeat were the only significant predictors of QoL in regression model which also included age, prostate cancer side effect symptoms and fear of cancer recurrence.

Conclusions: HA may provide a more nuanced interpretation of the psychological impacts of being treated for PC and is associated with impaired QoL and theorised cognitive biases and beliefs.

Keywords: Health Anxiety; Prostate Cancer; Quality of Life; Fear of Cancer Recurrence; Mental Defeat

Introduction

Receiving a cancer diagnosis has been found to be associated with the increased likelihood that an individual will experience ongoing negative psychological impacts (Armes et al., 2009; Harrison et al., 2009). While many can adjust well to life after diagnosis and treatment for cancer, there is evidence that some individuals experience psychological distress and impaired quality of life (QoL), meaning that psychological difficulties may become an issue alongside physical problems post-treatment (Boyes et al., 2012). Typically, this has been evaluated in terms of the prevalence rates of broad psychiatric diagnoses such as anxiety and depression being elevated in those surviving cancer (Boyes et al., 2011; Kessler et al., 2005; Niedzwiedz et al., 2019). In order to improve psychological wellbeing and QoL for the large numbers of people surviving cancer, it is important that we develop a nuanced understanding of the ways in which psychological processes operate to produce prolonged psychological distress and reduced QoL in this population. This study seeks to understand the role that health anxiety (HA) may play in impacting QoL for those living after curative treatment for prostate cancer.

Prostate cancer and treatments

Each year in the UK over 52,000 people are diagnosed with Prostate Cancer (PC) and there are over 410,000 men in England living after a PC diagnosis with prevalence rates predicted to further increase (Public Health England, 2021; Smittenaar et al., 2016). The routine use of screening tests and increased public awareness mean that increasing numbers of men are being diagnosed with localised PC, where tumor development is confined to the prostate gland. Diagnosed at this stage, individuals are provided a number of different treatment options with the aim of removing cancer from the body. Options for direct treatment of localised PC include surgery to remove the prostate (prostatectomy), brachytherapy and radiotherapy based treatments. These treatments provide an excellent prognosis, and 10-year survival rates are high (Office for National Statistics (ONS), 2019). However, such

treatments often come with a range of physical side effects, such as sexual dysfunction, urinary incontinence, urinary obstruction and irritation, bowel related symptoms, pain and fatigue. Living with these side effects has been likened to living with a chronic disease and is linked to impaired QoL (Lardas et al., 2017; Doyle-Lindrud, 2007; Fosså & Dahl, 2015).

Prostate cancer, psychological distress and QoL

Being diagnosed with and undergoing treatment for PC has been linked with experiencing psychological distress which has typically been measured by experiencing symptoms of anxiety and depression (Couper et al., 2010; De Sousa et al., 2012; Sharp et al., 2016; Watts et al., 2014). Having increased levels of anxiety after treatment has been linked to having lower QoL (Chien et al., 2019; Punnen et al., 2013). However, while PC patients are at more risk of anxiety and depression than men of a similar age, not all PC patients experience such negative psychological side effects. A number of factors such as stage of diagnosis, treatment types and age have been demonstrated to impact levels of anxiety and depression (Downing et al., 2019; Odeo & Degu, 2020). While the long-term physical side effects of PC treatments are well understood, the underlying impact that it has on QoL from a psychological perspective is not well understood (Binks et al., 2021). Limiting our understanding of the psychological mechanisms that are associated with PC diagnosis and treatment to categorical psychiatric diagnoses such as anxiety and depression may not be the best way to understand the complex reactions to the development of this potentially life-threatening condition. It is likely that a range of psychological processes like health anxiety, fear of cancer recurrence (FCR) or mental defeat may mediate the ways in which people respond to recovery from PC, and the associated impacts on physical functioning.

Health Anxiety

Health anxiety (HA) involves a preoccupation or excessive fear stemming from a belief that one has a serious illness in the absence of adequate evidence (Warwick & Salkovskis, 1990). The cognitive behavioural model proposes that HA may be triggered by the

misinterpretion of ambiguous stimuli linked to a feared illness (Salkovskis, 1996). HA is thus characterised by exaggerated threat interpretations focused on one's present and future health (Rachman, 2012). Enduring beliefs about health interact with health-relevant information to produce a sense of enduring threat (Salkovskis & Warwick, 1986; Warwick & Salkovskis, 1990). Those vulnerable to HA are hypothesised to have lowered thresholds for making threat-related (mis)interpretations and misattributions. The resulting anxiety can cause a range of behavioural, attentional, affective and physiological responses which serve to maintain threat appraisals such as increased monitoring for bodily variations, emotional and situational avoidance, excessive reassurance-seeking and dysfunctional cognitions about health (Halldorsson & Salkovskis, 2017, 2023; Salkovskis et al., 2003).

HA processes have been identified in anxious patients with physical health problems such as those with cardiac problems who make catastrophic somatic attributions for bodily sensations which are congruent to their underlying condition (e.g. interpretating a raised heart rate as a sign of a heart attack) (Ratcliffe et al., 2006). It has also been identified as a mediating process in patients with chronic conditions such as Multiple Sclerosis (MS), where HA was associated with reduced QoL, and to be elevated in those who have had a successful cancer treatment (Carrigan et al., 2018; Hayter et al., 2016; Jones et al., 2014). It may then be the case that HA interacts with the chronic physical symptoms associated with PC in order to maintain a sense of threat from their treated cancer serving to increase psychological distress, reduce QoL and increase the perception that their cancer may recur.

Catastrophising can also manifest as MD where the focus is on the way in which physical problems adversely impact on an individual's social identity and status. MD has been linked to increased psychological distress in those living with chronic health conditions such as chronic pain (Hazeldine-Baker et al., 2018; Tang et al., 2007, 2010). It is characterised as self-catastrophising that is linked to negative thoughts and beliefs surrounding a loss of the one's identity, agency, autonomy and self-concept in relation to social role (Tang et al.,

2007). It has also been studied in those who have survived other cancer types where it has been identified as a significant predictor of psychological distress (Košir et al., 2020).

Other psychological factors implicated in impaired QoL

Responsibility beliefs: A response linked to threat interpretations is having inflated beliefs of responsibility to prevent harm (Gustavsson et al., 2021; Gústavsson et al., 2022; Salkovskis, 1985). Inflated appraisals of responsibility to prevent harm have been demonstrated to be a key concept in the maintenance of Obsessive Compulsive Disorder (OCD) (Salkovskis, 1985). Links to HA have been empirically observed in research which has shown the associations between responsibility beliefs and clinical HA and the symptoms of generalised anxiety disorder (Avard & Garratt-Reed, 2021; Melli et al., 2014).

Fear of cancer recurrence (FCR) is conceptualised here as a highly specific form of HA. FCR is common in those living post-treatment for cancer and has also been related to HA in cancer patients (Grassi et al., 2004; Jones et al., 2012, 2014; Stark et al., 2002). FCR is the fear or worry that the disease will return or progress in the same organ or in another part of the body (Lebel et al., 2016). While normal levels of FCR can promote adequate threat-monitoring behaviour, high levels of FCR could be regarded as a problematic type of misinterpretation linked to HA (Maheu et al., 2021). FCR has been found to be associated with increased reassurance-seeking behaviours, impaired QoL and psychological distress (Koch et al., 2014; Thewes et al., 2018). It has been estimated that a third of PC survivors experience elevated FCR, and it has been identified as the most common unmet cancer need after treatment, linked with lower QoL and increased symptom burden (James et al., 2022; van de Wal et al., 2016).

Aims

The aim of the present study is to examine the psychological factors associated with impaired QoL in those who have received curative treatment for their PC. PC survivors with relatively low levels of HA will be compared with those with high levels of HA and benchmarked against a group of men of a similar age with no cancer history and subclinical HA. It is predicted that elevated HA will be associated with reduced QoL and increased levels of FCR and mental defeat.

Hypotheses

- The High-HA group will have significantly lower mean scores on measures of QoL, higher scores of FCR and mental defeat relative to Low-HA and healthy benchmark groups.
- The High-HA group will have significantly higher mean scores on measures of dysfunctional health cognitions and inflated responsibility beliefs relative to Low-HA and benchmark groups.

Method

Design

A quantitative cross-sectional between-subjects design was used where participants were allocated into three groups based on whether they had received a PC diagnosis and their scores on the Health Anxiety Inventory (HAI).

- Group 1: Individuals who have completed curative treatment for PC with high levels of HA (High-HA).
- Group 2: Individuals who have completed curative treatment for PC with low levels of HA (Low-HA).
- Group 3: A healthy benchmark group of men aged between 50 and 85 years without a diagnosis of cancer past or present and who are below the clinical cutoff for HA.

Procedure

The study was designed with involvement of individuals who had been diagnosed and received treatment for prostate cancer through a number of discussions. Ethical approval was obtained from the Central University Research Ethics Committee (CUREC) at the University of Oxford (REF: R88678/RE001) in October 2023 (Appendix C.4.). Participants were recruited between November 2023 and March 2024 using social media, direct contact with PC support groups, and charity organisations across the UK. Inclusion criteria for being eligible to participate in the research was the capacity to provide informed consent, and the ability to read and understand English. Eligibility criteria for the PC group included being aged 18 years or older, having received a diagnosis of PC, having undertaken curative treatment for PC (e.g. surgery; radiotherapy; brachytherapy) and to not have had a recurrence of cancer. Inclusion criteria for the HC group were to be a male, aged 50 to 85 years, and to not have received a diagnosis of cancer past or present. Participants were directed to the Qualtrics XM Online survey platform and those who gave informed consent proceeded to undertake the study.

Power

Published research on HA was consulted to determine the effect sizes which had been reported between independent and dependent study variables. There were no existing studies which studied HA in individuals following a PC diagnosis. HA has shown to be related to QoL between groups of those reporting high-HA and low-HA in a Multiple sclerosis sample with a large effect size (d=1.56) (Hayter et al., 2016). HA has been linked with moderate effect sizes to HCQ (r=.22-.48) and responsibility beliefs (r=.28) (Hadjistavropoulos et al., 2012; Melli et al., 2014). Based on this we adopted a conservative approach to our power calculation aiming to be able to detect small effect sizes on group differences for hypotheses testing. To determine the required sample size to test the hypotheses a power analysis was conducted based on the primary hypothesis, which employs a mixed-model ANCOVA. This

determined a sample size of 177 (59 per group) was required to detect an interaction with a small effect size (Cohen's *f* =.1) with .9 power at alpha level 0.05 for 3 groups and 4 measures. A power calculation for an exploratory regression analysis determined a sample size of 160 was required to detect a medium effect size (f^2=0.15) using up to 8 predictor variables with 0.95 power with an alpha level of 0.05.

Measures

Demographic information was collected on age, ethnicity, marital status, education, employment and country of the UK. PC demographics included stage of cancer at diagnosis, year of diagnosis, treatment types and year of treatment.

Health Anxiety Inventory (Short-Form): The HAI is a short 14 item self-report questionnaire with higher scores indicating higher levels of HA. The HAI short form is a reliable and valid measure with comparable psychometric properties to the full-length scale, good internal consistency (α=0.95) and test-retest reliability (Salkovskis et al., 2002). Previous research has established that scores of ≥15 represent elevated levels of HA and scores of ≥18 represents a clinically significant threshold (Österman et al., 2022; Rode et al., 2006). Cronbach's alpha in the current study was α=.905.

Quality of Life Index (QLI): This scale assesses participants satisfaction and relative importance of different life areas in 33 items with higher scores (0-30) indicating higher QoL (Ferrans & Powers, 1992). The scale designed for cancer populations was used in this study. The scale includes 4 subscales to measure QoL across different domains: health and functioning, social and economic, psychological/ spiritual, and family. Reliability has been

demonstrated as high in cancer patients with Cronbach Alpha levels of over 0.9 being observed (Ferrans, 1990). Cronbach's alpha for this study α=.954.

Fear of Cancer Recurrence Inventory-(Short Form) (FCRI-SF): This measure was used to assess the presence and severity of intrusive thoughts associated with FCR. The scores range from 0-36, with the higher scores representing higher levels of FCR (α=.95) (Simard & Savard, 2009). α=.89 in this study.

*Worries About Recurrence and Progression Scale (WARPS)***:** This is a transdiagnostic measure of fear of recurrence or progression (FRP). It has demonstrated good construct validity and reliability in a recent validation paper (α=.96) (Sharpe et al., 2023). Scores range from 18 to 90. α=.976 in this study.

Responsibility Attitude Scale (RAS): This scale assesses general attitudes about responsibility for harm (α=.93) (Salkovskis et al., 2000). The score ranges from 26 (low responsibility attitudes) to 182 (high responsibility attitudes). Cronbach's alpha for this study α=.942.

*Health Cognitions Questionnaire (HCQ)***:** The HCQ is a 20-item measure that assesses Salkovskis and Warwick's (2001) four health-related dysfunctional beliefs suggested to underpin HA (Hadjistavropoulos et al., 2012). The four HCQ scales are as follows with reported reliability in validation paper and in this study: Difficulty Coping (α=.91; α=.88);

Medical Services Inadequacy (α=.81; α=0.83); Likelihood of Illness (α=.75; α=.71); and Awfulness of Illness (α=.76; α=.8).

*The Pain Self Perception Scale (PSPS)***:** The original PSPS assesses perceptions of mental defeat associated with a recent episode of intense pain and has excellent reliability (α=.98) (Tang et al., 2007). Higher scores (24-96) represent the higher levels of mental defeat. α=.98 in this study.

General Anxiety Disorder-7 (GAD-7): This is a 7-item questionnaire measuring anxiety symptoms with good reliability α=.92 (Spitzer et al., 2006). α=.93 for this study.

Patient Health Questionnaire (PHQ-8): This is an 8-item measure of depressive symptoms with high reliability α=.89 (Kroenke et al., 2001, 2009). α=.905 for this study.

European Organisation for Research and Treatment of Cancer (EORTC) QoL Prostate Module (EORTC-QLQ-PR25): This measure assesses specific PC physical functioning across six outcome domains in 25 items with mostly adequate reliability. The domains are urinary symptoms (α=.86), use of incontinence aids, bowel symptoms (α=.53), hormone treatment related symptoms (α=.41), sexual activity (α=.85) and sexual functioning (α=.70) (van Andel et al., 2004). α=.824 for this study.

Analysis Plan

Data was imported into IBM SPSS (Statistical Package for the Social Sciences, Version 29) for analysis and checked for missing data. Data was tested for linearity by assessing scatterplots, homogeneity of regression slopes by assessing interaction terms were not

significant and the normality of distribution of dependent variables was assessed using the Shapiro-Wilk test. Using Shapiro-Wilk test the assumption of normality was violated but due to the sample sizes of each group being over 30 it was assumed using Field's (2018) advice on central limit theorem that the data would be normally distributed. Assumptions of homoscedasticity of error variances were assessed as was homogeneity of variances using Levene's test. Outliers on scored variables were assessed through inspection of standardised scores. Values for outliers exceeding a value of ±3.29 were capped to a value within ±3.29 using a *z*-score calculation following Field's guidelines (see Appendix C.3. for overview of numbers of outliers on each measure and group) (Field, 2018).

Group determinants

High-HA and Low-HA groups were created from the participants who had received curative treatment for PC using scores on the HAI. Cut off scores were determined based on using an enhanced median split which used the standard error of measurement (SEM) to calculate thresholds for groups based on median scores ±1.96 SEM. This meant that group thresholds of scores of ≤7 for the Low-HA group, and ≥16 for the High-HA group were selected as this meant that there was a 95% confidence interval between those within the groups. The recruitment strategy for the healthy benchmark group resulted in a sample with high levels of elevated HA. To address this, those scoring above the clinical threshold for HA (HAI ≥18) were removed from analysis. The remaining sample for the healthy benchmark group still had 9% with elevated HA (HAI ≥15) which was comparable to those in other older adult studies which estimate that between 3%-10% of older adults have elevated rates of HA (Boston & Merrick, 2010; El-Gabalawy et al., 2013).

Hypothesis testing

The High-HA, Low-HA and HC groups were compared using one way ANOVA on dependent variables. Post hoc tests (Tukey HSD) were used to determine where differences in mean scores were on dependent variables across groups. If Levene's test of homogeneity of

variances was violated a one-way Welch ANOVA was used and Games-Howell post hoc tests used. A mixed-model ANCOVA was conducted to test the primary hypothesis for QOL with the analysis groups as a between-subjects factor, the mean QoL subscale scores as a within-subjects factor and age as a covariate. When Mauchly's Test of Sphericity was violated a Greenhouse-Geisser correction was applied. Where an interaction effect was found simple main effects were explored using ANOVA and post-hoc tests. Finally, a hierarchical multiple regression was performed to determine predictors of QoL.

Results

A total of 414 participants provided informed consent to participate in the study. This included 290 individuals who had been diagnosed with PC, but as a number did not meet eligibility criteria (14 had not undertaken curative treatment; 35 were still living with cancer; 2 were not living in UK) a total of 239 participants diagnosed with PC completed the study and were included in the analysis. A total of 124 individuals who had never been diagnosed with cancer provided informed consent. After exclusions for not meeting eligibility criteria (2 who were not living in the UK) and 22 who scored above the clinical threshold for HA, a benchmark group of 100 men aged 50-85 were included in analysis.

Demographic analysis

Table 3.1 represents the demographic information of all groups involved in the analysis. Tests between groups were conducted between High-HA (*n*=61) and Low-HA (*n*=69) groups, and where appropriate with the healthy benchmark group. On demographic variables, there were significant differences between groups on age, whether living in England and on the proportions retired. Between the High-HA and Low-HA PC groups there were significant differences on age at diagnosis, urinary symptoms, bowel symptoms, sexual functioning and hormone treatment related symptoms. One-way ANOVAs also revealed statistically significant differences among groups on levels of anxiety and depression.

Table 3.1

Demographics, Prostate cancer variables, outcomes of participants by group

Characteristic	All PC survivors (*n*=239)	PC Low Health Anxiety (HAI<8) (*n*=69)	PC High Health Anxiety (HAI>15) (*n*=61)	Healthy benchmark group (*n*=100)	Statistic
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	*F or* χ^2 *or t*
Age (y)	69.36 (7.44)	71.80 (6.61)[a†]	66.28 (7.78)[b]	66.25 (6.99)[b]	$F_{(2,227)}$ = 14.69, ***p*<0.001**
UK Country (% England) (*n*)	93.7% (224)	95.7% (66)[a]	90.2% (55)[a]	70.0% (70)[b]	$\chi_{(2)}$= 22.07, ***p*<0.001**
Educational (% University) (*n*)	44.4% (106)	46.4% (32)	41.0% (25)	54.0% (54)	$\chi_{(2)}$= 2.71, *p*=0.26
Marital status (% Married or living with partner) (*n*)	88.3% (211)	88.4% (61)	88.5% (54)	78.0% (78)	$\chi_{(2)}$= 4.58, *p*=0.1
Employment (% Retired) (*n*)	74.1% (177)	87.0% (60)[a]	60.7% (37)[b]	66.0% (66)[b]	$\chi_{(2)}$= 12.88, ***p*=0.002**
Ethnicity (% White) (*n*)	95.4% (228)	98.6% (68)	98.4% (60)	99.0% (99)	$\chi_{(2)}$= 0.14, *p*=0.93
Years since diagnosis	5.75 (4.73)	6.41 (4.52)	5.23 (4.56)		$t_{(128)}$= 1.47, *p*=0.14
Age at Diagnosis	63.59 (6.89)	65.39 (6.28)[a]	61.00 (7.90)[b]		$t_{(128)}$= 3.53, ***p*<0.001**
Years since finished treatment	4.45 (4.16)	5.00 (4.19)	4.11 (4.01)		$t_{(127)}$= 1.23, *p*=0.22
Treatment type:					
Active Surveillance/ monitoring	19.7% (47)	23.2% (16)	11.5% (7)		$\chi_{(1)}$= 3.05, *p*=0.08
Prostatectomy – surgery to have the prostate removed	64.0% (153)	65.2% (45)	60.7% (37)		$\chi_{(1)}$ = 0.29, *p*=0.59
Brachytherapy	10.5% (25)	10.1% (7)	3.3% (2)		$\chi_{(1)}$= 2.37, *p*=0.12
Radiotherapy	38.5% (92)	43.5% (30)	47.5% (29)		$\chi_{(1)}$= 0.22, *p*=0.64
Hormone treatment	33.1% (79)	31.9% (22)	44.3% (27)		$\chi_{(1)}$= 2.11, *p*=0.15
Chemotherapy	2.9% (7)	1.4% (1)	4.9% (3)		$\chi_{(1)}$= 1.31, *p*=0.25
Clinical Trail	4.2% (10)	5.8% (4)	6.6% (4)		$\chi_{(1)}$= 0.03, *p*=0.86
Other	3.8% (9)	4.3% (3)	0% (0)		$\chi_{(1)}$ = 2.72, *p*=0.1
Number of Treatments	1.72 (0.91)	1.80 (1.01)	1.72 (0.82)		$t_{(128)}$= 0.47, *p*=0.64
Urinary Symptoms	1.71 (0.51)	1.55 (0.43)[a]	1.99 (0.56)[b]		$t_{(128)}$= -4.99, ***p*<0.001**
Bowel Symptoms	1.24 (0.34)	1.15 (0.24)[a]	1.44 (0.48)[b]		$t_{(128)}$= -4.3, ***p*<0.001**
Hormone Treatment Symptoms	1.47 (0.44)	1.34 (0.34)[a]	1.74 (0.48)[b]		$t_{(128)}$= -5.47, ***p*<0.001**
Sexual Activity	2.65 (0.87)	2.73 (0.84)	2.80 (0.90)		$t_{(128)}$= -0.41, *p*=0.68
Sexual Functioning	2.78 (0.84)	2.52 (0.70)[a]	3.19 (0.77)[b]		$t_{(80)}$= -4.1, ***p*<0.001**
Incontinence aid	1.76 (0.86)	1.70 (0.70)	2.00 (1.00)		$t_{(54)}$= -1.26, *p*=0.21
Anxiety (GAD7)	4.04 (4.70)	1.08 (1.95)[a]	8.31 (5.15)[b]	3.07 (3.55)[c]	Welch's $F_{(2,125.6)}$ = 57.03, ***p*<0.001**
Depression (PHQ8)	4.47 (4.64)	1.85 (2.74)[a]	9.16 (5.39)[b]	3.59 (4.25)[c]	Welch's $F_{(2,131.1)}$ = 45.82, ***p*<0.001**
Health Anxiety Inventory (HAI)	12.16 (6.71)	4.87 (1.76)[a]	21.28 (4.41)[b]	8.11 (4.24)[c]	Welch's $F_{(2,124.5)}$ = 372.45, ***p*<0.001**

†[a,b,c] Different lettered superscripts indicate significant differences between groups (*p*<.05); having the same superscript indicates a non-significant difference.

PC=Prostate Cancer; SD= Standard Deviation

Primary Hypothesis: QoL and HA

QoL was analysed in a 3 x 4 mixed-model ANCOVA with group (3) as a between-subjects factor, the mean QoL subscale (4) scores as a within-subjects factor and age as a covariate to determine whether QoL domains affected the relationship between groups and QoL. The assumption of sphericity was violated as Mauchly's test of sphericity, ($X^2_{(5)}$=55.01, p<0.001) meaning a Greenhouse-Geisser correction was applied (ε=0.865). The main effect of QoL subscale was not significant ($F_{(2.6, 573.75)}$=1.6, p=0.192), but group was ($F_{(2,221)}$=38.7, p<0.001). This effect was modified by a significant subscale x group interaction effect ($F_{(5.19, 573.75)}$=14.01, p<0.001, partial η^2=0.11) (Figure 3.1).

As the interaction effect was significant across groups, simple main effects ANOVAs were run to determine whether there were significant differences across the analysis groups on the individual subscales. There were statistically significant differences between groups on each subscale (Table 3.2, Figure 3.1). Post hoc tests revealed that there were significant differences between all the groups on each subscale aside from the family subscale where there were no significant differences between PC Low-HA group and healthy benchmarks.

Figure 3.1 – Graph of group by subscale interaction for QoL Subscales with age as covariate

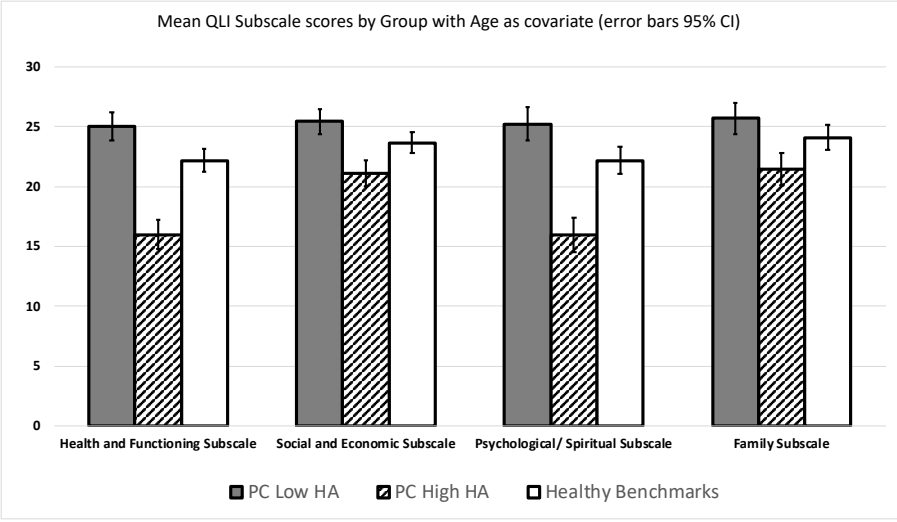


Table 3.2

Descriptive statistics of dependent variables and group comparisons

Characteristic	All PC survivors (*n*=239)	PC Low Health Anxiety (HAI<8) (*n*=69)	PC High Health Anxiety (HAI>15) (*n*=61)	Healthy benchmark group (*n*=100)	Statistic
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	*F or t*
Primary hypothesis: Quality of Life (QoL)					
Quality of Life Total Score (QLI)	22.28 (4.66)	25.34 (3.11)[a†]	17.90 (4.99)[b]	22.64 (4.65)[c]	Welch's $F_{(2,135.7)}$ = 51.09, ***p*<0.001**
Health and Functioning Subscale	21.30 (5.38)	24.97 (3.35)[a]	16.02 (5.40)[b]	22.17 (5.21)[c]	Welch's $F_{(2,135.98)}$= 62.53, ***p*<0.001**
Social and Economic Subscale	23.67 (4.46)	25.65 (3.38)[a]	21.03 (5.16)[b]	23.52 (4.24)[c]	Welch's $F_{(2,133.62)}$= 18.83, ***p*<0.001**
Psychological/ Spiritual subscale	21.46 (6.10)	25.49 (3.92)[a]	15.87 (6.71)[b]	21.86 (6.20)[c]	Welch's $F_{(2,134.61)}$= 49.63, ***p*<0.001**
Family Subscale	24.19 (4.95)	25.74 (3.58)[a]	21.43 (6.00)[b]	24.10 (5.65)[a]	Welch's $F_{(2,133.69)}$= 12.28, ***p*<0.001**
Co-Primary hypotheses: Fear of Cancer Recurrence and Mental Defeat					
Fear of Cancer Recurrence (FCR)	14.55 (7.24)	8.95 (5.01)[a]	21.26 (6.12)[b]		$t_{(128)}$= -12.6, ***p*<0.001**
Fear of cancer recurrence or progression (WARPS)	51.41 (17.86)	33.71 (13.27)[a]	67.85 (11.39)[b]		$t_{(128)}$= -15.64, ***p*<0.001**
Mental Defeat (PSPS)	10.25 (15.05)	2.8 (6.47)[a]	26.89 (23.25)[b]	13.11 (16.97)[c]	Welch's $F_{(2,117.6)}$ = 41.53, ***p*<0.001**
Secondary hypotheses: Responsibility Appraisals & Dysfunctional health cognitions					
Responsibility Beliefs (RAS)	84.08 (27.62)	71.43 (23.73)[a]	103.82 (27.78)[b]	85.41 (27.53)[c]	$F_{(2,227)}$ = 24.202, ***p*<0.001**
Health Cognitions Questionnaire Total Score (HCQ)	58.41 (10.07)	51.36 (8.29)[a]	66.55 (8.99)[b]	58.43 (9.02)[c]	Welch's $F_{(2,138.2)}$= 49.53, ***p*<0.001**
HCQ: Difficulty Coping	21.01 (4.86)	18.03 (4.63)[a]	24.79 (4.48)[b]	21.23 (4.59)[c]	$F_{(2,227)}$=36.65, ***p*<0.001**
HCQ: Medical Services	10.29 (3.55)	9.06 (3.6)[a]	11.43 (3.23)[b]	11.19 (2.95)[b]	$F_{(2,227)}$=11.54, ***p*<0.001**
HCQ: Likelihood	12.70 (2.64)	11.25 (2.46)[a]	14.56 (2.23)[b]	12.09 (2.6)[a]	$F_{(2,227)}$=31.58, ***p*<0.001**
HCQ: Awfulness	14.43 (2.69)	13.03 (3.18)[a]	15.79 (2.07)[b]	13.92 (3.24)[a]	Welch's $F_{(2,144.7)}$=20.58, ***p*<0.001**

[†a,b,c] Different lettered superscripts indicate significant differences between groups (p<.05); having the same superscript indicates a non-significant difference.

SD=Standard Deviation; Prostate Cancer; QLI=Quality of Life Index; HCQ=Health Cognitions Questionnaire

Co-Primary Hypothesis: Fear of Cancer Recurrence and Mental Defeat

An independent samples *t*-test indicated that levels of FCR were higher in those with High-HA compared to those with low-HA with a statistically significant difference ($t_{(128)}$=-12.6, p<0.001, d=2.2). The same test was also run using the WARPS measure of FCR or progression. The result was also statistically significant ($t_{(128)}$=-15.64, p<0.001, d=2.76) with the High-HA group having higher mean scores of FCR as measured on the WARPS.

A one-way ANOVA found that there were significant differences between the three groups on the reported levels of mental defeat (Welch's $F_{(2,117.6)}$=41.53, p<0.001). Post-hoc tests revealed that there were significant differences between the mean scores of all groups, with the Low-HA group having lower scores of mental defeat compared to the High-HA group and healthy benchmark group.

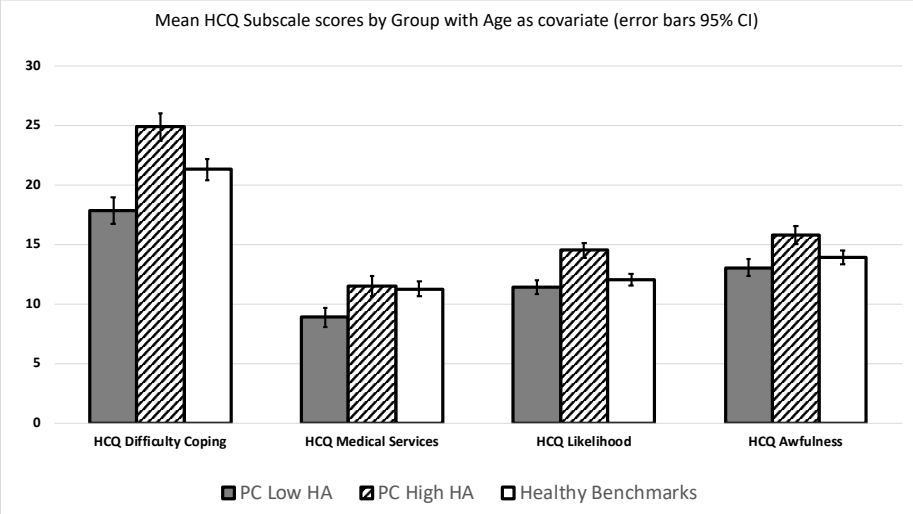
Secondary Hypothesis: Responsibility Beliefs and Dysfunctional Health Cognitions

One-way ANOVA found that there were significant differences between the mean scores of responsibility beliefs across the analysis groups ($F_{(2,227)}$=24.20, p<0.001) with significant differences between all groups (Table 3.2).

Dysfunctional health cognitions were analysed in a mixed-model ANCOVA with group as a between-subjects factor, the mean HCQ subscale scores as a within-subjects factor and age as a covariate to determine whether HCQ subscales affected the relationship between groups and overall ratings of dysfunctional health cognitions. Mauchly's test of sphericity was violated ($X^2_{(5)}$=29.77, p<0.001), meaning a Greenhouse-Geisser correction was applied (ε=0.922). The main effect of HCQ subscale was significant ($F_{(2.76,\ 625.25)}$=5.33, p=0.002) and the main effect of group was also significant ($F_{(2,226)}$=45.92, p<0.001). This effect was modified by a significant subscale by group interaction effect ($F_{(5.53,\ 625.25)}$=10.09, p<0.001, partial η^2=0.08). Analysis of simple main effects using one-way ANOVA demonstrated

significant differences across groups on each subscale with post hoc tests showing that only the difficulty coping scale had differences between all groups (Figure 3.2, Table 3.2).

Figure 3.2 - Graph of group by subscale interaction for HCQ Subscales with age as covariate



Predicting QoL in those living post-PC

In an exploratory analysis a hierarchical linear regression model was run to assess the significant predictors of QoL in all participants who were living after curative treatment for PC (n=239). The predictors included age (step 1), PC physical symptoms (step 2), health anxiety, mental defeat (step 3) and FCR (step 4). The final model accounted for 57% of the variance in predicting QoL (*Adj.* R^2=.574) which was significant ($F_{(8,230)}$=41.06, p<0.01) with a large effect size f^2=1.43. In the final model, only HA (β=-0.26, p<0.01) and mental defeat (β=-0.15, p<.001) were significant predictors.

Table 3.4
Hierarchical multiple regression analysis to predict Quality of Life (QLI Total Score)

Step:	β	t	p	R^2	Adj. R^2	Δ R^2	$F(k,238\text{-}k)$	ΔF p	p	f^2
1	15.34	5.47	<0.001	0.026	0.021	0.026	6.20	0.013	0.013	0.03
Age	0.1	2.49	**0.013**							
2	24.45	8.55	<0.001	0.211	0.194	0.185	12.45	<0.001	<0.001	0.27
Age	0.108	2.945	**0.004**							
Sexual activity	-0.625	-1.977	**0.049**							
Urinary symptoms	-2.139	-3.448	**0.001**							
Bowel symptoms	-2.091	-2.152	**0.032**							
HRT symptoms	-1.163	-1.565	0.119							
3	30.42	14.07	<0.001	0.588	0.575	0.377	47.07	<0.001	<0.001	1.43
Age	-0.024	-0.870	0.385							
Sexual activity	-0.340	-1.464	0.145							
Urinary symptoms	-0.471	-1.013	0.312							
Bowel symptoms	-0.671	-0.942	0.347							
HRT symptoms	0.399	0.725	0.469							
Health Anxiety	-0.246	-6.357	**<0.001**							
Mental defeat	-0.145	-8.332	**<0.001**							
4	30.28	13.825	<0.001	0.588	0.574	0.00	41.06	0.67	<0.001	1.43
Age	-0.024	-0.836	0.404							
Sexual activity	-0.329	-1.405	0.161							
Urinary symptoms	-0.473	-1.015	0.311							
Bowel symptoms	-0.674	-0.945	0.346							
HRT symptoms	0.365	0.655	0.513							
Health Anxiety	-0.256	-5.699	**<0.001**							
Mental defeat	-0.145	-8.327	**<0.001**							
Fear of Cancer Recurrence	0.016	0.425	0.671							

QLI=Quality Life Index; Sexual Activity = EORTC QLQPR25 Sexual activity subscale; Urinary Symptoms=EORTC QLQPR25 Urinary symptoms subscale; Bowel symptoms= EORTC QLQPR25 Bowel symptoms subscale; HRT Symptoms = EORTC QLQPR25 Hormone Related Treatment Symptoms; Health Anxiety = Short Health Anxiety Inventory; Mental defeat = Pain Self Perception Scale; Fear of Cancer Recurrence = Fear of Cancer recurrence scale.

Discussion

This study examined factors associated with QoL outcomes in those who have received curative treatment for PC. Among PC participants High-HA was associated with impaired QoL and increased FCR. There were also higher levels of adherence to dysfunctional beliefs on health, beliefs of responsibility to prevent harm and mental defeat in the high-HA compared to low-HA groups and healthy benchmark groups. It was also found that HA and mental defeat were the only statistically significant predictors of QoL after age, physical side effect symptoms and fear of cancer recurrence were accounted for.

The findings suggest that HA and linked constructs may play an important and specific role in contributing to the psychological distress found in those living after treatment for PC (Brunckhorst et al., 2021; Dinesh et al., 2021). This study provides a more nuanced approach to understanding the psychological impacts of PC than previous studies, which have focused on broad categories of anxiety and depression (De Sousa et al., 2012; Duarte et al., 2022; Sánchez Sánchez et al., 2020; Watts et al., 2015). Like other studies focusing on the psychological impacts of PC, this has found that adverse psychological outcomes are associated with poorer QoL (Chien et al., 2019; Irusen et al., 2022; Pan et al., 2023).

Also in this study, higher levels of HA were associated with increased rating of impacts of the physical side effects of treatment such as urinary, bowel and hormone treatment related symptoms. Like other studies, this could demonstrate that the impacts of the physical side effects of treatments of PC contribute to poorer QoL and increased psychological distress or vice versa (Dinesh et al., 2021; McAteer & Gillanders, 2019; Punnen et al., 2013). This study also suggests links between FCR and PC and found that those with higher HA also had higher levels of FCR (James et al., 2022; Parker et al., 2016; Sevier-Guy et al., 2021). However, this study also illustrated that once HA and mental defeat were taken into consideration, FCR was no longer a significant predictor of QoL. This may be due to the

overlapping aspects of the constructs of FCR and HA which have been identified in breast cancer research such as anxious preoccupations determined by illness representations and increased vigilance to somatic sensations (Maheu et al., 2021).

The findings also show that HA is a significant predictor of QoL after accounting for the impacts of physical symptoms. This is similar to research among participants who have other clinical health problems which include physical symptoms (Carrigan et al., 2018; Hayter et al., 2016; Jones et al., 2012, 2014). Hayter et al., (2016) found that HA impacted on QoL in patients with Multiple Sclerosis (MS) and this remained so after accounting for physical disability and cognitive impairments linked to MS. That study found that misinterpretations of bodily sensations and cognitive performance were linked to higher HA - a finding consistent with the cognitive model of the maintenance of persistent HA (Salkovskis & Warwick, 1986; Warwick & Salkovskis, 1990). In the study reported here it may be that a sense of enduring threat to health was perceived based on the misinterpretation of physical urinary, bowel or hormone symptoms as catastrophic. As a type of self-catastrophising, higher levels of mental defeat was also associated with higher HA within those with PC similar to the findings of previous cancer research (Košir et al., 2020). The cognitive model of HA also hypothesises that dysfunctional beliefs about health maintain elevated HA, and this study has shown that this may be so for individuals living post-treatment for PC (Fergus, 2014). The hypothesised links between inflated beliefs about one's responsibility to prevent harm and higher levels of anxiety were also confirmed in this study as those with higher levels of HA had higher levels of responsibility appraisals (Avard & Garratt-Reed, 2021; Gustavsson et al., 2021).

Limitations

The study is limited in that it is an observational study and causality cannot be assumed. The sampling strategy relied on using existing networks of PC support groups and charities and individuals who are involved with such groups may not be representative of the wider population of PC survivors. The study sample's demographics demonstrate that there were

few men of non-white ethnicities who participated and they may experience different psychological responses to PC (Consedine, 2012). The sampling strategy used to recruit a healthy benchmark group relied upon responses to social media advertisements concerning a study on health anxiety. This resulted in a more health anxious sample of older males and therefore the benchmark group was capped at HAI scores of 18, the identified clinical threshold in previous research (Österman et al., 2022). Despite this, the rates of those with elevated HA for the healthy benchmark group included here were similar to prevalence rates in other studies (Boston & Merrick, 2010; El-Gabalawy et al., 2013). For hypothesis testing on subscales which measured different aspects of QoL and dysfunctional health cognitions in we used a mixed-model approach. When testing within and between subject effects of repeated similar measures a mixed-model methodology is equivalent to using a MANOVA model especially in large sample sizes such as this as both approaches rely on the same underlying statistical assumptions (Huang, 2020; Schuster & Lubbe, 2015). A further limitation to the study is that it did not control for confounding factors such as the impacts of other physical health conditions which are highly prevalent in older adults. Future studies might seek to include a measure of any long-term physical conditions that may impact on HA or QoL.

Research Implications

As this study demonstrates the links between HA and QoL in those living after successful curative treatment for PC, future studies might seek to determine whether clinically reducing HA or FCR can improve QoL for those surviving PC. In addition to physical threats from side effects or cancer return, social threats or impairments to social roles (e.g. through fears of incontinence, impairments of intimacy or masculinity) may be important to examine. Similarly, targeting populations with demographic differences may provide more insight into how health anxiety may impact on QoL for those with advanced forms of PC, individuals who are diagnosed at a comparably younger age, or for those of different ethnic or cultural backgrounds.

Clinical implications

The results of this study highlight the need to recognize and screen for health specific forms of anxiety in those living after treatment for PC. The National Institute for Clinical Excellence (NICE) guidelines for improving supportive care for adults with cancer recommends a four-level model of professional psychological assessment and intervention for those living with cancer (National Institute for Clinical Excellence (NICE), 2004). They suggest that at levels 1 and 2, all health and social care professionals involved in the care of those living with cancer should be able to recognise psychological distress. It suggests that more severe psychological distress at levels 3 or 4 should be assessed by a variety of psychological specialists. HA is not routinely screened for at any level of care so as an initial step ensuring trained and accredited psychological specialists incorporate specific screening for HA into their assessment of those living after a cancer diagnosis. For those who do have high levels of psychological distress following treatment for PC, interventions like CBT which target the cognitive biases and beliefs associated with the maintenance of HA might be an effective form of treatment. CBT has been shown to be an effective treatment for HA and for those who are living with the management of chronic illnesses (Cooper et al., 2017; Petricone-Westwood et al., 2019). A large scale randomized controlled trial (RCT) which introduced screening for HA in general hospital clinics by physical health professionals for those seeking treatment for a range of physical health problems (Tyrer et al., 2011; Tyrer et al., 2017). Those who were identified using the HAI to have clinically significant HA were offed the chance to participate in a trail of delivering CBT for HA by a range of healthcare professionals. The results found that CBT was a highly effective treatment for HA when compared to standard care with lasting benefits after 5 years follow up. This illustrates the importance of screening and if oncologists, urologists, cancer nurses or GPs were able to introduce screening for HA in those with PC at diagnosis, treatment completion, or a follow-up PSA test appointment, those who had elevated levels of HA could be referred for targeted and specialist CBT treatment.

Conclusions

This study demonstrated that some individuals who live after successful curative treatment for prostate cancer have high levels of HA and that this may adversely impact on their QoL. HA was associated with increased FCR and mental defeat as well as theorised cognitions such as dysfunctional beliefs about health and inflated responsibility appraisals. HA and mental defeat were the only significant predictors to QoL after accounting for the impacts of the physical side effects of treatment. As HA and these appraisals can be targeted through CBT treatments, it offers an opportunity for targeted interventions to improve QoL for those living after treatment for PC.

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Executive Summary

The impact of health anxiety after curative treatment for prostate cancer: Quality of life, fear of cancer recurrence, cognitive maintenance processes and mental defeat.

What did we study and why?

- Prostate cancer is the most common form of cancer among males in the UK and with improvements in, and awareness of, the importance of testing, more people are being diagnosed with early stage prostate cancer and can undertake a form of curative treatment.
- Previous research into the psychological impacts of being diagnosed with and treated for prostate cancer show that it is a psychologically distressing experience that is linked with high rates of anxiety and depression. We think that this psychological distress might be more specific than these two broad categories through which it has typically been studied. We designed this study to find out whether health anxiety, a specific type of anxiety which is focused on perceived threats to one's health, may be an important issue for those who undergo this experience.
- Based on the Cognitive Behavioural theoretical understanding of what maintains health anxiety, we think that some of those who have had treatment for prostate cancer may have elevated levels of perceived threat to their health and may interpret some of the physical side effects of their treatment as indicating an ongoing threat to their health.
- Previous studies of health anxiety have linked it to resulting in lower quality of life (QoL) for individuals who have elevated levels so, we predicted that this link would also exist within those living after prostate cancer with elevated health anxiety.
- The type of thinking bias associated with health anxiety is a specific form of catastrophising linked to health, and we therefore believed that those who had elevated

forms of this may have similar forms of catastrophising in other psychological processes such as fear of cancer recurrence and mental defeat.

- In addition to this we also thought that health anxiety would be linked to some of the thinking styles which are theorised to contribute to it. These included having dysfunctional beliefs about health such as not being able to cope if you got a serious illness, or that the doctors around you would not be able to help you. Similarly, health anxiety has been linked to having beliefs about your responsibility to prevent harm, and we wanted to test this theory in this study.
- This is important because a type of psychological therapy known as Cognitive Behavioural Therapy (CBT) can target these types of thinking patterns.

What were our aims?

- We wanted to test whether health anxiety was linked to quality of life in those who were living after a successful treatment for prostate cancer. We also tested whether health anxiety was linked to higher levels of fear of cancer recurrence and mental defeat as we predicted it would be.
- We also wanted to test whether the thinking styles and beliefs about health and responsibility beliefs that were theorised to underpin health anxiety were linked to those people who had high levels of health anxiety.

What did we do?

- We first went and asked the advice of some people who had lived through this experience to see what they thought about our ideas and to get their advice on how to proceed.
- We then recruited a sample of people who had been diagnosed with prostate cancer and received a form of curative treatment for this. We asked these people to give their informed consent to undertake a series of questionnaires using an online survey

platform. We calculated scores to these validated questionnaires and we looked at the relationships and associations in the data using certain types of statistical analysis that allowed us to be confident about when there was a significant finding.

- For some of our analysis, we divided this group of people who had treatment for prostate cancer into those who had low levels of health anxiety, and those who had high levels of health anxiety. This allowed us to compare the relative difference that health anxiety might play in shaping how people thought or behaved.
- In order to compare these groups to individuals who did not have cancer, we also recruited a healthy benchmark group of males who were of similar ages (50-85) but did not have cancer or treatment.

What did we find out?

- We found out that health anxiety was higher in those who reported worse physical side effects of treatment for prostate cancer, and in those who had higher levels of anxiety and depression.
- We found out health anxiety was linked with impairments in quality of life as the group of people who had higher levels of health anxiety also had lower levels of quality of life than those who had low levels of health anxiety or our healthy benchmark group across all quality of life domains.
- We also found out that health anxiety was also linked to having elevated levels of fear of cancer recurrence and mental defeat showing that other forms of catastrophising are linked.
- As we predicted, people with high levels of health anxiety also were more likely to have elevated dysfunctional beliefs about health and inflated beliefs about taking responsibility for preventing harm.

- We also found out that health anxiety and mental defeat were the only significant predictors of quality of life even when we considered age and the physical side effects of treatment.

How is this relevant?

- This is relevant to our understanding of the specific aspects of the psychological implications of being diagnosed with and treated for prostate cancer. This shows that health anxiety is a significant form of psychological distress for those who get successful treatment for prostate cancer. We also found out that high levels of health anxiety were associated with impaired quality of life, fear of cancer recurrence and mental defeat
- We know that treatments for psychological distress such as health anxiety can be beneficial in helping with adjustment to life after cancer and improving quality of life. Such treatments are underpinned by targeting changes in interpretations and beliefs associated with health anxiety such as the interpretation of physical pain, beliefs about health and responsibility.

Connecting Reflective Narrative

On joining this doctoral course, my primary research interests focused on understanding the links between traumatic experiences, PTSD and personality disorder presentations. My secondary interests were related to factors which might influence the links between these, like attachment, dissociation, source monitoring and cognitive and affective biases resulting in the activation of self-schemas and identity disturbances that follow traumatic experiences. While cognitive behavioural theory has an excellent evidence base in treating anxiety disorders, there have been less robust theoretical links to the understanding or treatment of severe and enduring mental health problems, such as personality disorders or complex forms of trauma. The following research projects integrate these considerations and navigate the intersection which can be found between cognitive behavioural theory and other theoretical approaches to self-processing.

Service Improvement Project (SIP): I approached the Intensive Management of Personality Disorders and Clinical Therapies Team (IMPACTT) in Berkshire NHS Foundation Trust (BHFT) and after initial consultations with the senior leadership team, I decided to undertake my project within the Service User Network (SUN) Team, as I found this type of service a relatively novel form of ongoing support for individuals struggling with issues associated with personality disorders, and I was interested in learning about its operations. My external supervisors in the SUN team provided helpful context to guide a study that would be most useful for the service. They helped me secure ethical clearance from the clinical audit team within BHFT to collect data from service users, and we also involved service users in its design through consultation.

I really enjoyed meeting and interviewing service users about their experiences and expectations for the SUN service. I had analysed qualitative data in previous research, but this was my first time applying a framework analysis. This type of analysis was selected in

order to ensure that differences in experiences or perspectives of different user profiles could be demonstrated in the final report, which was also important to the service. The theoretical framework that was applied had potentially wider applications for our understanding of service user pathways and what facilitates trust in any system. In Appendix B.11, I have included some of the feedback received from the SUN Service after disseminating the findings and recommendations. It was rewarding to know that the findings of this project were useful to those making decisions about the service's operation.

Theory Driven Research Project: Developing a project which focused on health anxiety within those living after treatment for prostate cancer was a good opportunity to work with some of the theory associated with the cognitive behavioural model, which greatly benefitted my understanding and subsequent clinical work. Undertaking this project helped me to better discern the cognitive behavioural model and how certain appraisals or interpretations of an event might influence processing and outcomes. Understanding the theory specifically clarified the ways in which cognitive and affective processing during a traumatic experience might shape an individual's interpretations of sensory experiences. I was interested in the application of beliefs of inflated responsibility to prevent harm as a maintaining factor for anxiety and wanted to test this association empirically.

Prior to the course, I had some experience working with those who had been diagnosed and treated for prostate cancer, so I had an awareness of the unmet clinical needs of this large group of individuals. This project sought to bring a new way of understanding psychological distress post-treatment for prostate cancer, and through considering health anxiety, it may be important in helping those who need support after diagnosis and treatment. Working with charities and organisations involved in providing information and support gave the relevant interest groups an opportunity to take part in the study. The findings illustrate robustly that health anxiety is an important factor for men living after prostate cancer treatment, and it also identifies a number of appraisals and beliefs that can be targeted in CBT treatment.

Systematic Review of the Literature: Though I had limited prior experience of the literature or theory on the psychological impacts of living with chronic pain, I enjoyed reading some of the wider theories of pain and about the sensory experience of pain linked to cognitive and affective processing, as well as the interpretation of pain and its meaning for the self. Undertaking this project was also my first experience researching mental defeat - a specific type of self-catastrophising that follows entrapment and humiliation - a process in the PTSD literature which I had not well understood previously. My own research interests had focused on the dissociative processes which may underpin the attribution of affect and cognitions following traumatic experiences to self or others. However, exploring mental defeat with Professor Paul Salkovskis helped me understand how this type of self-catastrophising may become active in individuals who might have had a history of coping with threats to their self from others through activating particular cognitive and affective schema, and aided my ability to work with individuals with personality disorders. While our project focused on the threats to self-identity from consistent chronic forms of pain, these theoretical links were of wider relevance to my understanding of how traumatic experiences might influence processing, particularly in relation to self and others during and after traumatic experiences. At this point in the research process, I was also on placement in a specialist trauma service working with individuals with Complex-PTSD and in a specialist service working with individuals with issues associated with personality disorder presentations using mentalisation-based treatment (MBT). An understanding that disturbances in identity may result from early relational experiences of mental defeat and in a schema activation in order to avoid such experiences happening again in other relationships ultimately aided my clinical work with those who possess mentalizing difficulties. Linking this theory to clinical practice has been a rewarding experience. I hope to continue to use research and theory in this way to ensure that my own clinical work is underpinned by data analysis and evaluation to determine its efficacy where possible contribute to the evidence base.

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I would like to extend a special thanks to everyone who advised on the projects or helped with recruitment. This includes people with lived experience who took part in consultations to determine the design and recruitment strategies. I would like to thank charities Prostate Cancer UK and Prostate Scotland for their help in distributing the survey on social media. I would also like to thank every prostate cancer support group who helped distribute information about this survey to their membership. I would like to thank every individual who gave up their time to participate in any of these research projects to answer questions about their experiences.

I can only thank God for Amanda Westcott.

Appendices

Appendix A – Systematic Review of the Literature

Appendix A.1 – Instructions to Authors for Clinical Journal of Pain

INSTRUCTIONS FOR AUTHORS

The Clinical Journal of Pain publishes original articles in the following forms: *Clinical investigations:* Present results of original clinical research. *Case reports:* **Case reports are no longer accepted for publication in *Clinical Journal of Pain* of June 13, 2013.** *Reviews:* Comprehensive surveys covering a broad area. They consolidate old ideas and may suggest new ones. They must provide a critique of the literature. *Special articles:* On subjects not easily classified above (e.g., articles on history, education, demography, ethics, socioeconomics, etc.). *Letters to the editor:* These may offer criticism of published material, but must be objective, constructive, and educational. A few references, a small table, or relevant illustrations may be used.

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Appendix A.2 – Table containing all relationships and associations across domains with mental defeat

Appendix A.2 - All relationships and associations across domains with mental defeat									
Study (year)	**Domain associated with mental defeat**	**Variable associated with mental defeat (measure)**	**Questionnaire (related variable)**	**MD included as [X] variable**	**Type of relationship with mental defeat (statistical test)**	**Population**	**Effect size**	**Effect size interpretation**	**Quality Score**
Behavioural associations and relationships with mental defeat									
Tang et al., 2010	Behaviours	Functional Disability	Pain Disability Questionnaire (PDQ)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.49, *p*<0.001	Medium	11
Turner-Cobb et al., 2015	Behaviours	Functional Disability	Roland Morris Disability Questionnaire (RMDQ)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=64)	*r*=0.36, *p*=0.008	Medium	13
Tang et al., 2010	Behaviours	Functional Disability	Pain Disability Questionnaire (PDQ)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=0.96	Large	11
Tang et al., 2010	Behaviours	Functional Disability	Pain Disability Questionnaire (PDQ)	Independent variable	Linear Regression	Chronic Pain Patients (*n*=133)	Dependent variable: Functional Disability Predictor(s): Worry, Health anxiety, pain intensity, rumination (R^2=0.24). Mental defeat was added and was a significant predictor (R^2 =0.24). Catastrophising was the strongest predictor of Functional Disability in a model that predicted (R^2 =0.26) of the variance in Functional Disability.		11

Tang et al., 2010	Behaviours	Functional Disability	Pain Disability Questionnaire (PDQ)	Independent variable	Stepwise Regression	Chronic Pain Patients (*n*=133)	Mental defeat was not a significant predictor of functional disability. pain intensity and catastrophising were alongside rumination tendency ($F_{(2,129)}$=36.1, p<0.001). Together these accounted for 46% of the variance in Functional Disability. Catastrophising accounted for 26% of the variance, rumination tendency for 8% and pain intensity for 12%.	Not significant	11
Tang et al., 2010	Behaviours	Functional Disability (wth Pain intensity and age partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.41, *p*<0.001	Medium	11
Tang et al., 2010	Behaviours	Functional Disability (wth Pain intensity partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.43, *p*<0.001	Medium	11
Tang et al., 2010	Behaviours	Functional Disability (wth Pain intensity, age and body mass index partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.41, *p*<0.001	Medium	11
Hazeldine-Baker et al., 2018	Behaviours	Pain Self-Efficacy	The Pain Self-Efficacy Questionnaire (PSEQ)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=59)	*r*= - 0.69, *p*<0.001	Large	14
Tang et al., 2016	Behaviours	Pain Self-Efficacy	The Pain Self-Efficacy Questionnaire (PSEQ)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*= - 0.52, *p*<0.001	Large	14

Hazeldine-Baker et al., 2018	Behaviours	Pain Self-Efficacy	The Pain Self-Efficacy Questionnaire (PSEQ)	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=59)	The total model predicted R^2=0.47 of variance of Self-efficacy. Mental defeat was the only significant predictor with *B*= - 0.69, *p*<0.001. ($R^{2=}$0.47, $F_{(1,59)}$=52.26, *p*=0.001)	Large	14
Tang et al., 2010	Behaviours	Psychosocial (wth Pain intensity and age partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.57, *p*<0.001	Large	11
Tang et al., 2010	Behaviours	Psychosocial Disability	Pain Disability Questionnaire (PDQ)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.61, *p*<0.001	Large	11
Tang et al., 2010	Behaviours	Psychosocial Disability	Pain Disability Questionnaire (PDQ)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=1.35	Large	11
Tang et al., 2010	Behaviours	Psychosocial Disability	Pain Disability Questionnaire (PDQ)	Independent variable	Linear Regression	Chronic Pain Patients (*n*=133)	Dependent variable: Psychosocial Disability Predictor Variables: Mental defeat was entered alonside Catastophizing, Pain intensity, Health Anxiety, Rumination and worry. Mental defeat was the 2nd strongest predictor and predicted 24% of the variance with other variables aside from Catastrophising. (R^2=0.24, *p*<0.008).		11
Tang et al., 2010	Behaviours	Psychosocial disability	Pain Disability Questionnaire (PDQ)	Independent variable	Stepwise Regression	Chronic Pain Patients (*n*=133)	Mental defeat was not a significant predictor of functional disability. pain intensity and catastrophising were alongside rumination tendency ($F_{(2,129)}$=36.1, p<0.001). Together these accounted for 46% of the variance in	Not Significant	11

							Functional Disability. Catastrophising accounted for 26% of the variance, rumination tendency for 8% and pain intensity for 12%.		
Tang et al., 2010	Behaviours	Psychosocial Disability (wth Pain intensity partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.57, *p*<0.001	Large	11
Tang et al., 2010	Behaviours	Psychosocial Disability (wth Pain intensity, age and body mass index partialled out)	Pain Disability Questionnaire (PDQ)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.57, *p*<0.001	Large	11
Tang et al., 2010	Behaviours	Sleep interference	Insomnia Severity Index (ISI)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.35, *p*<0.001	Medium	11
Tang et al., 2010	Behaviours	Sleep interference	Insomnia Severity Index (ISI)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=0.53, *p*<0.001	Medium	11

Tang et al., 2010	Behaviours	Sleep interference	Insomnia Severity Index (ISI)	Independent variable	Linear regression	Chronic Pain Patients (*n*=133)	Dependent variable: Sleep interference Predictor variables: Mental defeat was entered alonside Catastophizing, Pain intensity, Health Anxiety, Rumination and worry. Catastrophising was the strongest predictor of Sleep interference in a model that predicted 15% of the variance in Sleep interference. Mental defeat was the 2nd strongest predictor and predicted 12% of the variance with other variables aside from Catastrophising. (R^2=0.12, p<0.008).		11
Tang et al., 2010	Behaviours	Sleep interference	Insomnia Severity Index (ISI)	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=133)	Mental defeat was not a significant predictor of sleep interference. pain intensity and catastrophising were ($F_{(2,130)}$=59.1, p<0.001). Together these accounted for 22% of the variance in Pain interference. Pain intensity accounting for 7% and Catastrophising accounting for 15%.	not significant	11
Tang et al., 2010	Behaviours	Sleep interference (wth Pain intensity and age partialled out)	Insomnia Severity Index (ISI)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.28, p<0.01	Small - Medium	11
Tang et al., 2010	Behaviours	Sleep interference (wth Pain intensity partialled out)	Insomnia Severity Index (ISI)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.28, p<0.001	Small - Medium	11
Tang et al., 2010	Behaviours	Sleep interference (wth Pain intensity, age and body mass index	Insomnia Severity Index (ISI)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.29, p<0.01	Small - Medium	11

		partialled out)							
Tang et al., 2016	Behaviours	Suicide	Worst ever suicide attempt - Beck Scale of Suicidal Ideation	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.45, *p*<0.001	Medium	14
Tang et al., 2016	Behaviours	Suicide	Present suicide intent - Beck Scale of Suicidal Ideation	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.13, not significant	Not Significant	14
Themelis et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Dependent Variable	t test	Chronic Pain Participants (*n*=524) Group 1 - Those at no/ low risk of suicide (*n*=319) Group 2 - Those at higher risk of suicide (*n*=202)	*t* = - 9.37, *p*<0.001, *d*= -.84	Large	10
Cheatle et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Dependent Variable	t test	Chronic Pain Patients (*n*=609) Group 1 - Chronic non-cancer Pain (CNCP) and Opiod Use Disorder (OUD) after long term opiod therapy (LTOT) (*n*=175) Group 2 - Controls - CNCP on LTOT with no OUD (*n*=434)	Cohen's *d*= 1.11, *p*<0.001	Large	14
Themelis et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	Univariate Logistic Regression	Chronic Pain (*n*=524)	PSPS=1.035 odds ratio, *p*.001		10

Themelis et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	Multivariate Logistic Regression	Chronic Pain (*n*=524)	In a multivariable model, mental defeat, depression, perceived stress, head pain, and active smoking status significantly increased the odds of suicide risk at 6 months. The elevated mental defeat was associated with increased suicide risk when adjusting for depression, perceived stress, head pain, and smoking status, evident by an OR of 1.02 (95% CI: 1.00, 1.04). Specifically, each 1-point increase in PSPS scores assessing mental defeat was associated with a 2% increase in the OR for suicide risk.		10
Themelis et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	ROC Curve Analysis	Chronic Pain (*n*=524)	Mental defeat had the highest AUC compared to perceived stress and Depression. PSPS cut-off score of 36.5 provided a sensitivity value of .707 and a 1-specificity value of .307. this cut-off score demonstrated an acceptable ability to predict participant classification as SBQ-R score > 7. The AUC was = .740 (95% CI:.688–.792) and statistically significant (P < .001). Based on the optimal cut-off of 36.5 and the final multivariable model from this analysis, an individual meeting this cut-off score is estimated to have an odds ratio of 73% higher than individuals with no symptoms of mental defeat (e.g., a score of 0 on the PSPS). Using the PSPS cut-off of 36.5, the PPV value was 56.12% and the NPV was 76.57%.	Large	10
Cheatle et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	Univariate Logistic Regression	Chronic pain patients (*n*=609)	PSPS=1.03 odds ratio, *p*<.001		14

Cheatle et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	Multivariate Logistic Regression	Chronic pain patients (*n*=609)	PSPS=1.02 Adjusted odds ratio, *p*<.001, VIF=1.55		14
Cheatle et al., 2023	Behaviours	Suicide	Suicidal behaviour questionnaire revised (SBQ-R)	Independent variable	ROC Curve Analysis	Chronic pain patients (*n*=609)	In a ROC Curve analysis using mental defeat and pain catastrophising indicated that they performed similarity in predicting suicidal behaviours. This identified a mental defeat (PSPS) score of 40 and a pain catastrophising socre of 16 (Coping Strategies Questionnaire (CSQ) - Catastrophising subscale score) were comparable in estimating a suicidal behaviour score of 8 or more.		14
Tang et al., 2016	Behaviours	Suicide	Worst ever suicide attempt – Beck Scale of Suicidal Ideation	Independent variable	Hierarchical Multiple Regression	chronic Pain Patients (*n*=57)	Dependent variable: Worst ever suicide attempt (model controlled for impact of pain characteristics). Predictor variables: Pain intensity R^2=0.11. Mental defeat was added and was significant, R^2=0.23. Effect size attributable to the addition of mental defeat= f^2=0.15. Anxiety, depression, and pain catastrophising were non- significant predictors of worst-ever suicide intent in this sample. Although the additional predictors boosted the amount of variance explained by 1% (R^2=0.24)	Medium	14
Tang et al., 2016	Behaviours	Suicide	Worst ever suicide attempt – Beck Scale of Suicidal Ideation	Independent variable	Hierarchical Multiple Regression	chronic Pain Patients (*n*=57)	Dependent variable: Worst ever suicide attempt (model comparing to other psychological predictors). Predictor variables: Pain intensity, anxiety, depression, pain catastrophising R^2=0.19. Mental defeat was added and was significant, R^2=0.24. Effect size attributable to the addition of mental defeat= f^2=0.15.	Medium	14

Cognitive Associations and Relationships with Mental Defeat									
Tang et al., 2016	Cognitive	Hopelessness	Beck Hopelessness Scale (BHS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.07, not significant	Not significant	14
Tang et al., 2016	Cognitive	Pain Catastrophising	Catastrophising in pain scale (CIPS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.67, *p*<0.001	Large	14
Garcia-Campayo et al., 2010	Cognitive	Pain Catastrophising	Pain Catastrophising Scale (PCS)	Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.40, *p*<0.001	Medium	14
Ayache et al., 2021	Cognitive	Post Traumatic Growth and Depreciation	Paired Format Posttraumatic growth Inventory	Dependent Variable	One Way ANOVA		n^2=0.29	large	13
Philips, 2015	Cognitive	The Likelihood of cognitive bias associated with pain images	Image-Event Fusion- Pain (IEF-p)	Association	Pearson's Correlation	Pain Patients with physical disabilities (*n*=44)	*r*= - 0.327, *p*<0.01	Medium	8
Demographic associations and relationships with Mental Defeat									
Garcia-Campayo et al., 2010	Demographic	Age		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.076, *p*<0.653 - not significant	Not significant	14
Tang et al., 2013	Demographic	Age		Association	Pearson's Correlation	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.15, not significant	Not significant	15
Tang et al., 2013	Demographic	BMI		Association	Pearson's Correlation	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.13, not significant	Not significant	15
Garcia-Campayo et al., 2010	Demographic	Education		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.198, *p*<0.411 - not significant	Not significant	14

Tang et al., 2013	Demographic	Education		Association	Spearman Rank correlation coefficients	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.34, *p*<0.001	Medium	15
Tang et al., 2013	Demographic	Employment		Association	Spearman Rank correlation coefficients	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*= - 0.18, not significant	Not significant	15
Garcia-Campayo et al., 2010	Demographic	Gender		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.113, *p*<0.192 - not significant	Not significant	14
Garcia-Campayo et al., 2010	Demographic	Marital Status		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.214, *p*<0.342 - not significant	Not significant	14
Tang et al., 2013	Demographic	Marital Status		Association	Spearman Rank correlation coefficients	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*= - 0.03, not significant	Not significant	15
Tang et al., 2013	Demographic	Sex		Association	Spearman Rank correlation coefficients	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.11, not significant	Not significant	15
Garcia-Campayo et al., 2010	Demographic	Work Status		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.123, *p*<0.093 - not significant	Not significant	14
Pain Characteristics and Associations and Relationships with Mental Defeat									
Hazeldine-Baker et al., 2018	Pain	Affective Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) - Affective pain scores	Association	Pearson's Correlation	Chronic Pain Patients (*n*=59)	*r*=0.62, *p*<0.001	Large	14
Tang et al., 2007	Pain	Affective Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) - Affective pain scores	Association	Pearson's Correlation	Chronic Pain Patients (*n*=126)	*r*=0.53, *p*<0.001	Large	15

Hazeldine-Baker et al., 2018	Pain	Affective Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) - Affective pain scores	Independent variable	Stepwise Regression	Chronic Pain Patients (*n*=59)	The total model predicted R^2=0.39 of variance of affective pain. Mental defeat was the only significant predictor with *B*= 0.62, *p*<0.001	Large	14
Garcia-Campayo et al., 2010	Pain	Global Function - Fibromylgia	Fibromyalgia Impact Questionnaire (FIQ)	Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.41, *p*<0.001	Medium	14
Garcia-Campayo et al., 2010	Pain	Pain Duration		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*= -0.096, *p*<0.604 - not significant	Not significant	14
Tang et al., 2016	Pain	Pain Duration		Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*= -0.05, not significant	Not significant	14
Tang et al., 2013	Pain	Pain Duration		Association	Spearman Rank correlation coefficients	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.03, not significant	Not significant	15
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.51, *p*<0.001	Medium - Large	11
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Association	Partial Correlation	Chronic Pain Patients (n=133)	*r*=0.45, *p*<0.001	Medium	11
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.44, *p*<0.001	Medium	11
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.44, *p*<0.001	Medium	11
Tang et al., 2013	Pain	Pain interference	Brief Pain Inventory (BPI)	Association	Pearson's Correlation	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.65, *p*<0.001	Large	15

Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=0.88	Large	11
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Independent variable	Linear regression	Chronic Pain Patients (*n*=133)	Dependent variable: Pain interference Predictor(s):Worry, Rumination, Health Anxiety, Pain intensity, Catastrophising (R^2=0.23). Mental defeat was added and was a significant predictor (Model R^2 change=0.26) Effect size attributable to the addition of mental defeat= f^2=0.30	Medium	11
Tang et al., 2010	Pain	Pain interference	Brief Pain Inventory (BPI)	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=133)	Mental defeat was a significant predictor of pain interference alongside pain intensity and catastrophising ($F_{(3,129)}$=25.2, p<0.001). Together these accounted for 37% of the variance in Pain interference. Mental defeat accounted for 26% of the variance, with Pain intensity accounting for 9% and Catastrophising accounting for 2%.		11
Tang et al., 2013	Pain	Pain interference	Brief Pain Inventory (BPI)	Independent variable	Hierarchical linear regression	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	Dependent variable: Pain interference Predictor(s):Education, Pain severity (R^2=0.31). Mental defeat was added and was a significant predictor (Standardised B=0.58 (F change = 21.60, p<0.001)) Model R^2=0.47, R^2 change=0.16)	Medium	15

							Effect size attributable to the addition of mental defeat= f^2=0.30		
Garcia-Campayo et al., 2010	Pain	Pain Levels/ Insensity / Severity		Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.42, *p*<0.001	Medium	14
Hazeldine-Baker et al., 2018	Pain	Pain Levels/ Insensity / Severity		Association	Pearson's Correlation	Chronic Pain Patients (*n*=59)	*r*=0.51, *p*<0.001	Medium	14
Tang et al., 2016	Pain	Pain Levels/ Insensity / Severity		Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.25, *p*<0.1 (not at .05 level)	Small	14
Tang et al., 2007	Pain	Pain Levels/ Insensity / Severity		Association	Pearson's Correlation	Chronic Pain Patients (*n*=126)	*r*=0.41, *p*<0.001	Medium	15
Tang et al., 2013	Pain	Pain Levels/ Insensity / Severity		Association	Pearson's Correlation	Chronic Pain (*n*=84, patients (*n*=43), volunteers (*n*=41))	*r*=0.53, *p*<0.001	Medium-Large	15
Hazeldine-Baker et al., 2018	Pain	Pain Levels/ Insensity / Severity		Independent variable	Stepwise regression	Chronic Pain Patients (*n*=59)		Not significant	14
Hazeldine-Baker et al., 2018	Pain	Sensory Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) - Sensory pain scores	Association	Pearson's Correlation	Chronic Pain Patients (*n*=59)	*r*=0.38, *p*<0.001	Medium	14
Tang et al., 2007	Pain	Sensory Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) - Sensory pain scores	Association	Pearson's Correlation	Chronic Pain Patients (*n*=126)	*r*=0.40, *p*<0.001	Medium	15
Hazeldine-Baker et al., 2018	Pain	Sensory Pain	Short-Form McGill Pain Questionnaire (SF-MPQ) -	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=59)	The total model predicted R^2=0.16 of variance of sensory pain. Pain Catastrophising was the only significant predictor with *B*=0.40, *p*=0.001. Mental defeat was not a significant predictor of	Not significant	14

			Sensory pain scores				Sensory pain alongside these co-predictors.		
Turner-Cobb et al., 2015	Pain Group	Pain Groups as Independent Variable	Pain Self Perception Scale (PSPS)	Dependent Variable	ANOVA	chronic musculoskeletal pain patients (*n*=64) pain free control group (*n*=63)	$F(1,125)=111.34$, $p<0.001$. Mental defeat explained 47% of the difference. *N*2p=0.47	Large	13
Tang et al., 2013	Pain Group	Pain Groups as Independent Variable	Pain Self Perception Scale (PSPS)	Dependent Variable	One Way ANOVA	Chronic pain patients (*n*=43), Chronic pain volunteers (*n*=41), Acute Pain Volunteers (*n*=23)	Cohens $F_{(2,102)} = 11.24$, $p<0.001$		15
Tang et al., 2007	Pain Group	Pain Groups as Independent Variable	Pain Self Perception Scale (PSPS)	Dependent Variable	One Way ANOVA	Chronic Pain Patients (*n*=94) Acute Pain Patients (*n*=38) Pain Free Volunteers (*n*=79) Acute Pain Volunteers (*n*=30) Chronic Pain Volunteers (*n*=32) Anxious Controls (*n*=31)	Cohens $F_{(5,298)} = 22.29$, $p<0.001$		15
Tang et al., 2007	Pain Group	Pain Groups as Independent Variable	Pain Self Perception Scale (PSPS)	Dependent Variable	t test	Chronic pain patients (*n*=27) Chronic pain volunteers (*n*=27)	$t_{(52)} = 2.20$, $p<0.032$		15
Tang et al., 2007	Pain Group	Pain Groups as Independent Variable	Pain Self Perception Scale (PSPS)	Dependent Variable	ANCOVA	Chronic pain patients (*n*=27) Chronic pain volunteers (*n*=27) The ANCOVA also controlled for the effects of age, anxiety and depression	$F_{(1,49)}=5.1$, $p<0.05$	Medium	15

Psychological Associations and Relationships with Mental Defeat									
Tang et al., 2010	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.60, *p*<0.001	Large	11
Tang et al., 2016	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.65, *p*<0.001	Large	14
Garcia-Campayo et al., 2010	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.57, *p*<0.001	Large	14
Tang et al., 2013	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.62, *p*<0.001	Large	15
Tang et al., 2007	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=126)	*r*=0.62, *p*<0.001	Large	15
Tang et al., 2010	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=1.11	Large	11
Tang et al., 2010	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Linear regression	Chronic Pain Patients (*n*=133)	Dependent variable: Anxiety Predictor(s):Pain Intensity, rumination, health anxiety, worry (R^2=0.36). Mental defeat was added and was a significant predictor, Model R^2=0.36). Pain catastrophising was entered and was the strongest predictor, Model R^2=0.39.		11

Tang et al., 2010	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=133)	Mental defeat was a significant predictor of anxiety alongside catastrophising, worry tendency, health anxiety (F(4,128)=37.7, p<0.001). Together these accounted for 54% of the variance in Anxiety. Mental defeat accounted for 2% of the variance, with catastrophising accounting for 39%, worry tendency for 10%, Health anxiety for 4%.		11
Tang et al., 2013	Psychological	Anxiety	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Hierarchical linear regression	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	Dependent variable: Anxiety Predictor(s):Pain Severity (R^2=0.14). Mental defeat was added and was a significant predictor (Standardised B=0.58 (*F* change = 30.48, *p*<0.001)) Model R^2=0.38, R2 change=0.25) Effect size attributable to the addition of mental defeat= f^2=0.38	Large	15
Tang et al., 2010	Psychological	Anxiety (wth Pain intensity and age partialled out)	Hospital Anxiety and Depression Scale (HADS) - removing pain intensity, age	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.58, *p*<0.001	Large	11
Tang et al., 2010	Psychological	Anxiety (wth Pain intensity partialled out) - removing pain intensity	Hospital Anxiety and Depression Scale (HADS) - pain intensity	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.59, *p*<0.001	Large	11
Tang et al., 2010	Psychological	Anxiety (wth Pain intensity, age and body mass index partialled out)	Hospital Anxiety and Depression Scale (HADS) - removing pain intensity, age, BMI	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	*r*=0.57, *p*<0.001	Large	11

Tang et al., 2010	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=133)	*r*=0.66, *p*<0.001	Large	11
Tang et al., 2016	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=57)	*r*=0.66, *p*<0.001	Large	14
Garcia-Campayo et al., 2010	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Fibromylgia Patients (*n*=250)	*r*=0.63, *p*<0.001	Large	14
Tang et al., 2013	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	*r*=0.61, *p*<0.001	Large	15
Tang et al., 2007	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Association	Pearson's Correlation	Chronic Pain Patients (*n*=126)	*r*=0.65, *p*<0.001	Large	15
Tang et al., 2010	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Independent variable	t test	Chronic Pain Patients (*n*=133): Group 1 - High Mental defeat (PSPS scores >23) (*n*=62) Group 2 - Low Mental defeat (PSPS scores <23) (*n*=71)	Cohen's *d*=1.12	Large	11
Tang et al., 2010	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Linear regression	Chronic Pain Patients (*n*=133)	Dependent variable: Depression Predictor variables: Catastrophising, Pain intensity, Health Anxiety, Rumination, worry (R^2=0.23). Mental defeat was added and was a significant predictor (Standardised *B*=0.66. Model R^2=0.43) Effect size attributable to the addition of mental defeat= f^2=0.35	Large	11

Tang et al., 2010	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Stepwise regression	Chronic Pain Patients (*n*=133)	Mental defeat was a significant predictor of depression alongside health anxiety ($F_{(2,130)}$=59.1, p<0.001). Together these factors accounted for 48% of the variance. Mental defeat accounted for 44% of the variance and health anxiety for 4%.		11
Tang et al., 2013	Psychological	Depression	Hospital Anxiety and Depression Scale (HADS)	Independent variable	Hierarchical linear regression	Chronic Pain (*n*=84, (patients (*n*=43), volunteers (*n*=41)))	Dependent variable: Depression Predictor(s):Employment, Pain severity (R^2=0.12). Mental defeat was added and was a significant predictor (Standardised B=0.64 (F change = 31.53, p<0.001)) Model R^2=0.38, R2 change=0.26) Effect size attributable to the addition of mental defeat= f^2=0.42	Large	15
Tang et al., 2010	Psychological	Depression (with Pain intensity and age partialled out)	Hospital Anxiety and Depression Scale (HADS) - removing pain intensity, age	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.62, p<0.001	Large	11
Tang et al., 2010	Psychological	Depression (with Pain intensity partialled out)	Hospital Anxiety and Depression Scale (HADS) - pain intensity	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.63, p<0.001	Large	11
Tang et al., 2010	Psychological	Depression (with Pain intensity, age and body mass index partialled out)	Hospital Anxiety and Depression Scale (HADS) - removing pain intensity, age, BMI	Association	Partial Correlation	Chronic Pain Patients (*n*=133)	r=0.63, p<0.001	Large	11
Treatment associations and Relationships with Mental Defeat									
Izquierdo-	Treatment	Hyperbaric Oxygen	Pre and post intervention	Dependent variable	MANOVA	Fibromyalgia - Intervention pre	d=0.74, p<0.001	Medium	20†

Alventosa et al., 2024		Therapy treatment (8 weeks, 5 sessions per week) vs control group	group vs pre and post control group			(*n*=17) & post (*n*=17). Control group pre (*n*=16) & post (*n*=16).			
† Score derived using full Downs & Black Checklist scores are higher, max score=28 PSPS= Pain Self Perception Scale									

Appendix A.3 – Search Terms

The search of the databases was performed on May 14th 2024 using the search terms identified below.

Database	Search Terms	Records
Medline PsychINFO Embase	1. (Defeat adj3 (mental or sense or feeling)).ab,ti 2. Pain.ti,ab. 3. Chronic Pain/ or Pain/ 4. 2 or 3 5. 1 and 4	Medline = 19 PsychINFO=13 Embase = 26
PubMed	1. "pain"[MeSH Terms] OR "chronic pain"[MeSH Terms] 2. "pain"[Title/Abstract] 3. "pain"[MeSH Terms] OR "chronic pain"[MeSH Terms] OR "pain"[Title/Abstract] 4. "defeat"[Title/Abstract] AND ("sense"[Title/Abstract] OR "feeling"[Title/Abstract] OR "mental"[Title/Abstract]) 5. ("pain"[MeSH Terms] OR "chronic pain"[MeSH Terms] OR "pain"[Title/Abstract]) AND ("defeat"[Title/Abstract] AND ("sense"[Title/Abstract] OR "feeling"[Title/Abstract] OR "mental"[Title/Abstract]))	PubMed=28
CINAHL	1. TI (Defeat n3 (feeling or sense or mental)) OR AB (Defeat n3 (feeling or sense or mental)) 2. TI pain OR AB pain 3. (MH "Pain") OR (MH "Chronic Pain") 4. S2 OR S3 5. S1 AND S4	CINAHL=11
Scopus	(TITLE-ABS-KEY (defeat W/3 (feeling OR sense OR mental)) AND TITLE-ABS-KEY (pain))	Scopus= 26

Appendix A.4. – Items of Downs and Black's Risk of Bias Checklist

Reporting

1. *Is the hypothesis/aim/objective of the study clearly described*? YES = 1, NO = 0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?* If the main outcomes are first mentioned in the Results section, the question should be answered no. YES = 1, NO = 0

3. *Are the characteristics of the patients included in the study clearly described?*

In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given. YES=1, NO=0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?*

A list of principal confounders is provided. YES = 2, NO = 0, Partially = 1

6. *Are the main findings of the study clearly described?* YES = 1, NO = 0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?* YES = 1, NO = 0

10. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001? YES = 1, NO = 0

Items Excluded for Observational studies:

4. *Are the interventions of interest clearly described?* Treatments and placebo (where relevant) that are to be compared should be clearly described. YES = 1, NO = 0

8. Have all important adverse events that may be a consequence of the intervention been reported? YES = 1, NO = 0

9. *Have the characteristics of patients lost to follow-up been described?*

YES = 1, NO = 0

External Validity

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?*

YES = 1, NO = 0, unable to determine = 0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?*

YES = 1, NO = 0, Unable to determine = 0

13. *Were the staff places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?* YES = 1, NO = 0, Unable to determine = 0

Internal Validity – Bias

16. If any of the results of the study were based on "data dredging", was this made clear?

YES = 1, NO = 0, Unable to determine = 0

18. *Were the statistical tests used to assess the main outcomes appropriate?*

YES = 1, NO = 0, Unable to determine = 0

20. *Were the main outcome measures used accurate (valid and reliable)?* YES = 1, NO = 0, Unable to determine = 0

Items Excluded for Observational studies:

14. *Was an attempt made to blind study subjects to the intervention they have received*?

YES = 1, NO = 0, Unable to determine = 0

15. *Was an attempt made to blind those measuring the main outcomes of the intervention?*

YES = 1, NO = 0, Unable to determine = 0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?* YES = 1, NO = 0, Unable to determine = 0

19. *Was compliance with the intervention/s reliable?* YES = 1, NO = 0, Unable to determine = 0

Internal Validity – confounding (selection bias)

21.*Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?* YES = 1, NO = 0, Unable to determine = 0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?*

YES = 1, NO = 0, Unable to determine = 0

23. *Were study subjects randomised to intervention groups?*

YES = 1, NO = 0, Unable to determine = 0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?* YES = 1, NO = 0,

Unable to determine = 0

Items Excluded for Observational studies:

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?* YES = 1, NO = 0,

Unable to determine = 0

26. *Were losses of patients to follow-up taken into account?* YES = 1, NO = 0,

Unable to determine = 0

Power

27. *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?* YES=1, NO=0

Appendix A.5. – Quality and risk of bias ratings

Observational Studies

Author	Reporting Score (Max=8)	External validity score (max=3)	Internal Validity – Bias Score (Max=3)	Internal Validity confounding (selection bias) score (Max=4)	Power Score (Max=1)	TOTAL Score (max=19)
Tang et al., 2007	8	2	3	1	1	15
Tang, 2013	8	2	3	2	0	15
Cheatle et al., 2023	8	1	3	1	1	14
Garcia-Campayo et al., 2010	8	2	3	1	0	14
Hazeldine-Baker et al., 2018	8	1	3	1	1	14
Tang et al., 2016	6	3	3	2	0	14
Ayache et al., 2021	7	0	3	2	1	13
Turner-Cobb et al., 2015	7	2	3	1	0	13
Tang et al., 2010	7	1	3	0	0	11
Themelis et al., 2023	7	0	3	0	0	10
Philips, 2015	5	0	3	0	0	8

Experimental Studies

Author	Reporting Score (Max 11)	External validity score (max=3)	Internal Validity - Bias Score (Max=7)	Internal Validity confounding (selection bias) score (Max=6)	Power Score (Max=1)	TOTAL Score (max=28)
Izquierdo-Alventosa et al., 2024	8	1	6	4	1	20

Appendix A.6. – Conflict of interest statement for academic papers

The authors certify that they have no involvement or affiliation with any body or organisation that has a financial interest in the subject of this review. Authors McAteer and Risdon declare that they have no involvement or affiliation with any body or organisation with any non-financial interest in the subject of this review. Author Salkovskis declares authorship of four of the articles reviewed in this systematic review. However, all efforts were taken to reduce bias and author Salkovskis was not involved with conducting the search, undertaking the risk of bias/ quality assessment. He was involved in resolving a disagreement of opinion between the two reviewers on the inclusion of one article.

Appendix B – Service Improvement Project

Appendix B.1. – Instructions to Authors for Journal of Therapeutic Communities

Before you start

For queries relating to the status of your paper pre decision, please contact the Editor or Journal Editorial Office. For queries post acceptance, please contact the Supplier Project Manager. These details can be found in the Editorial Team section.

Author responsibilities

Our goal is to provide you with a professional and courteous experience at each stage of the review and publication process. There are also some responsibilities that sit with you as the author. Our expectation is that you will:

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- Treat communications between you and the journal editor as confidential until an editorial decision has been made.
- Read about our research ethics for authorship. These state that you must:
    - **Include** anyone who has made a substantial and meaningful contribution to the submission (anyone else involved in the paper should be listed in the acknowledgements).
    - **Exclude** anyone who hasn't contributed to the paper, or who has chosen not to be associated with the research.
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Article length / word count	Articles should be between 3000 and 5000 words in length. This includes all text, for example, the structured abstract, references, all text in tables, and figures and appendices. Please allow 350 words for each figure or table.
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Biographies and acknowledgements	If you want to include these items, save them in a separate Microsoft Word document and upload the file with your submission. Where they are included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Your article must reference all sources of external research funding in the acknowledgements section. You should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
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Headings	Headings must be concise, with a clear indication of the required hierarchy. The preferred format is for first level headings to be in bold, and subsequent sub-headings to be in medium italics.
Notes/endnotes	Notes or endnotes should only be used if absolutely necessary. They should be identified in the text by consecutive numbers enclosed in square brackets. These numbers should then be listed, and explained, at the end of the article.
Figures	All figures (charts, diagrams, line drawings, webpages/screenshots, and photographic images) should be submitted electronically. Both colour and black and white files are accepted. There are a few other important points to note: □All figures should be supplied at the highest resolution/quality possible with numbers and text clearly legible. □Acceptable formats are .ai, .eps, .jpeg, .bmp, and .tif. □Electronic figures created in other applications should be supplied in their original formats and should also be either copied and pasted into a blank MS Word document, or submitted as a PDF file. □All figures should be numbered consecutively with Arabic numerals and have clear captions. □All photographs should be numbered as Plate 1, 2, 3, etc. and have clear captions. □All figure/table captions should include the necessary credit line, acknowledgement, or attribution if you have been given permission to use the figure/table; if the figure/table is the property of the author(s), this should be acknowledged in the caption.
Tables	Tables should be typed and submitted in a separate file to the main body of the article. The position of each table should be clearly labelled in the main body of the article with corresponding labels

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For books	Surname, initials (year), *title of book*, publisher, place of publication. e.g. Harrow, R. (2005), *No Place to Hide*, Simon & Schuster, New York, NY.

For book chapters	Surname, initials (year), "chapter title", editor's surname, initials (Ed.), *title of book*, publisher, place of publication, page numbers. e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", Stankosky, M. (Ed.), *Creating the Discipline of Knowledge Management*, Elsevier, New York, NY, pp.15-20.
For journals	Surname, initials (year), "title of article", *journal name*, volume issue, page numbers. e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", *Journal of Consumer Marketing*, Vol. 22 No. 2, pp.72-80.
For published conference proceedings	Surname, initials (year of publication), "title of paper", in editor's surname, initials (Ed.), *title of published proceeding which may include place and date(s) held*, publisher, place of publication, page numbers. e.g. Wilde, S. and Cox, C. (2008), "Principal factors contributing to the competitiveness of tourism destinations at varying stages of development", in Richardson, S., Fredline, L., Patiar A., & Ternel, M. (Ed.s), *CAUTHE 2008: Where the 'bloody hell' are we?*, Griffith University, Gold Coast, Qld, pp.115-118.
For unpublished conference proceedings	Surname, initials (year), "title of paper", paper presented at [name of conference], [date of conference], [place of conference], available at: URL if freely available on the internet (accessed date). e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).
For working papers	Surname, initials (year), "title of article", working paper [number if available], institution or organization, place of organization, date. e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.
For encyclopaedia entries (with no author or editor)	*Title of encyclopaedia* (year), "title of entry", volume, edition, title of encyclopaedia, publisher, place of publication, page numbers. e.g. *Encyclopaedia Britannica* (1926), "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp.765-771. (for authored entries, please refer to book chapter guidelines above)
For newspaper articles (authored)	Surname, initials (year), "article title", *newspaper*, date, page numbers. e.g. Smith, A. (2008), "Money for old rope", *Daily News*, 21 January, pp.1, 3-4.

For newspaper articles (non-authored)	*Newspaper* (year), "article title", date, page numbers. e.g. *Daily News* (2008), "Small change", 2 February, p.7.
For archival or other unpublished sources	Surname, initials (year), "title of document", unpublished manuscript, collection name, inventory record, name of archive, location of archive. e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", unpublished manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.
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For data	Surname, initials (year), *title of dataset*, name of data repository, available at: persistent URL, (accessed date month year). e.g. Campbell, A. and Kahn, R.L. (2015), *American National Election Study, 1948*, ICPSR07218-v4, Inter-university Consortium for Political and Social Research (distributor), Ann Arbor, MI, available at: https://doi.org/10.3886/ICPSR07218.v4 (accessed 20 June 2018)

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- Does your manuscript comply with our research and publishing ethics guidelines?
- Have you cleared any necessary publishing permissions?

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    - Any acknowledgments or author biographies should be uploaded as separate files.
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Appendix B.2. – Lay Summary

This project aimed to provide recommendations to improve the Service User Network (SUN) Service in Berkshire Healthcare NHS Foundation Trust. The service offers support to those in the community who have personality disorders or similar problems with relationships or emotional regulation. The project employed an analysis of quantitative data collected by the service as well as interviews and focus groups conducted with people who use the service and those who facilitate its groups. The data was analysed to find that the service was offering a consistent space to provide peer-support groups in the style of a therapeutic community. While recent staffing issues had limited the number of groups and overall appointments that the service offered in recent months, 598 people had been referred to the service and just over half of these had attended at least one group. The analysis of the service user and staff focus groups and interviews were understood through a thematic framework based on a theoretical model of a therapeutic community. These themes included experiences of *attachment* to the SUN community and finding a culture of belonging, being *contained* by the community in a culture of safety, *communication* providing a culture of openness, *involvement* and inclusion in a culture of participation and citizenship, and to find personal *agency* in a culture of empowerment. Recommendations to improve the service were made based on areas identified in the analysis.

Appendix B.3. – Participant Information Sheet

Service Improvement Project of the Service User Network (SUN) in Berkshire NHS Foundation Trust

Participant Information Sheet

You have been invited to participate in a service improvement project being conducted in the Service User Network (SUN). The project is being conducted as one part of a Doctorate in Clinical Psychology based at the University of Oxford. The project has approval from the clinical audit team in NHS Berkshire Healthcare Foundation Trust. Before you decide whether you wish to participate, it is important to understand why the project is being conducted and what it will involve. Please read the following information carefully before you consider being involved in the project.

What is the purpose of the project?

This project aims to explore experiences of people who have been offered the SUN service. It seeks to gain the perspectives of both those who use the service, and those who have self-referred to the service but have not attended. This is with the aim to understand what members' experiences of using the service are, the things that are being done well by the service, and identify ways to improve the service for those who use the service. It will also explore how you use the service and how the SUN connects people. In addition to speaking with members, the project will also engage with staff who facilitate group in order to get their perspectives and experiences.

Why have I been chosen?

All people who have been invited to the SUN Service have been invited to participate in the service evaluation via this email. Those who volunteer to participate in the project will be eligible to join the focus groups or individual interviews. Unfortunately, due to the limited numbers of people who can be involved in the focus group or individual interviews, not everyone who volunteers can be involved. Those who complete the registration form but will not be involved in the service evaluation project will be e-mailed to thank them for registering their interest. Rather than speaking to a large number of people, the aim is to speak to people who span a range of different demographic categories as well as different levels of service use. This means that a number of people will be selected and invited to participate and these people will be e-mailed to arrange a time.

What will taking part involve?

Taking part will involve completing the online form which was attached to the e-mail you received and providing your voluntary and informed consent to participate. Responses to this form go to the project coordinator and not the SUN Staff. After answering some short questions on your demographic information and providing your e-mail address you can submit the form. In this information form you will be asked whether you would like to be considered for the focus group or for the individual interviews. If you are selected to participate you will be contacted by the project coordinator via e-mail. You will be sent a consent form which you will need to complete and return. Interviews will be organised at a time when you are available. The focus group will take place on Wednesday 29th March 2023 at 10am and will last for 2 hours. Individual interviews will be arranged at a time convenient to you and will last approximately 30-45 minutes. This will involve talking with a member of the service improvement project team via Microsoft Teams or on the telephone. The interview

and focus group will be audio recorded and the conversation will be transcribed into a written format.

Who will know I have taken part if I choose to do so?

Participation in this project will remain anonymous from the staff team who operate the SUN service. No personal information on your involvement will be presented back to the staff team. Only other members who attend the focus group will be aware of anyone else who is participating in the project. Those who are involved in individual interviews will not be identified to others. Information on demographics will be used to describe the sample profile of people who participate, by collecting broad information such as broad age band, but identifiable information such as names and e-mail addresses will not be passed to the SUN staff team.

Do I have to take part?

There is no obligation to take part in the project. You will not be penalised for not participating in any aspect of the project. If you do decide to participate, you can withdraw from the project at any time during the data collection period. Once we have received your online form, the project coordinator will contact you via e-mail and ask you to participate in either a focus group or an individual interview using Microsoft Teams or the telephone and attach a consent form sheet. You may withdraw at any time without giving a reason by contacting the project coordinator (see below). This will not affect your ability to engage with the SUN service in any way.

What are the benefits of taking part?

We value your participation as you will be helping to improve our understanding of how people engage with the SUN service and your experiences of using it or why you may not use it. This will be reported back to the SUN service in a way that can inform staff on what works well and where improvements can be made to best support people who use the service. Unfortunately, there is no paid incentive for participating but giving your input and voice to the project will allow for your perspectives to be taken into account and used to make recommendations to improve the service.

What are the possible disadvantages and risks of taking part?

The interviewer will ask you about your experiences of using the SUN service. There is potential for this to bring up a range of emotions. We advise that you take as many breaks as you need. You may also withdraw at any point without giving a reason or any penalty. If there are any concerns about risk of harm to yourself or others, this will be fed back to the SUN service and you may receive a follow-up call. You are also welcome to contact the project coordinator if you have any questions around this.

What will happen with my data?

The information you give will be anonymised and kept confidential within a secure location on NHS Berkshire Health Foundation trust servers with only the project coordinator (see below) having access to your interview responses. This means that nobody will be able to identify you from the answers you give. The audio recordings of the interviews will be deleted immediately once they have been transcribed into a written format and will not form part of your clinical notes. We will analyse the anonymised data from all participants to explore themes related to your experiences. Your anonymous data will be stored on a password protected device and deleted after five years. The team running the service evaluation will have access to the anonymised data. Data will be managed in adherence to Berkshire

Healthcare Foundation Trust (BHFT) Information Governance Policy. All personal information that could identify you will be removed or changed before feedback is shared with the SUN team.

Will the project be published?

The project write up will be circulated to those involved with the organisation and running of the SUN service in order to communicate findings and recommendations to improve service. The write up may be submitted to an academic journal to help disseminate findings. In this publication, we may use quotes that have been said during the focus group or depth interview but you will never be able to be identified from these quotes. The project findings will also be communicated to the SUN Service Users through a summary of key findings and at a discussion at a Your Say Morning.

What if there is a problem?

If you have a concern about any aspect of this study, please contact Gareth McAteer (Gareth.mcateer@gtc.ox.ac.uk) or Alasdair Churchard (alasdair.churchard@hmc.ox.ac.uk) and we will do our best to answer your query.

We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact: Loretta Verrall (loretta.verrall@berkshire.nhs.uk)

If you have any further questions about the study before deciding whether to participate, please contact the project coordinator Gareth McAteer (gareth.mcateer@berkshire.nhs.uk).

Appendix B.4. – Participant Consent Form

Service Improvement Project of the Service User Network (SUN) in Berkshire NHS Foundation Trust
Consent Form

Purpose of the project
This project aims to explore experiences of people who use SUN service as well as those who do not use the service or who have been offered to use the service but have not regularly done so. This is with the aim to understand what members' experiences of using the service are, what is being done well by the service, what members would like to see improve and what might remove some barriers from participating and engaging.
Please read through the following statements and put an 'X' in the box to the right to indicate your consent to participate:

1. I confirm that I have read and understood the information sheet and I have had the opportunity to consider the information, ask questions and have had any questions answered.	
2. I understand that the aim of the project is to evaluate the service provided by the service user network (SUN) and provide recommendations for possible improvements.	
3. I understand that my participation is voluntary and is not related to any healthcare I receive. I understand that I am free to withdraw at any time without adverse consequence or penalty, without giving a reason and I have been told how to do this.	
4. I understand that the interview/ focus group will be audio recorded and transcribed into a written format that will be anonymised. I understand that the audio recordings will then be deleted.	
5. I understand that the data collected during the project will be held securely and may be accessed by people in the service improvement project team. I give permission for these people to access my data.	
6. I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project	
7. I understand that the interview recording and transcript will not form any part of my clinical notes. As data will be anonymised, the SUN service will not be able to respond to any comments made.	
8. I understand how to raise a concern or how make a complaint based on the information provided in the information sheet.	
9. I consent to participating in the project	

Signature:
Print Name:
Date:
Project Coordinator: Gareth McAteer – gareth.mcateer@berkshire.nhs.uk

Appendix B.5. – Interview Schedule/ Guide

Service User Network – Service User Interviews Topic Guide	
Introductions *Introduce self* *Introduce the Service Improvement Project:* This service improvement project aims to get an understanding of the Service User Network (SUN) from the people who use the SUN service. - *Explain that the interview will last up to 45 minutes* - *Provide reassurances of anonymity and confidentiality. Explain that no information about individuals will be passed on to anyone outside the project and they will not be made known to the SUN team unless they reveal this themselves.* - *We will be asking about a range of topics today including your perceptions of the service, how you access it, your perceptions of what could be done to improve it. You do not have to answer any questions or give any information that may be too personal or that you do not wish to share. If anything that distressing comes up let me know and feel free to take a break or leave the interview at any point.* - *Request permission to record interview.* - *Do you have any questions you'd like to ask before we start?* **Allow respondents to introduce themselves:** • We would like to get to know you all a little today so perhaps you could introduce yourself • How long you have been using the SUN service? • Have you ever/ How often or regularly attend SUN groups?	
Section 1: Perceptions of the service	
1.1	Can you tell me a little bit about the SUN service as it is? • Prompts: • How does the service operate? • What types of things does the service provide you? • How does the service run at the minute?
1.2	What do you think the purposes or aims of the service are?
Section 2: Awareness of current service provisions	
2.1	Can you describe to me what it is like to participate in a group? • Probe: • What happens in a typical group? • Is there a structure to each group? (Check in; Agenda etc.) Have you a crisis support plan you could tell me about? • When did you agree this? • Is this useful to you? • What were your experiences of doing this?
2.2	How does the service communicate with you? • How do you find out what is going on within the service? • How do you know when groups are available to join?
Section 3: Accessing the service	
3.1	We are now going to explore how you accessed or enrolled with the SUN service. This will include how you found out about the service and got involved, as well as your continued access to the service. Can you describe how you heard about/ became involved with the service? • Probe: • How did you get in touch with the group to self-refer?

	• How would you describe the referral process?
3.2	What encourages you to use the service? • Probe: • Are there times you use the service more than other times? • Would you want to use the service more? • Is using the service more frequently a good thing for you? Are there any barriers you experience to using the service? • Probe: • Any reasons why you do not attend more regularly? • Is there anything you can think of that would increase your attendance at the service? • Is there anything that would increase your engagement in groups you do attend?
3.3	IF NEVER USED OR NON-REGULAR What would encourage you to use the SUN service/ use the service more regularly? What are the reasons you have not used the service? / What are the reasons you have stopped using the service?
IF USED SERVICE: Section 4: Experiences of using the service/ Group culture	
4.1	Do you feel you are able to approach the service when you need it? • Is it easy to access a group? • How does the group usually respond to you?
4.2	I would now like you to think of being within a group that you have attended. Do you feel like the group you are in supports you? • How are you able to communicate within the group? • Do you feel like you are seen by the group? • Can you describe the relationships between people within the group?
4.3	How would you describe the culture and environments within the groups you have attended? • Probe: • Interactions with group • Interactions with staff
4.4	Can you describe to me what an ideal SUN session would involve for you? • How would it be run? • Who would be in the group with you?
IF USED SERVICE: Section 5: Changes/ Benefits from using the service	
5.1	Has using the service had any impacts on your life? • How would you describe these impacts? (positive/ negative) • What are some of the positive impacts (benefits)? • Are there any negative impacts or drawbacks?
5.2	Has attending the service had any wider benefits to your life? • Probe: • Completing tasks • Managing finances • In close relationships • Feeling alone or isolated from relationships
5.3	Has attending the service helped you improved in your ability to cope during difficult times? • How has it improved your ability to cope? • Have you used other healthcare services less because you use the SUN service?

5.4	Do you feel sharing with others and hearing their experiences has had an impact on you? • Probe: • Why has this been useful? What are your goals for using the service? • Have you identified any common goals with others in the groups?
IF USED SERVICE: Section 6: Attitudes towards the group/ Attachment	
6.1	Do you feel the service offers a supportive environment? • Probe: • In what ways is it supportive? • What aspects are supportive? • Does it feel safe?
6.2	Do you feel connected to the other people who are in the SUN community? • What connects you to the community? • Do you notice when you have not attended the groups in a while?
6.3	Who are you within the SUN group? • Probe: Have you changed over time within the group? • Context (do not read out): Membership of the therapeutic community is viewed in the model as offering service users an opportunity to engage in 'referencing' within the group by establishing themselves 'within a context specific narrative' in order to feel a sense of self being accurately perceived.
Section 7: Service Improvements	
7.1	In what ways do you think the service could improve? Why do you think this would improve your experiences? • Attend more? • Provide more resources or information? • Encourage others to attend? • Improve the environment in the service meetings? • Improve the support the service offers?
7.2	IF USED SERVICE: What would help you feel more accepted in groups you attend?
7.3	What would encourage you to use the SUN Service/ use the SUN Service more regularly?
Section 8: Closing	
8.1	**Closing** Any final thoughts on you and the SUN service? Thank participants and discuss dissemination. Offer participant chance to debrief after interview.

Appendix B.6. – Framework Analysis Stages

The table below details the stages of data analysis undertaken in the framework analysis of collected qualitative data. Data was analysed using the framework analysis approach to analysing qualitative data outlined by Goldsmith, (2021). This involves five stages of analysis and the considerations taken at each step are outlined.

Stage	Overview of stage procedures
1 – Data Familiarisation	This stage involved becoming familiar with the data. This included listening back to the collected interviews and transcribing data into text format. Following this, all data was categorised using the collected information participants provided. Each interview and focus group transcript was then read numerous times, and codes were applied to specific aspects of the collected data. These codes were generated iteratively and throughout the reading process. Transcripts were read numerous times to ensure that all information was coded. Service user data transcripts were analysed first and the codes generated at this were used when analysing data from the facilitator focus group transcript. While some new facilitator only codes were created to do this, many of the same codes used for service users encapsulated the facilitator data.
2 – Framework identification	The second step in the framework analysis approach is to develop a conceptual framework. As noted, the conceptual framework used to evaluate the efficacy of the SUN service was guided by the five principles outlined by Haigh (2013) that facilitate secondary emotional growth in a therapeutic community. The five top level themes and sub-themes were identified from the theoretical article. The coded data was then reviewed in order to determine whether this framework was appropriate. Minor alterations to the framework were made to ensure that all study data was accounted for. An example of an alteration to the framework structure included adding in an additional sub-theme to the theme of Attachment. This was to account for some experiences of users who had used the service and after lapsing in their use returned after some time. Appendix B.7. outlines the framework used to map the theoretical components required in the therapeutic community to the structures operating in the SUN service.
3 - Indexing	This stage involved mapping all coded data from the original coding phase to the identified conceptual framework. This was helped by the structured topic guide and the theoretical framework being linked to particular aspects of the therapeutic community. The final indexing step of mapping coded data to the theoretical framework themes and sub-themes can be seen in Appendix B.8 for the theme of *Containment*.
4 - Charting	After indexing, all study data was then charted in order to uncover patterns within the data with particular reference to service user profiles. All questions were charted and responses counted across the different service user profiles: *never used the service; lapsed users; irregular users, regular users* and *staff*. Appendix B.9. shows the matrix tables used to chart all study data for the *Attachment* theme.
5 – Mapping and interpretation	The final stage involves interpreting the data and uncovering patterns in it through mapping. This was completed by studying charted data using the framework and an excerpt of this is included in Appendix B.10.

Appendix B.7. – Framework

The table below details the final framework overview for understanding and mapping study data relating to service user and staff perspectives on the SUN Service. The themes identified by Haigh (2011) were used to determine the 5 top level themes and the sub-level themes related to an effective therapeutic community. The sub-themes derived from Haigh were mapped to component parts of the collected data set.

Sub Theme	Initial indexing of collected study data to framework
Theme 1 - Attachment	
Referral	How heard about the service
	Perceptions of the service
	Goals for using service
Joining	Barriers to approach
	Crisis and Support Plans (CASPs)
Leaving	Reasons for leaving
Returning	Factors encouraging approach
	Returning after some time
Theme 2 - Containment	
Rules	Structure of groups
	Unsupportive Behaviour
Support	Support from others
	Supporting Others
Boundaries	Boundaries in place
	Difficulties Asserting boundaries
	Safe Environment
Theme 3 - Communication	
Groups	Communication between members
	Communication between members and facilitators
	Conflict
Correspondence	Communication about service from facilitators
	Communication from or about service
Ethos	Service Aims
	What makes a good group
	What makes a bad group
Theme 4 – Involvement	
Community	Culture and environments
	Connection to others
Participation	What is it like to participate
	Group sees you
Learning	Impacts and benefits
	Learn through involvement
Interdependence	Depend
	Help to cope
Theme 5 - Agency	
Empowerment	Impacts of attending
	Ability to manage
	Decisions
Individuation	Identity
	Seniority
Establishing self as seat of action	Responsibility inside groups
	Responsibility outside groups

Appendix B.8. – Framework themes and Codes Indexing

The table below illustrates how all codes that were derived from the reading of the data were indexed to the identified framework.

Sub Theme	Sub-theme component	Codes
Theme 2 – Containment		
Rules	Structure of groups	A : Awareness of SUN model B : Change in service since christmas - less groups C : Group sizes D : groups are confidential E : Offers online and in-person groups F : Rigidity of structure G : Structure of group H : Two facilitators who lead session I : Balanced groups - supportive J : Groups are structured K : there are less groups now than before L : barr - few or reduced groups offered difficult to find one to join M : barr - physically getting to groups N : barr - staff reductions less groups O : Ideal - online groups very convenient when having a tough time P : Not ideal - online groups hard to see other people Q : Not ideal - online groups hard to speak R : Online groups can be easier to participate - can raise hand S : online groups can have technological issues which get in the way of support T : Support depends on size of group U : being seen depends on group size V : Not seen because not available - no groups at appropriate times W : Improve - More consistency of facilitators - rules X : Improve - Structure of groups can vary with facilitators Y : Group structure could be communicated better Z : Groups can be rigid in structure and rules AA : There are no boundaries AB : Facilitators not consistent with how structure is implemented AC : Facilitators on group platform AD : reduce length of them AE : Facilitators on structure of groups AF : Facilitators on SUN model AG : CASP - for new members
	Unsupportive Behaviour	A : Unsupportive behaviour B : Facilitators attacked by members C : Facilitators can be unsupportive D : Other members - cliques E : Other members nasty - bullying F : People can be banned in groups G : Relationships with other members can be frustrating

		H : Not ideal - feeling attacked by other members I : Some members not supportive J : Support depends on other members present K : Support differs by which facilitators are there L : Support experiences influenced by facilitators responses M : cliquey N : Connected - NOT because cliques O : Safe - NO - certain other members P : Facilitators who put boundaries in get aggression Q : Facilitators boundaries to keep them safe R : Facilitators not regulating members conflicts S : Facilitators on whether supportive environment T : Responsibility for members to facilitate U : Responsibility to regulate groups
Support	Support from others	A : cheap support - not real support B : Offer Support in recovery journey C : Support each other D : Support for people who are struggling E : Balanced groups - supportive F : Finding others like you - positive G : Groups can be supportive H : Other members giving support I : 60-40 supportive J : Groups can involve conflict with other members K : Member cliques can impact support L : Members in crisis on screen can be difficult M : Not supported to call out perceived antisocial behaviour N : Online groups can be easier to participate - can raise hand O : online groups can have technological issues which get in the way of support P : Positive support experiences Q : Some members not supportive R : Support - facilitators are kind S : Support - not enough for some people T : support - through shared understanding U : Support depends on other members present V : Support depends on size of group W : Support differs by which facilitators are there X : Support experiences influenced by facilitators responses Y : Supportive Z : Safe - NO - certain other members AA : Safe - NO - drugs AB : Safe - NO - members in crisis AC : Safe - NO - unsure AD : Faciliators on challenges facilitating - different members

		AE : Facilitators encourage members to be supportive to others AF : Facilitators give good advice AG : Facilitators have supervision AH : problem solving vs hypothetical open discussions AI : Facilitators on whether supportive environment
	Supporting Others	A : giving support to others is positive5555 B : Helping others feels good C : positive experiences of support D : Not supported to call out perceived antisocial behaviour E : Positive support experiences F : Some members not supportive G : Support depends on other members present H : Support differs by which facilitators are there I : Supportive J : goals - to support others K : Facilitators encourage members to be supportive to others L : Facilitators on whether supportive environment M : The group is inconsistent so hard for facilitators to be
Boundaries	Boundaries in place	A : Rigidity of structure B : Groups are structured C : Ideal - good boundaries D : Groups can be rigid in structure and rules E : Facilitators - what happens in group stays in group F : Facilitators boundaries to keep them safe G : Responsibility for members to facilitate
	Difficulties Asserting boundaries	A : Facilitators attacked by members B : Group structure needs to be more clear C : Groups are not vetted - anyone can come D : Other members - strong willed E : Other members nasty - bullying F : some groups are chaos G : barr - unsafe emotional environment - unsupportive - triggering H : bad experiences with other members I : Not emotionally safe environment J : Not professional K : Not ideal - feeling attacked by other members L : Not ideal - people checking out early M : Members in crisis on screen can be difficult N : Not supported to call out perceived antisocial behaviour O : Improve - Clarification for who the service is for - diagnosis or not P : Improve - Ensure that everyone has time to speak and be heard Q : Improve - Groups can be overcrowded and there is not space for everyone R : Improve - Managing conflicts in groups

		S : Improve - More consistency of facilitators - rules T : Improve - reduce lengths of groups U : Improve - Structure of groups can vary with facilitators V : Facilitators who put boundaries in get aggression W : Group structure could be communicated better X : Groups are not vetted Y : Hard for group to uphold boundaries Z : Need to be able to get on with people but choose not to be friends outside group AA : There are no boundaries AB : Which language can be used and not Trigger others AC : worried the group will call on me for emotional support at home AD : Faciliators on challenges facilitating - different members AE : Facilitators find it hard to manage risks AF : Facilitators need more consistency AG : Facilitators not consistent with how structure is implemented AH : Facilitators not regulating members conflicts AI : Responsibility for members to facilitate
	Safe Environment	A : Groups can feel not safe B : Other members nasty - bullying C : some groups are chaos D : bad experience E : bad experiences with other members F : Groups can be volitile G : Ideal - good boundaries H : Ideal - good facilitators I : Ideal - group size J : Ideal - to feel heard K : Impacts - going to group makes you feel better L : Impacts - positive knowing you are not going to be abandoned by Service M : Safe - NO - certain other members N : Safe - NO - drugs O : Safe - NO - members in crisis P : Safe - NO - unsure Q : Facilitators boundaries to keep them safe

Appendix B.9. – Matrix Tables

This section demonstrates step 4 of the Framework analysis step of charting. The tables below indicate the charting of study data and coding for specific nodes by service user and staff profiles. This allows for differences across groups to be easily identified.

1101 - How heard about the service	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : filled in some questionnaires before attending			X		
B : Getting involved was easy				X	
C : Heard about the service through friends or other channels	X				
D : Referred after crisis				X	
E : Referred after other therapy	X	X			
F : Referred by another MH practitioner	XX	X	X	XX	
G : Referred thinking group would help with additctions	X				
H : Referred while I waited for psychological therapy				XX	

1102 - Perceptions of the service	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : Awareness of SUN model				X	
B : CASP - for new members					X
C : Change in service since christmas - less groups				X	
D : facilitators raise concerns with things in groups			X		X
E : For people who have mental illness	X	X	X		
F : Group sizes					X
G : groups are confidential			X		
H : I do not think it could work - not valuing peer support	X				X
I : Less Groups means more distress				X	X
J : Members lead the groups	X			X	X
K : More cancelled groups - lack of current groups available				X	
L : No subject off limits			X		
M : Not widely advertised - specific needs or diagnoses			X		
N : Offers online and in-person groups			X		
O : Peer Support Group	XXX	X	XX	XX	X
P : People suffering from similar experiences	X	X	X	XX	
Q : People who are in distress				X	
R : Regular - weekly meetings	X				
S : Rigidity of structure				X	X

T : Service is for people in crisis situations - might not be bad enough	X				X
U : Structure of group			XX	XX	X
V : Taking anonymous minutes of groups				XX	X
W : Tension between members				X	
X : Tension between members and facilitators				XX	X
Y : To support self and support other			X		
Z : Two facilitators who lead session	X	X	X	X	X
AA : Unsupportive behaviour			X		X
AB : cheap support - not real support				X	
AC : Don't know - unsure	XX			X	
AD : Don't need a diagnosis			X		
AE : Easy to access support	X				
AF : For people who don't meet criteria for therapy		X			
AG : Its not therapy or treatment		X	X	X	
AH : No clincial responsibility		X		X	

1103 - Goals					
A : goals - get better				X	
B : goals - get ideas from other people			X	X	
C : goals - increase my understanding				X	
D : goals - stop lonliness				X	X
E : goals - to support others			X		

1201 - Barriers to approach	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : barr - Aversion to CASP	X				
B : barr - few or reduced groups offered difficult to find one to join			X	XX	
C : barr - groups are long	X	X	XX		X
D : barr - Have private therapy so less need	X				
E : barr - I don't belong - I am not bad enough	X				
F : barr - mental health barriers - not a therapy group so won't help		X			
G : barr - nervous to attend in person group			X		
H : barr - neurodivergent difficulties				X	
I : barr - not knowing which facilitators might be there - bad experiences with facilitators			X		X
J : barr - physically getting to groups				X	
K : barr - social anxiety	X				
L : barr - staff reductions less groups				X	X

M : barr - unable to make session times			X		
N : barr - unsafe emotional environment - unsupportive - triggering			X		
O : not fitting in - I'm not bad enough	X				
P : Not sure it would be helpful to me	X				
Q : Put off by CASP	X				
R : Sessions seem long	X				
S : Social anxiety	X				
T : worried that group other members will require emotional support outside of groups from me	X				

1202 - CASPs	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : CASP - A working document that is updated					X
B : CASP - Can be triggering			X	X	
C : CASP - can take a long time in session			X	XX	X
D : CASP - detracts from main forum			X	XX	X
E : CASP - Difficult to fill out				XX	
F : CASP - First session				XX	
G : CASP - Frustrating when new members do not return			X	X	X
H : CASP - Helpful			X	XX	
I : CASP - is posted to you after group			X		
J : CASP - legal issue no clinical responsibility				X	
K : CASP - Not used it since 1st session		X		XX	
L : CASP - Not useful			X		
M : CASP - people dont want to fill it out on first group				X	
N : CASP - Supported by other members when doing it			XX		
O : CASP - Used to doing CASPS in mental health services				X	
P : CASP - Useful			XX	X	X
Q : CASPS - Fill out before session alone				X	
R : Improve - CASP - takes a lot of time in groups			X	XX	
S : Improve - Contact new potential members before joining first group and doing CASP	XX			X	X
T : Facilitators on CASPS					XX

1301 - Reasons for leaving	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : Anxiety about which facilitators may be involved			X	X	X
B : bad experience		X	X	X	

C : bad experiences with other members		X			
D : Group is not helping - not therapy		X			
E : Groups not on at a time I can make - no evening groups			X		
F : Nervous to attend F2F group			X		
G : Not emotionally safe environment			X		
H : Not professional		X			
I : Too many people in a room		X			
J : Improve - new members do not return					X
K : Improve - staff retention					X
L : Facilitators on high turn over of staff					X
M : Facilitators on new members returning					X
N : Facilitators on staff dynamics					X
O : Facilitators on staff leaving and incentives to stay					X

1401 - Encourage approach	Never Used the Service	Lapsed User	Irregular User	Regular User	Staff
A : Coming regularly is a good thing				X	
B : Coming regularly likely means I am struggling more				X	
C : Coming regularly might be too much				X	X
D : community - friendship - social opportunities			X	X	X
E : Groups can be volitile			X		
F : Helping others feels good				XX	
G : I enjoy going to groups				X	
H : I feel I need to engage less in groups I do attend				X	
I : its part of my routine				XX	X
J : Lonliness				X	X
K : Negative experiences of other members - avoid members			X	X	
L : Other services did not give continuity of care - regular support			X		
M : positive experiences of support		X	X	X	
N : Support system - when I need help				XX	
O : Approach - difficult with limited timetable				X	
P : Approach - yes				XX	
Q : Improve - new members do not return					X
R : assess people before groups					X
S : Facilitators on new members returning					X

Appendix B.10. – Data Interpretation

Below is an excerpt from the data interpretation of the matrix tables and data

Sub Theme	Findings of framework analysis
Theme 1 - Attachment	
Referral	**How service users first heard about the service**
	Overview: Referral by a mental health practitioner was a common way in which people had first become involved with the service. Some were referred while they waited for other therapeutic involvement while others had been referred from SUN following therapeutic engagement. Some had contacted the service after hearing about it following a period of crisis or had contacted the service after hearing about it from a friend. **Differences by user profile:** Some of those who had not attended a group reported having believed the group to be for another problem (e.g. anxiety; addictions). Some who had not used the service had little idea who the service was targeted towards and therefore had not used the service thinking they might not be 'bad' enough. **Issues/ areas of service improvement:** A number of service users who had not used the service were unsure about who exactly the service was targeted towards or what joining would mean. Some were unsure about what it required. Providing more clear information when service users contact the service initially may provide more awareness and encourage new users to prepare for an undertaking of joining and increase retention in the community.
	Perceptions of the service
	Overview: When asked to describe the service, almost all participants identified it was a peer support group and many noting that it was designed for people with similar experiences that were experiencing mental health problems. **Differences by user profile**: Regular members were more likely to acknowledge the SUN model, undertaking the CASP in early sessions, the structure that underpins group, that groups took anonymous minutes of what happened and that there could be tensions within groups. Regular members were also more likely to describe changes in the service this year or since the groups merged between East and West. Members who had not yet used the service were not quite sure what to expect or how the service operated. The lack of 'clinical responsibility' and that it was not a therapy group were raised by members who had stopped attending. Members who had not yet used the service also were less clear on who it was for and whether it was only for those in crisis or distress.
	Goals for using service
	Overview: Goals for joining were also identified by a number of participants. These included wanting to get better, increase understanding of themselves, to get ideas on how to manage from other people with similar experiences. The social aspects of the community were reflected in wanting to decrease loneliness and wanting to support other people.
Joining	**Barriers to approach**
	Overview: A common barrier noted by a number of service users was that attending groups takes a long time at 2.5 hours. Other barriers revealed not being able to find an appropriate time for a group, not being able to or want to attend an in-person group and worries about which facilitators may be there.

	Recent changes to the timetable and the number of groups offered meant that a number of regular and irregular uses commented on the reduction in groups and how this made it more difficult to find on to join. Staff also commented on the reduction of staff and the timetable reductions. For some users this meant they could no longer find a time for a group to attend. **Differences by user profile:** Those who had never used the service said they had reservations about undertaking a CASP, that they were unsure if they would fit the profile of a user, were not sure that joining would be helpful to them and had social anxiety about attending. Irregular users commented on feeling like the groups were not safe emotional environments after having a negative experience with another group member or facilitator. **Issues/ areas of service improvement:** Some users were not returning to service because of a negative or unresolved experience within a group. More information before joining and encouraging members to engage with such negative experiences and returning to reflect upon them for community learning and growth may reduce the impact of such
	Crisis and Support Plans (CASPs)
	Overview: Both service users and staff said they had found undertaking the CASP to be a useful aspect of joining the first group. Staff referred positively to the design of the CASP and how it can be one of the most emotive aspects of doing a group and how it is a working document that can be regularly updated. Others did not find doing the CASP useful or said they had not used it since their first session. A common emerging theme was that doing CASPs can take a large amount of time within groups. This is especially the case if there are numerous new members present in a group. It was viewed by some as detracting from discussions within the main group forum and given the amount of time it takes, that it can be especially frustrating when new members do not return. **Differences by user profile:** Those who had never used the service found that being contacted before joining to consider their CASP would be useful as it was cited as a barrier to joining knowing it would be undertaken in the first session. Staff discussed how they encourage other members to help new members undertake their CASP and to provide support while doing it. Irregular uses had noted that they had been supported by members when they were doing their CASP. **Issues/ areas of service improvement:** Undertaking a CASP in front of others can be a daunting idea and more information provided to new members might be communicated before joining. Consider having service users who are intending to join to fill in CASP on paper prior to joining first session. Consider limiting the time dedicated to CASPs in session or limiting new members in each session to only one.
Leaving	**Reasons for leaving**
	Overview: A number of service users identified that they had a negative experience within a group with other members or the facilitators and this had contributed to not wanting to return. Other reasons provided included feeling that the service did not offer an emotionally safe environment, the group was not helping as it wasn't therapy, that there were too many people in a group and that groups were no longer on at a time that the individual could attend.

	Differences by user profile: Lapsed users commented on the negative experiences they had within a group as contributing to not wanting to return. This included bad experiences with other service users. Staff comments noted that many new members to the service do not return. Staff also commented on staff leaving the service, the high turnover of staff. They identified team dynamics, relationships with service users and a lack of career progression opportunities as reasons other staff members had chosen to leave. **Issues/ areas of service improvement:** Given many new members attend but do not return, encouraging new members to be ready for a commitment to attend a number of groups might be communicated to prospective service users. Consider ways to encourage staff retention. Consider ways to encourage reparation of conflicts within groups so that bad experiences are used in order for growth and learning and encouraging members to return after a negative experience.
Returning	**Factors encouraging approach**
	Overview: Factors that encouraged users to use the service identified included using the service for social opportunities and friendship. It was also a way to feel good about helping other people and being an important part of a weekly routine. Service users also drew attention to their having experienced positive experiences of support from attending a service as a key driver in encouraging them to come back when they needed support. **Differences by user profile:** Regular users said they enjoyed going to groups and used them for social opportunities or that it was a part of their weekly routine. They also mentioned using the service to avoid feelings of lonliness and that their role in helping other people during a group feels good. Regular users were more likely to say they used the service as a support system that they could attend when they needed help. Irregular users and lapsed users identified positive support experiences as being key to returning as well as the continuity of care that the service offers given that it can be attended regularly. **Issues/ areas of service improvement:** Factors promoting returning to the service were based on experiencing positive experiences of support. Encourage return despite negative emotional experiences in order to facilitate learning.
	Returning after some time
	Overview: Users who had stopped using the service for some time but returned said they were encouraged to do so for a number of reasons. This included having seen the service as something they could reach out to when they needed additional support. While coming to groups regularly was seen as a positive by some service users, others felt that regularly using groups was a sign that they might be struggling more and required support. **Issues/ areas of service improvement:** Many users who leave the service do not return.

Appendix B.11. – Dissemination of the Service Improvement Project: Feedback from service

Gareth delivered a very insightful and comprehensive report. His findings and recommendations were discussed as a team, to promoting learning. During this meeting, feasibility of proposed changes was discussed, alongside the meaning to some of his findings. Within this discussion, there was also a recognition thar the SUN service has changed and developed significantly over the past 6 months, with stability in the team vastly improved. As such, some of the recommendations were less applicable to the present-day service but were still important to hold in mind and learn from as the service continues to expand over the next year. I have highlighted two findings and recommendations below that were of particular interest.

Findings- Crisis and Support Plan (CASP):
Completion of the CASP document, or more specifically the amount of CASPs or time spent on this document in a group was cited as a barrier to engagement with the SUN service, and in some instances contributed to members leaving the service. This finding clearly has implications for member retention and member experience of groups. As a team we discussed the level of detail needed for this document; the team felt it was important for this document to have sufficient detail to be meaningful, however were mindful of time taken to complete this document recognising this can negatively impact on member experience of the group. Unequal or inadequate time for members to check in and use open forum was a concern. Service user choice, and quick access to the service was also a concern, when considering limiting the amount of CASPs per group.

This conversation resulted in SUN revisiting our processes with the notion of limiting/capping the number of CASP documents completed to one per group. This will be set as the ideal, but with some flexibility that two can be completed per group if needed, for example in the event of a significant waiting list or if a new member is not able to attend an alternative group. As part of this, the admin process for enrolling new members into their first group is being revisited.

Findings- Ambiguity of service:
Additionally, the report highlighted an unclear understanding and mixed expectations of what SUN does and provides as a service. Specifically, some individuals were unsure who SUN was targeted at, e.g. is it for people in crisis only, do you need to have a diagnosis. These findings also mirror observations from community events this year. To help improve with the above, SUN is in the process of reviewing its webpage and self- enrolment form, to provide clearer information and improve access to the service. Phase one of the website revamp has been completed. For the second stage, SUN will be seeking member feedback and recovery stories to add to the webpage. In conjunction with this, staff will continue to hold the guidelines in group, and explain to new and existing members the structure and purpose of group.

Overall, it was a thought provoking report, and as a service we have been able to action and consider some of the findings and recommendations that seemed most relevant.

Charlie Thomas – Service Manager for SUN
30/04/2024

Appendix C – Theoretically Driven Research Paper

Appendix C.1. – Instructions to Authors for the British Journal of Health Psychology

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

New submissions should be made via the Research Exchange submission portal. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the “My Submissions” button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

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

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

- experimental and clinical research on aetiology
- management of acute and chronic illness
- responses to ill-health
- health-related behaviour change and maintenance
- screening and medical procedures
- psychosocial mediators and moderators of health-related behaviours
- influence of emotion on health and health-related behaviours
- psychosocial processes relevant to disease outcomes
- psychological interventions in health and disease
- emotional and behavioural responses to ill health, screening and medical procedures

- psychological aspects of prevention

Papers must make a clear potential contribution to health psychology theory, knowledge and/or practice and employ rigorous research design and methodology.

We do not typically publish cross-sectional studies or those using only student populations unless there is a strong rationale for doing so.

Papers describing intervention development (without also presenting an analysis of the outcomes of the intervention) will usually only be considered if they make a contribution to health psychology theory, knowledge and/or practice beyond the specific intervention context.

3. MANUSCRIPT CATEGORIES

The types of paper invited are:

- papers reporting original empirical investigations, using quantitative, qualitative or mixed methods;
- theoretical papers which report analyses of theories in health psychology;
- review papers, which should provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses);
- methodological papers dealing with methodological issues of particular relevance to health psychology;
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Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

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Appendix C.2. – Profile of Sample Demographics

Profile of sample demographics				
Characteristic	**Prostate Cancer survivors (*n*=239)**	**Healthy benchmark group (*n*=100)**	**PC Low Health Anxiety (HAI<8) (*n*=69)**	**PC High Health Anxiety (HAI>15) (*n*=61)**
	% (N)	**% (N)**	**% (N)**	**% (N)**
Age				
Under 60	9.2 (22)	18 (18)	4.3 (3)	21.3 (13)
60 - 64	15.1 (36)	23 (23)	10.1 (7)	19.7 (12)
65 - 69	23 (55)	20 (20)	20.3 (14)	21.3 (13)
70 - 74	25.9 (62)	26 (26)	23.2 (16)	23 (14)
75 - 79	20.9 (50)	12 (12)	30.4 (21)	11.5 (7)
80 +	5.9 (14)	1 (1)	11.6 (8)	3.3 (2)
Country of residence				
U.K. (Scotland)	2.1 (5)	13 (13)	2.9 (2)	1.6 (1)
U.K. (England)	93.7 (224)	70 (70)	95.7 (66)	90.2 (55)
U.K. (Wales)	3.8 (9)	9 (9)	1.4 (1)	6.6 (4)
U.K. (Northern Ireland)	0.4 (1)	8 (8)	0 (0)	1.6 (1)
Educational Attainment				
No Qualifications	6.3 (15)	2 (2)	5.8 (4)	6.6 (4)
School Qualification (leaving cert.; Standard grades)	5 (12)	5 (5)	2.9 (2)	11.5 (7)
GCSE/ O Levels / Higher Grades	14.2 (34)	15 (15)	17.4 (12)	14.8 (9)
A Level/ AS Level/ Advanced Higher or equivalent	8.4 (20)	5 (5)	10.1 (7)	6.6 (4)
Access to higher education diploma	16.7 (40)	17 (17)	14.5 (10)	16.4 (10)
First Degree Level (Undergraduate)	29.3 (70)	39 (39)	34.8 (24)	29.5 (18)
University higher Degree (Masters, PhD)	15.1 (36)	15 (15)	11.6 (8)	11.5 (7)
Other	5 (12)	2 (2)	2.9 (2)	3.3 (2)
Marital status				
Single/ Never Married	2.9 (7)	7 (7)	2.9 (2)	6.6 (4)
Married / Civil Partnership	80.8 (193)	68 (68)	84.1 (58)	80.3 (49)
Divorced	4.6 (11)	6 (6)	1.4 (1)	3.3 (2)
Widowed	4.2 (10)	9 (9)	7.2 (5)	1.6 (1)
Living with long term partner but not married	7.5 (18)	10 (10)	4.3 (3)	8.2 (5)
Employment Status				
Working Full Time	18 (43)	19 (19)	10.1 (7)	27.9 (17)
Working part-time	6.7 (16)	14 (14)	2.9 (2)	6.6 (4)
Retired	74.1 (177)	66 (66)	87 (60)	60.7 (37)
Don't work due to long term illness/ disability	1.3 (3)	1 (1)	0 (0)	4.9 (3)
Ethnicity				
White	95.4 (228)	99 (99)	98.6 (68)	98.4 (60)
Mixed or multiple ethnic groups	0.8 (2)			
Asian or Asian British	0 (0)	1 (1)	0 (0)	0 (0)
Black, Black British, Caribbean or African	2.5 (6)	0 (0)	1.4 (1)	1.6 (1)
Other	1.3 (3)			
Cancer Stage				
Early Prostate Cancer (Stage 1)	74.9 (179)		87 (60)	59 (36)
Locally Advanced Prostate Cancer (Stage 2)	23.4 (56)		11.6 (8)	37.7 (23)
Advanced prostate Cancer (Stage 3 and 4)	1.3 (3)		1.4 (1)	1.6 (1)
Don't know/ can't remember	0.4 (1)		0 (0)	1.6 (1)
Years since diagnosis				
0-2 years	32.6 (78)		23.2 (16)	37.7 (23)
3-4.9 years	16.7 (40)		15.9 (11)	21.3 (13)
5-10 years	36.4 (87)		43.5 (30)	27.9 (17)
11+ years	14.2 (34)		17.4 (12)	13.1 (8)
Age at Diagnosis				
Under 60	25.9 (62)		17.4 (12)	42.6 (26)
60 – 64	27.2 (65)		27.5 (19)	18 (11)
65 – 69	28.5 (68)		29 (20)	27.9 (17)

70+	18.4 (44)		26.1 (18)	11.5 (7)
Years since finished treatment				
Within the last year	27.7 (66)		13 (9)	33.3 (20)
2 – 3 years ago	28.2 (67)		37.7 (26)	26.7 (16)
4 – 5 years ago	16.4 (39)		18.8 (13)	16.7 (10)
5 – 9 years ago	16.4 (39)		15.9 (11)	13.3 (8)
10+ years ago	11.3 (27)		14.5 (10)	10 (6)
Treatment type				
Active Surveillance/ monitoring	19.7 (47)		23.2 (16)	11.5 (7)
Prostatectomy – surgery to have the prostate removed	64 (153)		65.2 (45)	60.7 (37)
Brachytherapy	10.5 (25)		10.1 (7)	3.3 (2)
Radiotherapy	38.5 (92)		43.5 (30)	47.5 (29)
Hormone treatment	33.1 (79)		31.9 (22)	44.3 (27)
Chemotherapy	2.9 (7)		1.4 (1)	4.9 (3)
Clinical Trail	4.2 (10)		5.8 (4)	6.6 (4)
Other	3.8 (9)		4.3 (3)	0 (0)
Number of treatments undertaken				
1	53.6 (128)		50.7 (35)	49.2 (30)
2	25.9 (62)		27.5 (19)	31.1 (19)
3	15.9 (38)		15.9 (11)	18 (11)
4	3.8 (9)		2.9 (2)	1.6 (1)
5	0.8 (2)		2.9 (2)	0 (0)
Anxiety (GAD7) Bands				
None -Minimal Anxiety Symptoms	61.1 (146)	69 (69)	92.8 (64)	19.7 (12)
Mild Anxiety symptoms	27.2 (65)	24 (24)	5.8 (4)	45.9 (28)
Moderate Anxiety symptoms	7.1 (17)	7 (7)	0 (0)	23 (14)
Severe Anxiety symptoms	4.6 (11)	0 (0)	1.4 (1)	11.5 (7)
Depression (PHQ8) bands				
None – Minimal	61.9 (148)	68 (68)	87 (60)	16.4 (10)
Mild	24.3 (58)	22 (22)	8.7 (6)	42.6 (26)
Moderate	9.2 (22)	7 (7)	4.3 (3)	23 (14)
Moderately severe	3.3 (8)	3 (3)	0 (0)	13.1 (8)
Severe	1.3 (3)	0 (0)	0 (0)	4.9 (3)

Appendix C.3. - Outliers

The table below provides an overview of the variables which were capped at either +3.29 for high outliers or at -3.29 for low outliers. This was done for each group used in the analyses and the number of outliers are listed beside each variable.

Variable	High (>3.29) or Low (<3.29) outliers	Group			
		All PC	All HC	High HA	Low HA
QLI – PSPS Subscale	<3.29				1
MD Total	>3.29	2	1		1
GAD7 Total	>3.29				1
PHQ8 Total	>3.29	3			2
Bowel Symptoms	>3.29	4		1	1
HRT Symptoms	>3.29				1
Year Diagnosis to treatment	>3.29	3		1	2
Age at Diagnosis	<3.29	2		1	
HCQ Total	>3.29				
Years since treatment	>3.29	3		1	
QLI – Soc Subscale	<3.29		1		
QLI – Family Subscale	<3.29	1	2		
HCQ - Likelihood	<3.29	1			
HCQ - Awfulness	<3.29	1			
Responsibility Total	>3.29	1			
HCQ – Difficulty Coping	>3.29	1			
Urinary Symptoms	>3.29	2			
Number of treatments	>3.29	2			

Appendix C.4. – Ethical Approval Letter from CUREC

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Professor Paul Salkovskis & Gareth McAteer
Oxford Institute for Clinical Psychology Research and Training
Isis Education Centre
Warneford Hospital
Oxford

24 October 2023

Dear Professor Salkovskis and Gareth,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R88678/RE001

Study title: The impact of health anxiety in patients after curative treatment for prostate cancer: Quality of life, fear of cancer recurrence, cognitive maintenance processes and mental defeat

Short title: Health Anxiety after curative treatment for prostate cancer

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted from **24th October 2023** until **23rd April 2025.**

Insurance-provided indemnity arrangements are in place for the duration of the approval stated above. It is your responsibility to ensure that you request an extension to the end date for indemnity to remain in place should you continue the research beyond the dates covered.

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

DocuSigned by:
Leah Butts
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Mrs Leah Butts
Research Ethics Administrator

for
Dr Helen Barnby-Porritt
Research Ethics Manager