

**A Mixed Methods Exploration of How Hospital Inpatients Understand and Use the
Verbal Rating Scale of Pain**

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Thesis Declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part 1 comprises a systematic review of attachment theory and adults with chronic pain.

This was an update and extension to a previous review by Meredith, Ownsworth, and Strong (2008). Thirteen papers met the study criteria and were reviewed. There was emerging evidence that attachment theory was a useful construct in understanding individual differences in chronic pain, but methodological limitations constrained the conclusions that could be drawn.

Part 2 describes a mixed methods study examining how 45 hospital inpatients understood and used the Verbal Rating Scale of Pain. Analysis revealed participants used unique ways to construct the scale categories based on different elements of their pain experience.

Their use of the scale was also affected by their relationship to painkillers and experiences of staff. Overall, this has implications for how staff interpret scale ratings, particularly that ratings do not necessarily reflect only pain intensity.

Part 3 covers a critical appraisal of the research process, examining the underlying assumptions, methodological concerns, and other problems that arose.

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Part 1: Literature Review

Adult Attachment Style and Chronic Pain: A Systematic Review

Abstract

Aims: Attachment theory has been proposed as a way to capture individual differences in the vulnerability to problematic chronic pain. A review was conducted by Meredith, Ownsworth and Strong (2008) who found an emerging but limited evidence base. The current review aimed to update and expand on the research.

Method: Two databases, PsychInfo and Medline, were searched for articles published in peer-reviewed journals that investigated attachment style and chronic pain in adults. Included studies were evaluated for quality using the AXIS tool.

Results: Thirteen studies in total were included in this review. These covered how attachment style was associated with response to treatment, pain beliefs, social support, and activity engagement. Generally, insecure attachment styles, particularly anxious attachment, were associated with poorer outcomes. However, many of the studies were cross-sectional, used attachment measures with low reliability, and did not control for confounding variables, which made drawing conclusions difficult.

Conclusions: There is some evidence that attachment style may be useful in capturing individual differences in chronic pain. However, there has been limited growth in studies since the previous review and are restricted by numerous methodological weaknesses. The research is also missing attachment theory specific hypotheses to explain the mechanisms behind negative associations with pain variables.

Introduction

Pain is defined as ‘an unpleasant sensory and emotional experience associated with actual or perceived tissue damage or described in terms of such damage’ (International Association for the Study of Pain, 1986). Historically, theories about the nature of pain were heavily rooted in biomedical models (Doleys, 2014). However, a number of phenomena lacked sufficient explanation, such as the apparent lack of pain in soldiers with serious injuries and the indifference of lobotomised patients to their pain. Melzack and Wall (1965) introduced the ‘Gate Control Theory’ to explain these theoretical gaps which integrated psychological and social factors involved in pain with neurological mechanisms. In addition to the ‘bottom-up’ nociceptive nerves involved in pain, the theory included ‘top-down’ inhibitory and excitatory pain signals from the brain. This formally introduced psychological factors and individual differences in the experience of pain, leading to the study of a multitude of implicated variables and the evolution of nonpharmacological pain interventions.

Pain is one of the leading reasons that people seek healthcare (Hadjistavropoulos & Craig, 2004) and features across many disorders (Taylor, 2006). The severity of the sensation of pain is only loosely correlated with an individual’s ability to cope with and manage their pain (Arnstein, 2000; Turk & Okifuji, 2002). In fact, contemporary Cognitive Behavioural Therapy (CBT) approaches for pain management aim to target some of the processes underlying this difficulty, such as pain catastrophizing (Smith, Herman & Smith, 2015). There have been a number of psychological factors that have been investigated in regards to the outcomes of chronic pain, such as pain beliefs.

An individual’s beliefs about their pain have been demonstrated to predict disability levels and response to treatment (Turk & Okifuji, 2002). These include appraisals about the

causes and onset (Turk, Okifuji, Starz & Sinclair, 1996), that pain indicates harm (Woby, Watson, Roach & Urmston, 2004), and self-efficacy (Arnstein, Caudill, Mandle, Norris & Beasley, 1999). These beliefs, combined with the social environment, can impact pain behaviour in either helpful or unhelpful ways. Maladaptive behavioural responses include avoidance, withdrawal from activities, and adapting a 'sick role' (Turk & Okifuji, 2002). However, what is less understood is what predisposes a person to develop negative beliefs and responses to pain. One area, attachment theory, has been proposed as a way to understand these individual differences in vulnerability (Kolb, 1982; Mikail & Henderson, 1994; Meredith, Ownsworth & Strong, 2008).

Attachment Theory

Attachment theory is an evolutionary theory initially developed by Bowlby (1969) who observed patterns in children separated from their mothers at an early age. The theory proposes that infants are innately predisposed to develop strong emotional bonds, attachments, with their caregivers. These attachments promote proximity to the caregiver when safety is threatened and allow the caregiver to act as a 'secure base' for the child to use for exploring the world. The exact nature of this attachment is determined through the repeated interactions between the infant and the caregiver over time, and is dependent on the caregiver's sensitivity and responsiveness to the child. As the child grows, it develops mental models about the expectations from their caregiver and the idiosyncratic attachment behaviours that will best serve the child with their caregiver. Bowlby argued that these mental models act as a 'blueprint' for future relationships, and thus can shape a person's interpersonal world. This includes therapeutic alliances during psychotherapy, where greater attachment insecurity is associated with poorer alliances (Diener & Monroe, 2011). Attachment style has been demonstrated to be fairly robust across the lifespan

(Waters, Merrick, Treboux, Crowell & Albersheim, 2000), although evidence for this is mixed (Groh et al., 2014).

Individual differences in infant attachment style were categorised using the 'Strange Situation Procedure' (SSP; Ainsworth, Blehar, Waters & Wall, 1978). Ainsworth and colleagues noted three 'types' of attachment organisations; secure, insecure-resistant, and insecure-avoidant. Main and Solomon (1990) later identified a fourth style: disorganised. These styles reflect the internal working models of the infant and their expectations of others and themselves.

Adult Attachment Styles

Attachment styles have also been investigated in adults within two main domains: attachment representation of parental experiences, and self-reports of romantic attachment (Crowell, Fraley & Roisman, 2016). This began with the Adult Attachment Interview (AAI; George, Kaplan & Main, 1985), a semi-structured interview that explores the participant's current state of mind regarding the childhood experiences of their caregivers. The AAI was initially developed from parental interviews of infants already assessed in the SSP and thus shares a similar construct. The result of the interview is that the person is categorised as one of several types: 'autonomous' (secure), 'dismissing', 'preoccupied', or 'cannot be classified'. Interviewees could be classified as 'unresolved' in addition to another category, or sometimes as its own separate category. People categorised as having a dismissing attachment undermined the importance of early relationships and gave short and contradicting evaluations of their relationships with parents (e.g. describing their childhood as 'good' while also reporting physical abuse). People categorised as having a preoccupied attachment were incoherent in their narratives of early experiences and still expressed anger about early attachment figures. In non-

clinical samples, 58% of people were classified as autonomous, 23% as dismissing, 19% as preoccupied, and with an additional 18% also as unresolved (Bakermans-Kranenburg & Van Ijzendoorn, 2009).

The second area of application of attachment measures was to self-reported romantic attachment styles. This field emerged from Hazan and Shaver (1987) who argued that romantic relationships mirrored many of the processes described in the attachment literature, such as seeking proximity to regulate affect in times of stress and the feelings of safety from having a responsive partner nearby. They developed a brief questionnaire based on the descriptions of infant classifications from Ainsworth et al. (1978) which categorised people into three groups: secure, avoidant and anxious-resistant. This three category system was later expanded on by Bartholomew and Horowitz (1991) who conceptualised attachment processes on two continua ranging from positive to negative models of self and others. Subsequently, a large number of self-report measures emerged (Brennan, Clark & Shaver, 1998), arising with a debate on the value of representing attachment as a category or on a dimension. At present, there exists multiple self-report measures that offer both methods, although dimensional approaches are generally considered to be statistically preferable (Crowell et al., 2016; Fraley & Waller, 1998).

AAI classifications and self-report romantic attachment have only a trivial to small correlation with each other and tend to predict other variables independently, such as couple interactions (Roisman et al., 2007). Thus, Crowell et al. (2016) emphasised that they are not interchangeable and caution should be used when extrapolating the attachment constructs they draw on.

Attachment Theory and Pain

There are a number of theoretical links between attachment style and chronic pain. Mikail et al. (1994) described how pain itself can be a threat that activates the attachment behaviour system. They hypothesise that people with different attachment styles will vary in their initial approach to seeking help from health care professionals, their use of their support networks, and use of treatment. This may predispose individuals to developing chronic pain problems due to the failure to act on health concerns and delay in receiving treatment. They describe how negative models of others (in dismissing and fearful attachments) might lead to the devaluing of professionals and advice, leading to a lack of trust and adherence to treatment. Likewise, a negative model of the self (dismissing and fearful attachments) may lead to a helpless approach to treatment due to low self-efficacy, or an outright sabotaging of treatment to maintain the interpersonal care gained from the pain condition.

Meredith, Ownsworth and Strong (2008) expanded on the existing theoretical links between attachment theory and chronic pain by proposing the 'Attachment-Diathesis Model of Chronic Pain' (ADMoCP; Figure 1). This model describes psychosocial variables that are known to be implicated in chronic pain and that might be affected by attachment style. These include cognitive appraisals in response to a pain stimulus (Section B), the behavioural response to these appraisals (Section C) and the subsequent impact on adjustment (Section D). This model describes how attachment style is both a predisposition to developing chronic pain, and a vulnerability for poorer outcomes in chronic pain. It was also intended to guide the organisation of research.

Another emerging idea that links attachment style and pain is described by Quirin, Prussner and Kuhl (2008). They propose that early experiences are linked to the development of the

hypothalamic-pituitary-adrenal (HPA) axis regulation in adulthood. They found that women with anxious attachment were significantly more physiologically reactive to stress. This suggests that their early experiences influence key brain areas related to the response to stress which, over the life time, lead to poorer outcomes in health. These experiences and related development pathways might be captured by the attachment style construct.

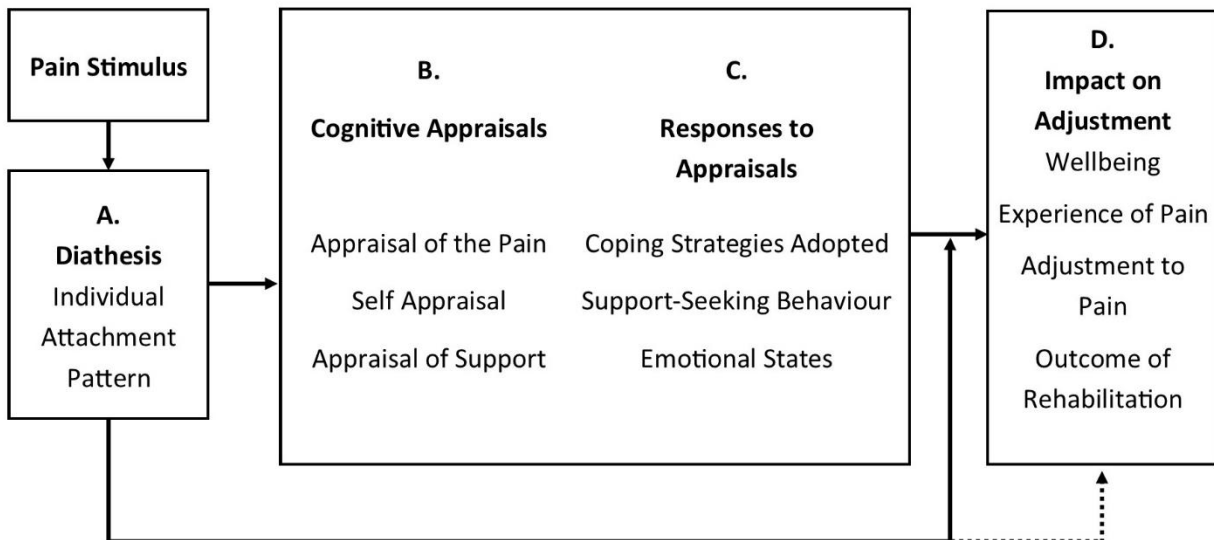


Figure 1: Attachment-Diathesis Model of Chronic Pain (ADMoCP) from Meredith et al. (2008)

Attachment Style and Pain Reviews

At present, there are two existing literature reviews of the evidence examining the relationships between pain and attachment styles. Meredith et al. (2008) explored chronic pain, while Meredith (2013) explored experimentally induced pain.

Meredith et al. (2008) identified 12 studies examining attachment and chronic pain. Generally, they found that insecure attachment was consistently negatively associated with a range of psychosocial variables, including problematic coping strategies, perceiving pain as more threatening, greater disability resulting from pain, and having lower pain self-efficacy. However, they noted that the number of studies available was relatively small,

used potentially biased sampling methods, and were mainly cross-sectional. Their review also had a number of limitations. Firstly, Meredith et al. (2008) did not report their methodology or criteria for identifying studies. Secondly, they included studies with different samples, such as two studies of pain-free individuals. Thirdly, they did not use a quality assessment tool, and included studies of a quality that is often excluded, such as two studies not published in a peer-reviewed journal. Fourthly, as the majority of the article was dedicated to describing the ADMoCP, there was limited synthesis of the results they presented.

Meredith (2013) identified eight studies of attachment and experimentally induced pain. These studies noted negative associations of insecure attachment style with the study outcomes: greater reported pain intensity, lower pain threshold, poorer pain tolerance and greater catastrophizing. However, some of these results were mixed such as, for example, one study where those with fearful attachment reported lower pain intensity. Again, Meredith (2013) commented that the number of studies was small, with a wide variety of attachment conceptualisations that made synthesising the results difficult.

In conclusion, there is emerging evidence that attachment theory is useful in understanding individual differences in pain outcomes. However, the research examining the explanatory mechanisms between insecure attachment and chronic pain adjustment (Section D in Figure 1) is still developing. This currently makes it difficult for practitioners to apply attachment principles in treatment for pain related problems in any meaningful way. Likewise, attachment reviews have not reported the magnitude of the relationship between attachment styles and pain variables. This makes it difficult to determine which of the variables identified are the most important in this field of research.

Aims

This literature review aims to expand on and update the previous review by Meredith et al. (2008). This review will focus specifically on people with chronic pain and attempt to address the shortcomings of the review by Meredith et al. (2008). In addition, it will focus on mechanisms linking attachment style and adjustment to chronic pain identified in the ADMoCP (Section B and C). However, it will also include 'Outcome of Rehabilitation' from Section D in the ADMoCP (see Figure 1), as variability in the use of healthcare is a hypothesis made by Mikail et al. (1994).

Overall, this study aims to review the literature examining the relationship between adult attachment style and individual differences in chronic pain variables, focusing on understanding mechanisms linking attachment style and adjustment.

Method

Due to the small number of articles published in this area, a general search was created that would retrieve all papers that examined adult attachment style and pain. This search was conducted in three stages. Firstly, the databases PsychInfo and Medline were searched using the search term below. These were chosen to cover both the psychologically and medically orientated journals. No year restriction was used.

((exp Attachment Theory/ or (attachment style OR attachment theory OR attachment self report OR revised adult attachment scale OR relationship scale questionnaire OR attachment style questionnaire OR relationship questionnaire OR experiences in close relationships questionnaire OR adult attachment interview)).mp.) AND (exp PAIN MANAGEMENT/ or exp PAIN MEASUREMENT/ or exp PAIN THRESHOLDS/ or exp PAIN PERCEPTION/ or exp NEUROPATHIC PAIN/ or

*exp CHRONIC PAIN/ or exp BACK PAIN/ or exp SOMATOFORM PAIN DISORDER/ or
exp PAIN/ or (pain).mp.)*

Secondly, the articles retrieved by this search were then screened by title and abstract for papers that potentially met the inclusion criteria. Thirdly, the remaining articles were read in-depth and compared with the inclusion and exclusion criteria. Articles retained after this final stage were included in this review.

Inclusion and Exclusion Criteria

Studies retrieved by the search above were included in the review if they:

- 1) Measured adult attachment style.
- 2) Measured a pain variable, i.e. any of the proposed variables in Section B and C of the ADMoCP or 'Outcomes of Rehabilitation' from Section D.
- 3) Used participants who experienced chronic pain, had a chronic condition associated with chronic pain, or a general sample that included people with chronic pain (e.g. Stanton & Campbell, 2014). Longitudinal studies examining risk factors for chronic pain with pain free individuals were also accepted.
- 4) Separated anxious and avoidant attachment styles in the analysis.
- 5) Used adult participants, aged 18 years old or more.
- 6) Were written in English.

Studies were excluded if they:

- 1) Reported only associations between attachment styles and pain adjustment without any explanatory mechanisms (i.e. measured only an association between attachment style and variables of Section D of the ADMoCP, without also measuring variables from Section B or C).
- 2) Used an idiographic, rather than nomothetic, methodology.

3) Combined anxious and avoidant attachment styles as one group (e.g. 'insecure').

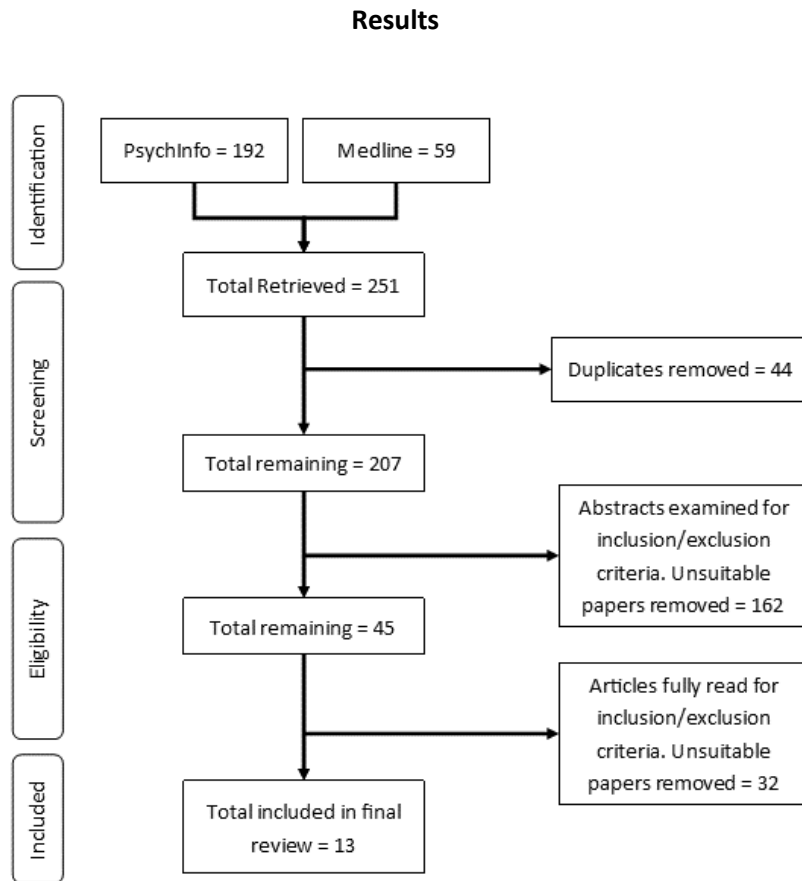


Figure 2: Flowchart of the review process

Figure 2 displays the screening and exclusion process. Of the 32 articles removed at the full text stage, reasons included that the paper only described a direct association between attachment and adjustment (e.g. Berry & Drummond, 2014), did not sample patients with chronic pain (e.g. Bailey, Holmberg, McWilliams & Hobson, 2015), or were too specific to be useful in this review (e.g. Anderson, Elklit & Brink, 2013).

In total, 13 peer-reviewed articles that met the inclusion criteria were retrieved (see Table 1). These related to five main areas: a) how attachment style affected the response to psychological treatment for chronic pain (three articles), b) how attachment style affected

the appraisals of chronic pain (two articles), c) the relationship between attachment style, self-efficacy, and pain-related disability (one article), d) the relationship between attachment style, social support and pain behaviour (six articles), and e) the relationship between attachment style and activity engagement (one article). Eight of the 12 papers examined by Meredith et al. (2008) were not included in the current literature review. Two studies (Mikulincer & Florian, 1998; Pearce, Creed & Cramond, 2001) were excluded as they did not appear in a peer-reviewed journal (book chapter and newsletter, respectively). Two studies (McWilliams & Amundson, 2007; Meredith, Strong & Feeney, 2006) were not included as they used pain-free participants. Four studies (Rossi et al., 2005; Schmidt, Strauss & Braehler, 2002; Meredith, Strong & Feeney, 2007; MacDonald & Kingsbury, 2006) were excluded as they only investigated direct associations between attachment style and pain adjustment. The remaining four studies were included in this review.

Of the final 13 papers, nine used cross-sectional analysis (i.e. data taken at one time point). Of these, all but one recruited participants with known health problems, such as arthritis or cancer. The remaining study used a general community sample of mixed health status. Four studies used a longitudinal design, of which three were pre- and post- measures of chronic pain treatment programs. The remaining study used a diary design.

Quality assessment

As the majority of the studies were cross-sectional (nine of 13), AXIS, a tool specifically for assessing the quality of cross-sectional studies, was chosen (Downes, Brennan, Williams & Dean, 2016). This involves rating 20 questions as either 'yes', 'no', or 'don't know' regarding the paper in question. Sample questions include 'was the sample size justified?' and 'were the outcome variables measured correctly using instruments that had been trialled, piloted or published previously?' (See Appendix A). The AXIS tool was used to identify weaknesses

that are listed in Table 1 and are discussed below in the context of the findings.

Weaknesses mainly involved the use of measures with low internal consistency, small sample sizes making statistical tests underpowered, or failure to report important information e.g. ethical approval, modification to measures. The key findings are divided by the five areas and are described below.

A Note on Attachment Terminology

The studies examined in this review use different terms when describing attachment. This is due to the different measures and conceptualisation of attachment. For simplicity, this review describes all continuous measures in terms of 'anxious' or 'avoidant' attachment scores, with the exception of studies that use the Attachment Style Questionnaire (ASQ), where 'comfort with closeness' is used to indicate low attachment avoidance. Categorical attachment styles are described as 'secure', 'preoccupied', 'dismissing' or 'fearful', in line with the most commonly used terms.

Table 1: Details of studies included in the review

Author	Design	Participants	Main Findings (Non pain-related results and direct associations are not reported)	Quality Appraisal (AXIS) highlighted weaknesses
a) Response to Treatment				
Kowal et al. (2015)	Longitudinal – pre and post measures of a 4 week group based interdisciplinary chronic pain management program (approximately 75 hours over four weeks) - post treatment measures time frame was unspecified	<i>n</i> = 235 Male = 91; Female = 144 Mean age (<i>SD</i>) = 48 (10) All participants had chronic pain, assessed by psychiatrist.	When controlling for demographics and pre-treatment scores, attachment avoidance predicted higher post-treatment catastrophizing; attachment anxiety and avoidance predicted lower post-treatment pain self-efficacy. Attachment style did not significantly predict post-treatment pain intensity or disability.	The time frame for follow-up measures are not described.
Ciechanowski, Sullivan, Jensen, Romano and Summers (2003)	Longitudinal – pre and post measures of a multidisciplinary chronic pain program (16.5 days across 3 weeks) – 12 month follow-up (secondary analysis)	<i>n</i> = 111 Male = 50; Female = 61 Mean age (<i>SD</i>) = 45 (11) Participants assessed to have chronic pain conditions.	When controlling for catastrophizing, depression and pre-treatment health care utilization, preoccupied attachment significantly predicted whether a participant reported greater than weekly health care visits post-treatment. Neither attachment style nor catastrophizing predicted whether participants reported greater than monthly visits at post-treatment.	RSQ attachment measure reported to have low internal consistency (Cronbach α = 0.30-0.64). Health care utilization was stratified into general groups (loss of statistical power).
Anderson (2012)	Longitudinal – pre and post measures of a	<i>n</i> = 72	Insecure group had significantly higher pre-treatment opioid use as measured by milligrams of morphine used (secure mean = 16.99,	In dichotomous analyses all types of insecure attachment

	<p>CBT and mindfulness based treatment group (3 hours weekly for 13 weeks)</p>	<p>Male = 10; Female = 62 Mean age (<i>SD</i>) = 43 (9)</p> <p>Participants diagnosed with a chronic pain condition.</p>	<p>insecure mean = 40.41), although attachment scores were not significant predictors in a regression model.</p> <p>Pre-treatment psychosocial disability significantly predicted by attachment anxiety scores when controlling for attachment avoidance, age, gender, and pain intensity (total explained variance = 22.7%, change when adding attachment variables = 7.7%).</p> <p>In models predicting post-treatment scores, neither attachment anxiety nor avoidance were significant predictors for any variable after including gender, age and pain intensity (change in explained variance when adding attachment variables ranged from 0.03% to 1.3%).</p> <p>Treatment was equally effective for both secure and insecure groups (no interaction effects).</p>	<p>were grouped into a general 'insecure' group.</p> <p>Sample size does not meet recommendations for multiple regression with 5 predictor variables.</p>
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b) Pain Appraisals and Beliefs

<p>Gerson et al. (2015)</p>	<p>Cross sectional analysis – 9 geographical sites across 7 countries</p>	<p><i>n</i> = 656 (control = 193; patients = 463) – controls matched on age and gender Male = 225; Female = 431 Mean age = 39 (<i>SD</i> not provided)</p>	<p>In a path analysis, attachment style indirectly predicted IBS symptom severity through catastrophizing and negative pain appraisals.</p> <p>Attachment anxiety was positively associated with catastrophizing ($\beta = 0.38$) and negative pain appraisals ($\beta = 0.26-0.40$). Attachment avoidance was associated with negative pain appraisals ($\beta = 0.13-0.20$), but not catastrophizing. Negative pain appraisals and catastrophizing predicted IBS symptom severity ($\beta = -0.20-0.31$).</p>	<p>Statistics apart from significance levels and correlations not reported (e.g. goodness of fit or standard errors for path analysis). Large emphasis on pain and pain beliefs but symptom severity measure only has one question on pain and is not considered separately in the analysis.</p>
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		Patients recruited from 'tertiary care centres'		Some speculation in the discussion section on the explanation of attachment style differences cross-culturally that is not derived from existing data. Ethical approval is not reported.
Meredith, Strong, and Feeney (2005)	Cross-sectional analysis – pre-treatment scores of pain management clinic	<i>n</i> = 141 Male = 83; Female = 58 Mean age (<i>SD</i>) = 39 (12) Participants were all attending a chronic pain rehabilitation program.	Those with secure attachment reported marginally less pain threat appraisals than fearful and dismissing groups (means: secure = 3.71, fearful = 4.36, dismissing = 4.31, where 6 = highest score of pain threat) although post-hoc tests were non-significant. Attachment anxiety was significantly correlated with catastrophizing (<i>r</i> = 0.41) and threat appraisal (<i>r</i> = 0.38). Attachment comfort was significantly correlated with challenge appraisals (<i>r</i> = 0.31). A regression model with stress, depression, anxiety, pain-related disability, catastrophizing, average pain intensity, and attachment anxiety predicting threat appraisal was significant (model explained variance = 42%). Catastrophizing was the only significant unique predictor. When controlling for age, compensation status, depression and 6 other undefined covariates, attachment comfort was a significant predictor of pain challenge appraisals (model explained variance = 17.2%).	Unable to compare participants and study decliners for selection bias. Small sample representing insecure groups (e.g. preoccupied group = 10) limits statistical power. 21 participants were missing attachment measure data.
c) Pain Related Self-Efficacy and Disability				

Meredith, Strong and Feeney (2006b)	Cross-sectional analysis – pre-treatment scores of a pain management clinic	<p>$n = 152$ Male = 88; Female = 63 Mean age (SD) = 39 (12)</p> <p>Participants were all attending a chronic pain rehabilitation program.</p>	<p>An ANOVA comparing the differences between pain self-efficacy of attachment style categories was significant, although post-hoc tests were non-significant (means: secure = 30.2, dismissing = 30.7, preoccupied = 23.9, fearful = 22.8).</p> <p>Male, but not female, attachment avoidance scores were significantly correlated with pain self-efficacy ($r=.41$).</p> <p>In regression models for pain related disability and pain intensity, attachment style was not found to be a significant predictor.</p> <p>Attachment avoidance moderated the relationship between pain related disability, pain intensity, and pain self-efficacy. Comfort with closeness was protective; those with low comfort with closeness and low pain self-efficacy reported higher levels of disability, while those with high comfort with closeness and low pain self-efficacy reported comparatively lower levels of disability. A similar moderating relationship of comfort with closeness was found between pain intensity and pain disability.</p>	Attachment categories on the RQ had a relatively small sample size (e.g. preoccupied = 16) making tests using categories potentially underpowered.
d) Social and Spousal Support				
Sirois and Gick (2016)	Cross-sectional analysis – community recruited.	<p>$n = 365$ Male = 66; Female = 299 Mean age (SD) = 44 (11)</p> <p>Recruited through online and community</p>	Used Structural Equation Modelling (SEM). There was both direct effects of avoidant attachment on coping efficacy (path coefficient [PC] of $-.17$) and indirect effects: avoidant scores were positively associated with stress appraisals ($.13$), which in turn were negatively correlated with coping efficacy ($-.40$). Likewise, avoidance was negatively associated with perceived social support ($-.29$) which in turn was positively correlated with coping efficacy ($.15$). Stress appraisals were negatively correlated with perceived social support ($-.18$).	Attachment measure is altered version of a lesser used measure (not specified how it was altered). <p>Stress appraisals are bespoke questions and therefore lack information on validity or reliability.</p>

		<p>advertisements. All diagnosed with arthritis; self-reported but screened further by reports of medication.</p>	<p>Anxious attachment was also found to have direct effects on coping efficacy (-.32) and indirect effects: anxious scores were positively correlated with stress appraisals (.13), which in turn negatively correlated with coping efficacy (-.35). Anxious scores also had a strong relationship with perceived social support (-.64) but there were no significant links between social support and coping efficacy or stress appraisals.</p>	<p>Ethical approval is not reported.</p>
Stanton and Campbell (2014)	Cross-sectional analysis – community recruited	<p><i>n</i> = 116 heterosexual couples recruited through newspaper adverts (paid participation) Mean age (<i>SD</i>): Males = 39 (11), Females = 37 (11)</p> <p>General community sample that included a variety of health status.</p>	<p>Found significant interaction effects in that attachment anxiety moderated the link between social support and some health outcomes. High social support lead to better outcomes for overall health perceptions, social functioning, physical functioning, and role functioning, except for those with high attachment anxiety who had poorer outcomes. However, this effect was not found for reported bodily pain.</p>	<p>N/A</p>
Gauthier et al. (2012)	Cross-sectional analysis – medical sample	<p><i>n</i> = 191 Male = 55, Female = 105</p>	<p>Attachment anxiety was a significant predictor of perceived punishing responses from significant others (total model explained variance = 9%). Whether the significant other was a spouse/partner, catastrophizing, and attachment avoidance significantly predicted</p>	<p>N/A</p>

		Mean age (<i>SD</i>) = 57 (12)	perceived solicitous responses (total model explained variance = 11.3%).	
		Participants recruited through various cancer and pain related departments at a hospital.	Catastrophizing and attachment avoidance significantly predicted perceived distracting responses (explained variance = 11.2%). They also found interactional effects; higher attachment anxiety predicted more perceptions of punishing responses regardless of catastrophizing (when the significant other was a spouse), and more perceptions of punishing responses in high catastrophizing (when significant other was not a spouse).	
Forsythe, Romano, Jensen, and Thorn (2012)	Cross-sectional analysis – survey	<i>n</i> = 182 Male = 74, Female = 107 Mean age (<i>SD</i>) = 49 (12)	Attachment style (except dismissing) was positively correlated with self-reported pain behaviours. Secure attachment was negatively correlated (-.28), while preoccupied and fearful attachment were positively correlated (.25 and .30, respectively). Similarly, attachment styles except dismissing were also significantly correlated with perceived negative spousal responses to pain. Secure was negatively correlated (-.25) while preoccupied and fearful attachment were positively correlated (.34 and .22, respectively).	Attachment measure (RSQ) has low internal consistency, although the authors create a combined index (with the RQ) with better reported consistency.
		Recruited through pain related medical clinics and newspaper advertisements (paid participation)	When controlling for pain intensity and source of pain, attachment style (preoccupied attachment was a significant predictor) significantly predicted self-reported pain behaviour, with the whole model explaining 35% of the variance (change in <i>R</i> ² when attaching attachment variables = .07). When including perceived spousal responses to pain, the model explained 48% of the variance.	
Kratz, Davis and Zautra (2012)	Longitudinal – quantitative diary study across 30 days	<i>n</i> = 210 (all females) Age not reported	Those with high attachment anxiety reported significantly greater catastrophizing in the context of pain increases compared to low attachment anxiety individuals (pseudo <i>R</i> ² : within-person = .07, between-persons = 0.25).	Female only sample.

		Participants diagnosed with fibromyalgia or osteoarthritis (paid participation)	Attachment avoidance moderated the association between daily changes in catastrophizing and the use of social coping. Those high in attachment avoidance had significantly less increases in social coping in the context of pain catastrophizing (pseudo R^2 : within-person = .07, between=person = .20).	
Porter et al. (2012)	Cross-sectional analysis – medical sample	$n = 127$ heterosexual couples Male = 79, Female = 48 Mean age (SD) = 65 (15) Participants all diagnosed with lung cancer.	Participant avoidant attachment significantly predicted functional well-being ($B = -1.73$) and social well-being ($B = -1.11$). Participant anxious attachment significantly predicted social well-being ($B = -0.92$). Spouse avoidant attachment significantly predicted participant pain scores ($B = 0.74$), functional wellbeing ($B = -2.74$). Spouse avoidant attachment scores significantly predicted participant pain ($B = -0.38$). These models controlled for age, gender, education, cancer stage, time since diagnosis, treatment with chemotherapy and radiation. Mean pain across the sample = 2.72 (2.46). Significant differences were found in partnerships where one or both of the spouses were insecure compared to where both were secure. E.g. for least square pain mean scores, both secure = 1.82, one insecure = 2.45/2.72, and both insecure = 3.96.	N/A
e) Activity Engagement				
Andrews, Meredith, Strong, and Donohue (2014)	Cross-sectional analysis – medical sample	$n = 164$ Male = 78, Female = 86 Mean age (SD) = 52 (12) Recruited from a pain treatment	Used an exploratory multiple-mediator model for links between attachment style, activity, catastrophizing, and thought suppression. Secure attachment was associated with lower levels of catastrophizing, and was not a predictor of overactivity or thought suppression.	Small representation of preoccupied attachment style ($n = 11$), although authors do only use continuous scales for analysis.

centre (non-cancer related pain)

Higher preoccupied attachment predicted both higher overactivity (direct effect) and activity avoidance (through catastrophizing, explaining 58%) when controlling for pain intensity, age, sex, and pain related disability. Higher preoccupied attachment was also associated with higher catastrophizing.

Dismissing attachment was a significant predictor of thought suppression, but not catastrophizing, avoidance behaviour, or overactivity.

Fearful attachment style was a significant positive predictor of overactivity when controlling for age, sex, pain intensity and disability (direct effects only). It was not associated with thought suppression but was with levels of catastrophizing. Fearful attachment was also indirectly associated with activity avoidance through catastrophizing.

When controlling for age, sex, disability and pain intensity both fearful and preoccupied attachment were predictive of scoring simultaneously high in both activity avoidance and overactivity (direct effects accounting for 59% and 31%, respectively). The indirect effect through catastrophizing was significant.

Measures

Table 2 displays the measures used across the studies. Each of the measures are labelled according to which section of the ADMoCP they fit into, e.g. 'Catastrophizing' is considered as an 'appraisal of the pain' (Section B) and 'Pain Disability' (the impact on functioning as a result of pain) is considered as 'adjustment to pain' (Section D). The most commonly used attachment style measure was the Relationship Questionnaire (RQ; Bartholomew & Horowitz, 1991), used in six studies, four of which were combined with another attachment measure. Sirois and Gick (2016) used a measure they referenced from Simpson et al. (1992) but did not report how they modified it. Likewise, Porter et al. (2012) adapted the Experiences of Close Relationships Scale (ECR; Brennan et al., 1998) for participants with cancer. All studies used a continuous attachment style score in their analysis. Some studies used a combination of categories and continuous variables, but the authors using categories often had much small sample sizes per group. Otherwise, across all the studies all the measures except two come from published articles, suggesting a good quality of measurement selection.

a) Response to Treatment

Three papers considered how attachment style affected the outcomes of people attending a multidisciplinary pain treatment program. All three studies used a longitudinal design. Anderson (2012) found that attachment style did not significantly predict any of the post-treatment outcomes when accounting for demographics and pre-treatment scores. They also concluded that people with both secure and insecure attachment responded equally to the treatment program. However, in similar regression models Kowal et al. (2015) found that both attachment avoidance and anxiety significantly predicted more negative post-treatment scores in catastrophizing and pain-self efficacy.

This difference for Anderson (2012) could be accounted for by the small sample size, especially considering the insecure group (containing fearful, preoccupied and dismissing attachments) only contained 25 participants, potentially making the test underpowered. However, Kowal et al. (2015) found that including attachment scores in regression models only improved the explained variance in the outcome variables from 3-4%, whereas pre-treatment scores alone explained variance ranged from 32-41%.

Ciechanowski et al. (2003) found that being categorised as having a preoccupied attachment significantly increased the odds of whether a participant attended more than weekly health care appointments following a treatment program. However, the authors did not distinguish whether these appointments were 'adaptive' (e.g. part of a treatment regime) or 'maladaptive' (e.g. non-essential emergency appointments).

In summary, there is mixed evidence that an insecure attachment style affects the outcomes of a chronic pain treatment program. Where significant differences between attachment styles are reported, there is only a small effect. These differences include that those with insecure attachment have higher levels of post-treatment catastrophizing and health care utilization, and lower pain self-efficacy.

Table 2: Measures used in included studies

Author(s)	Attachment Style ^a	Symptom severity/Health Status ^d	Pain-related Disability / Functioning ^d	Catastrophizing ^b	Mental Health ^d	Pain Self-Efficacy/Coping Efficacy ^b	Pain Intensity ^d	Perceived social support ^b / Response to pain ^c	Other
Kowal et al. (2015)	RQ ECR-R		FLM	PCS	PHQ-9	PSEQ	NRS		
Ciechanowski, Sullivan, Jensen, Romano and Summers (2003)	RSQ		RMDQ	Subscale of CSQ	CES-D				Health-care utilization – bespoke questions ^d
Anderson (2012)	RAAS		PDQ		HADS		VAS		Opioid use – based on patient journals ^c
Gerson et al. (2015)	ECR-R	IBS-SS		Subscale of CSQ			(IBS-SS)		Pain appraisals - INTRP ^b
Meredith, Strong and Feeney (2005)	RQ ASQ		ODI	Subscale of CSQ	DASS-21		VAS		Pain appraisals - PAI ^b
Meredith, Strong and Feeney (2006)	RQ ASQ		ODI		DASS-21	PSEQ	VAS		
Sirois and Gick (2016)	Based on Simpson, Rholes and Nelligan (1992) - one item missing		AIMS2 subscale			3 item efficacy scale (Gignac, Cott & Badley, 2000)	AIMS2 subscale	FSSQ	Stress appraisals – bespoke questions ^b
Stanton and Campbell (2014)	ECR-R	SIRS MOS						SPS	Marital satisfaction – DAS subscale

								Neuroticism – BFI subscale	
Gauthier et al. (2012)	ECR	CCI	KPS	PCS			BPI	MPI	Cognitive screen - SOMC
Forsythe, Romano, Jensen, and Thorn (2012)	RSQ RQ		RMDQ-11			CES-D	BPI	SRI	Pain behaviour – PBCL ^c
Kratz, Davis and Zautra (2012)	RQ			2 items from PCS				7 items adapted from Stone and Neal (1984)	NRS
Porter et al. (2012)	Modified ECR (questions regarding loss were removed or altered)					BDI STAI POMS-B (Spouse) CSI (Spouse)	Modified SSEQ	2 items from BPI	Quality of life – FACT subscale ^d Marital satisfaction - QMI
Andrews et al. (2014)	RQ		ODI	PCS					Activity – PARQ ^c Thought suppression – AEQ subscale ^c

^a = ADMoCP Section A variables; ^b = ADMoCP Section B variables, ^c = ADMoCP Section C variables, ^d = ADMoCP Section D variables

RQ = Relationship Questionnaire (Bartholomew & Horowitz, 1991); ECR = Experiences of Close Relationships (Brennan et al., 1998); ECR-R = Experiences of Close Relationships – Revised (Fraleigh, Waller & Brennan, 2000); RSQ = Relationship Scale Questionnaire (Griffin & Bartholomew, 1994); ASQ = Attachment Style Questionnaire (Feeney, Noller & Hanarahan, 1994); RAAS = Revised Adult Attachment Scale (Collin & Read, 1990); FLM = Functional Limitations Measure (International Association for the Study of Pain, 1995); PCS = Pain Catastrophizing Scale (Sullivan, Bishop, & Pivik, 1995); PHQ-9 = Physical Health Questionnaire 9 (Kroenke, Spitzer & Williams, 2001); NRS = Numerical Rating Scale (Jensen et al., 1999); IBS-SS = IBS Symptom Severity Scale (Francis, Morris, & Whorwell, 1997); RMDQ = Roland-Morris Disability Questionnaire (Roland & Morris, 1983); CES-D = Center for Epidemiological Studies-Depression Scale (Radloff, 1977); CSQ = Coping Strategies Questionnaire (Rosenstiel & Keefe, 1983); INTRP = Inventory of Negative Thoughts in Regard to Pain (Osman, Bunker, Osman & Fisher, 1993); DASS-21 = Depression Anxiety and Stress Scale 21 (Lovibond &

Lovibond, 1993); PAI = Pain Appraisal Inventory (Unruh & Ritchie, 1998); ODI = Oswestry Disability Index (Fairbank, Couper, Davies & O'Brien, 1980); VAS = Visual Analogue Scale (Turk & Melzack, 2001); PSEQ = Pain Self-Efficacy Questionnaire (Nicholas, 2007); AIMS2 = Arthritis Impact Measurement Scales 2 (Meenan, Mason, Anderson, Guccione & Kazis, 1992); FSSQ = Functional Social Support Questionnaire (Broadhead, Gehlbach, De Gruy, & Kaplan, 1988); SIRS = Serious Illness Rating Scale (Wyler, Masuda & Holmes, 1968); MOS = MOS Short-form General Health Survey (Stewart, Hays & Ware, 1988); SPS = Social Provisions Scale (Cutrona, 1984); DAS = Dyadic Adjustment Scale (Spanier, 1976); BF1 = Big Five Inventory (John & Srivastava, 1999); BPI = Brief Pain Inventory (Cleeland & Ryan, 1994); RMDQ-11 = Roland-Morris Disability Questionnaire 11 item version (Stroud, McKnight & Jensen, 2004); SRI = Spouse Response Inventory; (Schwartz, Jensen & Romano, 2005); PBCL = Pain Behaviour Check List (Kerns et al., 1991); MPI = Multidimensional Pain Inventory (Kern, Turk & Rudy, 1985); KPS = Karnofsky Performance Status Scale (Karnofsky & Burchenal, 1949); CCI = Charlson Comorbidity Index (Charlson, Pompei, Ales & MacKenzie, 1987); SOMC = Short Orientation-Memory-Concentration Test (Katzman et al., 1983); FACT = Functional Assessment of Cancer Therapy (Cella et al., 1995); BDI = Beck Depression Inventory (Beck & Beamesderfer, 1974); QMI = ; SSEQ = standard self-efficacy scale questionnaire (Lorig, Chastain, Ung, Shoor, & Holman, 1989); STAI = State trait anxiety inventory (Spielberger, 1983); POMS-B = Profile of Mood States-B (Lorr & McNair, 1982); HADS = Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); PDQ = Pain Disability Questionnaire (Gatchel, Mayer, & Theodore, 2006); PARQ = Pain and Activity Relations Questionnaire (McCracken & Samuel, 2007); AEQ = Avoidance-Endurance Questionnaire (Hasenbring, Hallner & Rusu, 2009).

b) Pain Appraisals and Beliefs

Two cross-sectional studies examined the relationship between attachment style and pain appraisals. Those with anxious attachment in both studies were associated with catastrophizing and negative pain appraisals (e.g. pain as a threat). Meredith et al. (2005) found that a regression model including anxious attachment scores and six other variables explained 42% of the variance in pain threat appraisals. However, anxious attachment was not found to be a significant individual predictor and they did not report the change in explained variance when including attachment anxiety. Therefore, it is difficult to determine the extent that anxious attachment predicts threat appraisal when controlling for other variables. Gerson et al. (2015) found that these appraisals in turn were associated with increased symptom severity in Irritable Bowel Syndrome (IBS), although pain symptoms are only a small part of the symptom severity measure they used, making it difficult to isolate the effects on pain. Likewise, they did not control for mental health variables (e.g. anxiety or depression) or other confounding variables that might have affected pain appraisals.

Avoidant attachment was also related to negative pain appraisals, although this relationship was smaller than that between negative appraisals and anxious attachment.

Avoidant attachment was not significantly related to catastrophizing in either study.

Meredith et al. (2005) reported that those with secure attachment rated pain threat lower than insecure attachment styles, although follow-up tests were non-significant. However, the small number of participants in some of the insecure groups likely meant that the test was underpowered.

In summary, anxious attachment in particular is associated with catastrophizing and greater pain threat appraisals. However, the extent to which attachment style alone predicts pain threat appraisals is difficult to determine, as these effects mostly disappear when

accounting for other variables. Likewise, the subsequent impact of the pain appraisals on other pain outcome variables is unknown.

c) Pain Related Self-Efficacy and Disability

One cross-sectional study (Meredith et al., 2006b) examined the relationship between attachment style, pain-related disability and pain self-efficacy. In regression models predicting pain-related disability and pain self-efficacy, neither avoidant nor anxious attachment was found to be significant predictors. However, 'comfort with closeness' (i.e. low avoidant attachment) mediated the relationship between pain self-efficacy and disability, as well as pain self-efficacy and pain intensity. In particular, comfort with closeness was protective: scoring highly meant that the participant had comparatively lower pain-related disability if they scored low in pain self-efficacy. Likewise, those with high comfort with closeness scores had better pain self-efficacy when pain intensity was high.

d) Social and Spousal Support

Six studies explored the relationship between attachment style and social support, covering three main areas, which are described below.

i) Pain Behaviour and Perceived Responses

Forsythe et al. (2012) found that insecure attachment styles were positively correlated with self-reported pain behaviours (measure consisting of distorted ambulation, affective distress, facial/audible expressions and help seeking) while secure attachment was inversely correlated, both with a small to moderate effect size. A similar relationship was found between attachment styles and perceived negative spousal responses to pain. In a regression model including pain intensity, pain source, attachment styles, and spousal responses to pain, the total explained variance of self-reported pain behaviour was 48%.

Preoccupied attachment in particular was a significant predictor. There were no interactions between attachment style and perceived spousal responses to pain in predicting pain behaviours. However, the authors did not control for other important confounding variables that would likely impact on pain behaviour, such as depression or anxiety. Likewise, adding the four attachment styles into the regression model only increased the explained variance by 7%.

Gauthier et al. (2012) found that attachment style predicted how spousal responses were perceived. Attachment anxiety predicted perceived punishing responses to pain behaviour and attachment avoidance and catastrophizing predicted perceived solicitous and distracting responses. When the significant other was a spouse, high attachment anxiety predicted perceptions of punishing responses regardless of catastrophizing. However, the explained variance of these models was small (9-11.2%). Similarly to Forsythe et al. (2012), they did not account for potentially confounding effects of mental states on the perceptions of spousal behaviour, such as depression, anxiety or stress.

In summary, participants with greater insecure attachment, particularly anxious attachment, tended to show more negative pain behaviour and perceive more frequent negative spousal responses. Combining attachment style with spousal responses to pain predicted a large amount of self-reported pain behaviour. However, attachment style only contributed a small amount to the regression models. In addition, the authors did not account for confounding variables, such as mental health problems, which is known to influence both behaviour and cognition, and for which insecure attachment is a vulnerability.

ii) Use of Social Support

One study used a diary design to explore how attachment style interacts with catastrophizing and the use of social support over a period of one month in people with

fibromyalgia or osteoporosis. They found that high attachment anxiety was related to greater catastrophizing in response to increases of pain intensity. In addition, people with more avoidant attachment used social support less in the context of greater catastrophizing. However, this study only used female participants (a large proportion of the target population) and may not generalise to males.

iii) Social Support, Wellbeing, and Coping

Three cross-sectional studies examined the association between social support and attachment style. In a sample of participants with arthritis, Sirois and Gick (2016) found both direct and indirect associations between attachment style, stress appraisals, perceived social support, and coping efficacy. Insecure attachment was associated with higher stress appraisals and poorer social support, which both in turn were associated with reduced coping efficacy. Similarly, Stanton and Campbell (2014) also found that attachment anxiety mediated the link between social support and health outcomes. In general, high attachment anxiety led to worse outcomes even for those with high social support. However, this effect did not apply to reports of bodily pain. Porter et al. (2012) examined these links further in people with cancer by also measuring the attachment style of their spouse. They found that spousal avoidant attachment significantly predicted greater pain and poorer functional well-being. In addition, in couples where one of or both spouses were categorised as having an insecure attachment they found poorer patient and spousal outcomes, including greater pain and poorer self-efficacy.

In summary, insecure attachment was associated with poorer social support which appeared to impact on a wide variety of outcomes. Insecure attachment also appeared to prevent the buffering effect of social support in coping with stress (e.g. Uchino, Cacioppo & Kiecolt-Glaser, 1996) as a result of a health condition. Furthermore, insecure spousal attachment seems to also negatively affect the patient's outcomes, even in terms of pain.

e) Activity Engagement

One cross-sectional study (Andrews et al., 2014) examined the relationship between attachment style and the two types of maladaptive approaches to activities: avoidance and overactivity. Overall, preoccupied attachment style was associated with higher levels of catastrophizing, activity avoidance and overactivity. Both preoccupied and fearful attachment were linked to both activity avoidance and overactivity (in the same individuals). Dismissing attachment was not linked to any variables except thought suppression.

Discussion

The aim of this study was to review the literature examining the relationship between adult attachment style and chronic pain variables, with an emphasis on understanding the mechanisms or processes linking the two. This was an extension and update of a similar review by Meredith et al. (2008), using more systematic methodology and narrow inclusion and exclusion criteria. Despite attachment theory being presented as a promising field of research for chronic pain, only a few new studies have been produced in the decade since the review by Meredith et al. (2008).

Similar to Meredith et al. (2008), this study found that insecure attachment style was negatively associated with many variables. These included poorer strategies for activity, reduced benefits of social support, more negative perceptions of spousal support, more negative pain behaviours, greater catastrophizing in response to pain, greater threatening appraisals of pain, more pain-related disability, poorer pain self-efficacy, and poorer response to chronic pain treatment programs. Anxious attachment in particular showed a stronger and more prevalent negative relationship to pain related variables than avoidant attachment.

A large majority of the ADMoCP mechanisms were covered in the studies in this review (some of factors were not covered in this review, for example, attachment and mental health problems in chronic pain). However, few studies examined multiple variables, so the relationship between them is difficult to determine, for example, how negative pain appraisals translate into behaviour.

Counter to predictions, such as by Mikail et al. (1994), avoidant attachment had smaller and fewer negative relationships with the chronic pain variables. One possible explanation for this could be the preference of those with avoidant attachment for self-sufficiency and independence. This provides a positive motivation for finding adaptive ways to cope with pain, especially if the consequence of alternatives might mean increasing dependence on others. Alternatively, the positive model of the self may be a more important factor in successful adaptation to pain than a positive model of others (Bartholomew & Horowitz, 1991). Despite this, a more negative perception and lack of use of social support was a consistent finding for avoidant attachment, which was in line with predictions by Mikail et al. (1994). The prediction that there would be a relationship between avoidant attachment and initial health-related help-seeking behaviour was not studied.

As found by Meredith et al. (2008), the majority of studies were cross-sectional, making it impossible to determine the direction of associations. This is particularly relevant for studies that used attachment measures for romantic relationships, where problematic chronic pain may have been detrimental to the relationship. These studies also have problems with self-selecting samples that may not represent the chronic pain group, especially as condition severity was noted to be worse in some of the studies where participants declined to take part. Due to the insecure attachment styles representing smaller parts of the population (Bakermans-Kranenburg & Van Ijzendoorn, 2009), many of the studies were underpowered when using categorical attachment styles. Future studies

would benefit from larger samples. In addition, despite consistent results, the magnitude of the effect or value of attachment style was arguably small in many studies. This questions the benefit of assessing another variable in regards to chronic pain, when more influential variables have already been implicated.

Existing theories linking attachment theory and chronic pain (e.g. Kolb, 1982; Mikail et al., 1994) make predictions about how people approach and use health care (e.g. erratic attendance, difficulty developing therapeutic alliances, ambivalence about change). These predictions are intended to account for both increased incidence of chronic pain and poorer outcomes in chronic pain for those with insecure attachment styles. However, none of the studies covered in this review examined these predictions. Likewise, Meredith et al. (2008) introduced the ADMoCP to organise future research and conceptualise the relationships between attachment style and chronic pain. However, this model does little to explain the relationships underlying general associations between variables. At present, an empirically supported explanatory model of attachment theory and chronic pain is lacking in the literature.

Clinical Implications

Attachment theory, as applied to chronic pain, supported by this and previous reviews, has a number of clinical implications related to delivering interventions and planning services.

There is some mixed evidence in this review that suggests that those with insecure attachment do not respond to treatment as well as secure individuals, although this difference is small. At present the reason for this disparity is unclear. One explanation could be that co-morbid psychiatric issues, which are more common in people with insecure attachment style, may interfere with treatment. These issues could affect motivation, engagement, retention or application of treatment techniques. Future studies would be strengthened by controlling for mental health variables, such as depression, anxiety, or

psychiatric diagnosis. Alternatively, those with insecure attachment may struggle more with forming a therapeutic alliance, which is a key ingredient in successful therapy.

Another idea that is currently untested in the literature is the hypothesis advanced by Kolb (1982) and Mikail et al. (1994) that an insecure attachment may predispose an individual to be intrinsically reinforced by the interpersonal care that comes with chronic pain. Most CBT programs promote independence and self-sufficiency which might involve reducing valued care and interpersonal contact from a person's life.

Many therapies and approaches aim for people to effectively use and manage their social resources such as partners, friends and professionals (e.g. by teaching 'assertiveness' skills). This review would reinforce that those with insecure attachment styles have more negative perceptions and use of their social support, but the reasons for this are unclear. As all of the studies depended on self-report, the correspondence between perceptions and actual behaviour cannot be determined. This review would suggest that an interpersonal focus in chronic pain treatments may be beneficial, and while this is included in some psychologically-based treatments, it is often sacrificed for brevity or convenience.

The studies included in this review provide several areas that could be targeted when assessing someone for treatment and considering their attachment style. These include maladaptive approaches to engaging in activities, catastrophizing, self-esteem/self-efficacy, negative pain appraisals, and use of social support. This relates to the multiplicity of attachment theory, which can affect behavioural, cognitive, affective and interpersonal systems.

Recommendations for Future Research

Results examining attachment theory and chronic pain are promising. There are several recommendations for future research.

- Many studies relied on romantic attachment style measures that have been demonstrated to have low reliability (e.g. RQ). Future studies would benefit from using a measure with stronger psychometric properties, such as the Experiences of Close Relationships-Revised (ECR-R; Fraley et al., 2000).
- There are currently no studies that use mental representations of childhood experience to conceptualise adult attachment style (e.g. AAI). This may be a useful alternative to romantic attachment, especially as romantic attachment measures may be vulnerable to the relationship damaging effects of a chronic pain condition.
- At present, the majority of studies examine general associations between romantic attachment style and widely used pain variables (e.g. self-efficacy). However, there are few attempts to investigate the pathway between attachment style and these negative associations, even where specific predictions are made. Future studies would benefit from clear hypothesis testing regarding the mechanisms of how an insecure attachment style leads to poorer outcomes. For example, studies examining how attachment style affects treatment outcomes could examine the therapeutic relationship, trust in information, adherence to strategies, and motivation to change.
- There are currently no studies that examine whether insecure attachment style is a vulnerability factor for developing a chronic pain. This is an untested area of the ADMoCP.
- Studies should control for psychiatric status and other mental health variables, such as depression and anxiety. As insecure attachment style is a known risk factor for developing mental health problems (Hankin, Kassel & Abela, 2005), this is a potential confounding variable in the outcomes of pain.
- Statistical tests using categorical measures of attachment style were frequently underpowered, increasing the chance of Type II error. As insecure attachment

styles represent the minority of a sample, larger samples are required to ensure there are enough people in each group to test for differences.

Limitations of This Review

Only two databases were searched for this review. While these were chosen to cover psychological and medical journals, there are likely areas that were missed. Likewise, other types of literature were excluded, such as several promising dissertations that may have contributed to this field. Attachment theory is an internationally recognised and investigated theory and because this review was restricted to studies written in English, other research, such as from Europe, is missed.

The AXIS tool was used as a way to identify study weaknesses. However, while the AXIS tool acted as a guide for evaluating each of the studies, it was still dependent on the researcher's subjective judgement. As this review did not use a second rater, the reliability of these ratings is unknown. It was decided not to report the total scores from the AXIS tool (i.e. out of a potential score of 20). This decision was made based on the knowledge that some weaknesses would have a substantially larger impact on the interpretation of the study than others. For example, two studies could both receive ratings of 19 out of 20, with one study not reporting their justification for their sample size, but the other using unstandardized and low quality measures. However, without a general rating or score, it can be difficult to compare the quality across the studies to decide which findings to give more 'weight'. In addition, the AXIS is a tool designed for cross-sectional studies, and may not have effectively evaluated the remaining four studies that used other designs. Similarly, the studies reviewed may have had weaknesses not captured by the AXIS tool. The review may have benefited from using a general and more established quality evaluation tool.

Conclusion

In conclusion, attachment style may be a useful psychological construct that captures natural variation in the variables associated with the outcomes of chronic pain. However, there has been limited growth in research since 2008, with a small number of new studies with narrow methodologies, making conclusions difficult. Despite this, insecure attachment style, particularly anxious attachment, was linked to poorer outcomes in cognitive, behavioural and interpersonal factors. Attachment style may therefore be useful to consider in clinical assessment and delivering interventions. However, specific hypotheses about the mechanisms underlying the associations between attachment style and chronic pain variables is an area that needs future research.

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Part Two: Empirical Paper

**A Mixed Methods Exploration of How Hospital Inpatients Understand and Use the Verbal
Rating Scale of Pain**

Abstract

Background: The pain experience is a complex integration of biomedical, psychological, social and contextual factors, few of which can be directly observed. Therefore, the assessment of pain is dependent on the patient's self-report. Hospitals routinely use pain scales, such as the Verbal Rating Scale (VRS), to record a patient's pain. However, these unidimensional scales are often used in a way that concatenates pain intensity with other pain elements, which makes choosing appropriate interventions difficult.

Aims: This study aims to understand how inpatients understand and use the VRS in a hospital setting.

Methods: Forty-five participants took part in a semi-structured interview and a task to develop their own personal pain scale. Qualitative data was analysed using Thematic Analysis (Braun & Clarke, 2006).

Results: Participants anchored their pain experience in the physical properties of pain, tolerability of pain, and impact on functioning. Their relationship to painkillers, personal coping style, and experiences of staff influenced how they used the VRS. Categories of the measure were not considered equidistant.

Conclusion: Participants grounded and explained their pain in semantically similar but idiosyncratic ways. The VRS was used in a way that combined pain intensity with multiple other elements of pain and was often used as a way to request painkillers. Therefore, pain scores need to be explored and interpreted by staff and not only used as the basis for providing painkillers.

Introduction

Pain is adaptive; it functions to protect the individual from harm, acting as an alarm that triggers escape and subsequent protection of the injured area to promote recovery (Wall, 1979). The experience is highly aversive, acting as an effective learning experience to prevent future harm (Walters, 1994). Furthermore, it has a social function that is conveyed through facial expressions, posture, and behaviour (e.g. Prkachin, 2009; Schiefenhövel, 1995). Pain is therefore a signal that is difficult to ignore both for the individual experiencing it and for those around them. Because pain is so aversive and evokes worry (Blyth et al., 2011), it is one of the main reasons people seek healthcare (Keefe & Wharrad, 2012).

Pain exists across a multitude of conditions (e.g. Taylor, 2006) and relates to monophasic events (e.g. an injury), chronic episodic conditions (e.g. headaches), or chronic persistent problems (e.g. arthritis; Stewart, Ricci, Chee, Morganstein & Lipton, 2003). However, pain is an internal experience and the relationship between actual physical damage and the magnitude of pain is variable (e.g. Arntz & Claasens, 2004; Bedson & Croft, 2008).

Therefore, pain cannot be directly and reliably observed by a clinician. As a result, the preferred method of assessing pain is to use patient self-report (or use proxy measures of pain when this is unavailable). Thus, pain is 'whatever the experiencing person says it is, existing whenever the experiencing person says it does' (McCaffery, 1968, p. 95). However, this is marred by a number of problems that involve both clinician's and the patient's understanding and communication of pain.

Despite being introduced as the 'fifth vital sign' by Campbell (1995) along with blood pressure, respiration, pulse and temperature, it is often not assessed alongside these other signs. If it is assessed, it is often perceived to be an exaggeration (Chiang et al., 2011; Chow & Chan, 2015). In cases where there is a discrepancy between pain and the underlying

medical cause (or in fact a complete absence of a physical cause), pain can be discounted by professionals altogether (Newton, Southall, Raphael, Ashford & LeMarchand, 2013). One assumption behind the under-treatment of pain is that nurses lack relevant knowledge (McCaffery & Ferrell, 1997), and that this can be addressed with education and training programs. There are a number of nursing education programs that are being used to challenge 'incorrect' beliefs around pain. Despite this, teaching hours for pain on nursing courses still only amounts to less than 1% of total teaching time (Keefe & Wharrad, 2012). Further, there is limited evidence that changing beliefs translates into behavioural change (Drake & Williams, 2016; Twycross, 2002).

Contemporary models of pain are biopsychosocial (e.g. Hadjistavropoulos et al., 2011; Turk & Okifuji, 2002) and integrate biomedical, psychological and social-contextual processes. Jensen and Karoly (1992) proposed separating the experience of pain into four constructs: pain intensity (how much a person hurts), pain affect (the degree of emotional arousal, e.g. fear or distress), pain quality (the physical sensations associated with pain e.g., 'stabbing' or 'hot') and pain location (the perceived location of pain). Melzack and Casey (1968) described similar dimensions, labelling them sensory-discriminative (i.e. pain intensity, quality and location), affective-motivational (i.e. pain affect) and cognitive-evaluative, the appraisals of meaning related to pain. The emotional and sensory dimensions are also associated with different neural pathways: the lateral pain system projects into the primary somatosensory cortex (the sensory part of the brain), and the medial pain pathway projects into the cingulate cortex and limbic system (the part of the brain associated with emotions). The cingulate cortex is of particular importance as this area is linked to 'central sensitization', chronic pain resulting from changes in the central nervous system (Lumley et al., 2011).

There are a number of methods to assess pain in routine hospital care. One of the most common is the Verbal Rating Scale (VRS; e.g. Ferreira-Valante, Pais-Ribeiro & Jensen, 2011; Seymour, 1984). Clinicians using this method ask patients to rate their pain using adjectives that loosely represent an ordinal scale of pain intensity (e.g. no pain, mild pain, moderate pain, severe pain, very severe pain). The answers resulting from this assessment are often assigned scores (e.g. no pain = 0, mild pain = 1, moderate pain = 2 etc.) and treated as an interval or ratio scale by transforming against various standardised measures (Jensen & Karoly, 1992). In research, this enables the use of quantitative statistics to examine the relationship of pain with other variables and change with treatment.

However, scoring verbal measures of pain has been criticised. Ordinal verbal categories provide no information about the 'distance' between points on the scale (Jensen & Karoly, 1992) that would inform accurate scoring, or even if those distances are consistent across people in pain. Regardless, some researchers have assumed that the distances between verbal categories are equal (e.g. Lund et al., 2005). Early attempts in the field of psychophysics, however, found that pain reports were significantly confounded by psychological and decisional processes and did not represent a linear structure assumed by equidistance (Rollman, 1977). Even in simple sensory discrimination studies such as smell, the relationship between categories resembled a logarithmic scale (see Figure 1: Green, Shaffer & Gilmore, 1993).

Taking into consideration that pain is multidimensional and that the use of verbal scales is influenced heavily by decisional processes, it may be incorrect to assume that they assess only pain intensity: other relevant factors include context (Hadjistavropoulos et al., 2011), social processes (Hadjistavropoulos & Craig, 2002), past experiences, communication about tolerance or resilience (Schiavenato & Craig, 2010), and the very individual understanding of the category labels themselves. Single ratings do not separate the constructs of pain

intensity, distress, and functional impairment, when in fact these are likely to be idiosyncratically linked (Williams, Davies & Chadury, 2000). Over 40 years ago Fordyce wrote that pain ratings should be considered pain behaviours, and that it is important to look beyond simple reports to the functional implications (Main, Keefe, Jensen, Vlaeyen & Vowles, 2015).

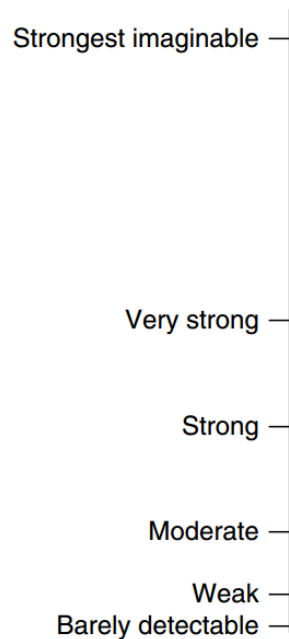


Figure 1: Labelled magnitude scale of oral sensations from Green et al. (1993)

In routine healthcare settings, the use of these measures could be considered reductionist, failing to differentiate between the dimensions of pain and thereby concatenating them in unknown ways in a single rating (e.g. Goodenough et al., 1999). Aside from the problematic validity of unidimensional pain scales, there are also clinical implications of the lack of understanding of how pain scales are used. Of particular importance is the lack of separation of pain and distress, i.e. the pain sensory intensity from the extent of emotional distress (Morone & Weiner, 2013).

Sullivan and Ballantyne (2016) argued that pain intensity and pain distress are different constructs that require different clinical interventions: for chronic pain, giving analgesic drugs for high pain ratings that result from emotional distress is both unhelpful and

potentially harmful. Morone and Weiner (2013) agreed, “The increase in prescription of opioids underscores the mistaken view that pain is a unidimensional problem. When both patients and clinicians view pain as a purely sensory experience, then management is necessarily limited to the sensation.” (p. 1729). They go on to recommend that clinicians need to interpret patient pain scores rather than accept them at face value. It is therefore important to understand how pain measures are used by patients in ecologically valid settings.

In summary, the pain experience is a complex integration of biomedical, psychological, social and contextual factors, few of which can be directly observed. Therefore the assessment of pain is dependent on the patient’s self-report. Hence, routine pain measures used in healthcare, such as the VRS, are communication tools for reporting the internal state of pain. However, these unidimensional measures are often used in a way that concatenates pain intensity with other pain elements. This makes decisions about appropriate interventions difficult. Therefore, it is essential to understand how patients are using the VRS and how they use it to conceptualise and communicate their pain. By understanding this process, clinicians would be better positioned to interpret pain scores.

Study Aims

This study aims to explore:

- How hospital inpatients translate their pain into the VRS categories
- How inpatients communicate about their pain to medical staff in the context of routine pain assessments

Method

Setting

Participants were recruited from the adult inpatient wards in a central London hospital. The researcher obtained an honorary contract with the specialist Complex Pain Team (see Appendix B), who acted as a liaison with the wards in the hospital. This hospital used a five point VRS as their routine pain measure for adults, with the categories of no pain, mild, moderate, severe, and very severe pain. The VRS was required to be completed at the same time as other routine observations, although it was often not assessed or recorded.

Ethical Approval

Ethical approval for this study was obtained through NHS Ethics (Project ID: 16/YH/0417; Appendix C). One concern I had was confidentiality. Due to practical limitations, the study was conducted at the participants' bedsides. As part of the process of obtaining consent, I ensured that participants made a fully informed decision about potentially being overheard and I only approached participants with capacity to weigh up the decision to take part.

Public and Patient Involvement

As part of the NHS Ethics process, I consulted an external pain expert through experience who facilitated changes in the documents and protocols used in this study.

Procedure

The on-site hospital Complex Pain Team were initially asked to liaise with the ward managers across the hospital to ask for permission for the researcher to approach ward staff about the study. The Complex Pain Team reported that a total of five wards responded and agreed.

The researcher then approached the nurse-in-charge or sister on shift to explain the study and ask for permission to collect data. If the senior staff member agreed, then she/he was also asked to identify and approach suitable patients based on the inclusion criteria. Data were collected across a period of four months, with the process of asking permission and identifying patients repeated each day of data collection and on each ward. No patients were approached unless specified by the nurse-in-charge and met study criteria.

Participants were considered for recruitment if they:

1. Were over 16 years old.
2. Could communicate effectively in English.
3. Were in a mental state that facilitated communication (a participant with temporary or permanent cognitive impairment would not be suitable).

Patients who were approached were asked if they were interested in participating. Those who expressed interest were given the Participant Information Sheet (Appendix D) and were left to consider the information for an agreed amount of time (a minimum of 10 minutes). The researcher then returned to answer any questions and check if the participant wanted to proceed. Those agreeing to participate were given the Consent Form (Appendix E) to review and sign.

The study consisted of two parts: (a) a semi-structured interview, and (b) a personal pain scale task. Both parts were conducted at the participant's bedside with his/her consent.

Interview Protocol

A semi-structured interview was developed based on the study aims. Overall, the interview aimed to understand how inpatients used the VRS and the basis for their pain ratings. The interview was informed by the assumption that selecting ratings on the VRS was a decisional process informed by the elements of the biopsychosocial model of pain (Turk &

Okifuji, 2002). The questions were developed to broadly cover relevant areas: (a) how participants understood the VRS categories, (b) how they decided to select a specific category, (c) how pain affected their emotions, (d) how they coped with their pain, (e) what they thought of the VRS, and (f) what they would want to communicate to the hospital staff about their pain. The interview protocol also included an introduction to 'set the scene', based on Smith, Flowers and Larkin (2009). The full interview protocol can be found in Appendix F. A semi-structured interview format was chosen so that the researcher could enquire about and clarify the participant's answers, as well as keeping an informal interview tone.

Personal Pain Scale Task

The second part of the study involved the participant developing his/her own personal pain scale using a horizontal line on a landscape A4 page as a template. Participants were initially asked to record the current categories (i.e. No Pain, Mild, Moderate, Severe and Very Severe) on the line before making any of their own additions or changes. During this task participants were asked to 'think out loud', so that their method of development could be understood. The full task instructions can be found in Appendix G.

The 'thinking out loud' data were originally planned to be analysed in accordance with the method described under 'Qualitative Analysis'. However, this data did not add any new substantial information in addition to the interview data, so was not included in this study.

Quantitative Analysis

The data from the Personal Pain Scale task were presented and analysed to address four main areas:

1. Mean positions the VRS categories

The positions of where participants placed each of the VRS categories were recorded and presented in a box plot accompanied with other descriptive information (means and standard deviations).

2. Whether the positions indicate discrete categories

As one of the category positions did not meet assumptions for normality, non-parametric tests (Kruskal-Wallis with follow-up Mann-Whitney tests) were used to compare the positions of categories to determine whether they were statistically different from each other.

3. Whether the distances between categories were equal (i.e. equidistant)

The distances between categories were also measured and compared. As the distances met assumptions for normality, parametric tests (ANOVA with follow-up t-tests) were conducted to determine whether there were equal distances between categories.

4. How participants modified their scale

Modifications to the measure were analysed by first looking iteratively across the personalised pain scales for commonalities in the types of changes. Each scale was categorised by the type of change made to the measure (e.g. expanding on the original categories, adding new categories). Representative examples were then chosen and presented in the Results section.

Demographic and Diagnostic Information

After each interview, a note was added to the participant's medical notes to record that they took part in the study. At this time, basic demographic information (gender, age and ethnicity) as well as diagnosis was recorded so that the sample could be 'situated' (Elliott,

Fischer & Rennie, 1999). Only the immediate diagnosis (i.e. the reason for hospital admission) was documented. For the sake of simplicity, comorbidities were not recorded.

Sample Size

As there is no previous research examining the use of pain measures, it was not possible to 'predict' the prevalence of potential themes that may appear to determine sample size as recommended by Fugard and Potts (2015). Alternatively, an empirical study by Guest, Bunce and Johnson (2006) examined theme 'saturation' across a sample of 60 interviews and found that the overarching themes were visible at 6 interviews and 'saturation' occurred at 12 interviews. However, considering the short length of the interview protocol and relatively narrow research focus, a sample size of 45 was chosen to ensure that a large variety of experience could be studied.

Qualitative Analysis

The interview data were analysed using Thematic Analysis (TA; Braun & Clarke, 2006). The analysis was grounded in a 'critical realist' epistemology. In this view, the experience of pain was recognised as 'real' and located in the body, but that each individual constructed the experience both in relation to him or herself and in communicating with others. This epistemological standpoint was chosen as it validates the participant's experience as accurate, but recognises that communicating the experience is influenced by both individual differences and social processes. The steps recommended by Braun and Clarke (2006) were followed:

1. Transcription of the data

Each of the interviews was transcribed using Express Scribe Transcription Software. I transcribed a total of 27 interviews with the remaining 18 interviews transcribed by a volunteer. These 18 interviews were checked by the researcher for accuracy by listening to

the tape and comparing the content with the transcription. The interviews were transcribed in accordance with recommendations in Barker, Pistrang and Elliott (2002): verbatim speech content, but without information about the tone, loudness, speed etc. of speech (see Appendix H for an extract of a transcribed interview).

2. 'Immersion' in the data

Aside from transcribing, I re-read all of the interview transcripts again before beginning coding so that I would be familiar with the data.

3. Generating initial codes

The transcripts were uploaded into Nvivo, qualitative analysis software. I then worked systematically through each of the transcripts, coding each unit of meaning found, and keeping as close to the original meaning as possible without implying any higher categorisation. I coded all the data, without making assumptions of what would be relevant to the research question. This was to protect against the loss of potential themes or sub-themes at later stages.

4. Searching for themes

I then began to systemically work through the codes of meaning I had identified and to merge codes based on meta-level meanings. This was based on the explicit content of what the participant reported, rather than implicit or implied meaning. Previous theory also partly informed the type of codes that were chosen, in particular, that the pain experience can be divided into sensory, affective, and cognitive elements. For example, text coded as 'stabbing', 'throbbing', and 'nagging' were coded under 'Quality of Pain'. I also began to focus on the research aims and discarded some codes that were irrelevant to the study. For example, a participant who identified as an alcoholic was anxious that he/she would not be able to stop drinking. I adopted a reflexive stance as a method to reduce my personal

influence on the generation of themes, for example, by continuously checking that the data matched the higher level category.

5. Reviewing and redefining themes

I then examined the themes that I had developed against Patton's (1990) criteria of internal homogeneity and external heterogeneity, in other words, whether the codes were similar enough to each other to constitute a wider theme, and whether the theme itself was different enough from other themes to be considered separately. For example, 'Quality of Pain' was later absorbed into a broader theme of 'Physical Properties of Pain'. This stage also involved credibility checks, described in the section below. Through this process the themes and subthemes evolved over several iterations before settling on the themes described in the results section.

Quality Evaluation

I aimed to adhere to Elliott et al.'s (1999) guidelines for qualitative research in order to improve the quality of this study. This includes: (a) reporting my perspective in the 'Reflexive Statement' section below to clarify my theoretical and personal orientations, (b) providing relevant information about the participants in the 'Participant Characteristics' section in order to situate the sample, (c) giving multiple participant quotes for each theme in order to ground the themes in the data, (d) using two forms of credibility checks: testimonial validity and inter-rater agreement of themes, described below, (e) organising the themes into clusters and highlighting the links between themes for the clarity of the reader, as seen in Figure 1, and (f) interviewing a large number of participants with a broad range of experiences of pain and hospital stays to improve the chance of developing a general understanding of the phenomena.

Credibility Checks

I used two forms of credibility checks to help improve the validity and reliability of this study. Testimonial validity involves asking the original participants, or a similar group, to give feedback on some part of the results or analysis. To do this I used 'synthesised member checking' as described by Birt, Scott, Cavers, Campbell, and Walter (2016). This involved firstly emailing participants who had provided their email addresses during the main study explaining the process of member checking and asking those who were interested to 'opt-in'. Those who expressed interest were provided a jargon-free summary of the study's themes with space for feedback, using open questions as prompts. Participants were asked to read the summary and provide feedback on the themes, focusing on three general questions: (a) Does this match your experience? (b) Would you change anything? (c) Would you add anything? The feedback provided was compared to the original themes and alterations were made where necessary. The member feedback provided can be found in Appendix I with my responses on how it was incorporated. It was made clear at all stages that this was optional and they could opt out at any time.

The second credibility check used was inter-rater agreement of themes. This involved asking another researcher to code five randomly selected transcripts. A meeting was then arranged with this researcher to examine these codes against my own coding process and discuss whether they converged on the initial themes I had developed.

Reflexive Statement

A reflexive position was taken in order to reduce the researcher's biases on the interpretations. I am a male Trainee Clinical Psychologist in my mid to late twenties training at University College London (UCL). I come from a working class family that generally demeaned post-modern epistemologies as irrelevant. My interest in constructionism was a reaction to these ideologies, although I still strongly favour pragmatism. My personal

preferences in psychological models have involved Cognitive Behavioural Therapy (CBT) and systemic approaches. These approaches combined emphasise the 'splitting' of experience into different elements and sequences, while also recognising the circular nature of phenomena. That is, cause and effect are rarely unidirectional. I have experience of working therapeutically with people with chronic pain difficulties during a six month training placement. I found this to be a generally frustrating experience, mainly because I formulated the experience of pain as strongly intertwined with interpersonal processes. I found that the CBT models I was introduced to at the time lacked a meaningful way to conceptualise and work with those relationship processes. I was drawn to the topic of the measurement of pain mainly due to dissatisfaction with what I perceived as an oversimplification of the approach to pain, as well as a desire for my research to have real world application.

Results

Participant Characteristics

In total, 45 participants completed the semi-structured interview and of these 29 agreed to complete the Personal Scale Task. Overall, 10 men and 35 women took part, with a mean age of 50 ($SD = 18$, Range = 19 – 81). The majority were White British (62%). Table 1 lists the characteristics of each participant, generalised to protect confidentiality. Of the diagnostic categories, the most frequent individual diagnosis of 'Arthritis related disorders and problems' was Coxarthrosis ($n = 9$), of 'Chronic disorders and related problems' it was Crohn's disease ($n = 6$), and for 'Other injuries and problems' it was fractures ($n = 5$). Across the participants the median duration of pain experienced as part of the condition was 6 years, with a range of one day to 40 years. When removing participants who had experienced pain for less than a year ($n = 10$), the mean time reported in pain was 13 years ($SD = 12$). The majority of participants were recruited from an Orthopaedics ward (47%),

followed by Gastroenterology (31%), Oncology (16%) and Short Stay Surgery (7%).

Descriptive data were missing for two participants.

Table 1: Participant Characteristics

Participant Number	Gender	Age Range	Ethnicity	Pain Chronicity	Diagnosis^a
1	F	40-49	White British	> 10 years	CD
2	F	20-29	White British	5-10 years	CD
3	F	60-69	White Other	< 7 days	AD
4	F	50-59	White Other	> 10 years	AD
5	F	70-79	White British	< 7 days	AD
6	F	80-89	White British	5-10 years	AD
7	M	60-69	Black British	> 10 years	AD
8	F	40-49	White British	> 10 years	CD
9	F	40-49	White Other	> 10 years	CD
10	F	30-39	Black Caribbean	> 10 years	CD
11	F	50-59	Black British	5-10 years	AD
12	F	70-79	White British	1-5 years	AD
13	F	N/A	N/A	1-5 years	N/A
14	F	30-39	White British	1-5 years	OI
15	F	60-69	Not Stated	5-10 years	AD
16	F	70-79	N/A	1-5 years	AD
17	M	60-69	N/A	Not reported	AD
18	M	50-59	White British	1-5 years	AD
19	F	60-69	British Indian	6-12 months	AD
20	F	40-49	Not Stated	> 10 years	AD
21	M	50-59	Black African	3-5 years	TD
22	M	N/A	N/A	< 7 days	N/A
23	F	70-79	White British	> 10 years	TD
24	F	20-29	White British	> 10 years	CD
25	M	70-79	White British	< 7 days	TD
26	F	20-29	White British	1-5 years	CD
27	F	20-29	White British	5-10 years	CD
28	F	20-29	White British	> 10 years	CD
29	F	30-39	White British	> 10 years	CD
30	F	20-29	White British	1-5 years	CD
31	F	60-69	White British	None reported	CD
32	F	60-69	White British	None reported	OI
33	M	50-59	White British	5-10 years	CD
34	F	50-59	White British	7-30 days	AD
35	F	60-69	White British	1-5 years	AD
36	F	70-79	White British	< 7 days	OI
37	F	60-69	White Irish	> 10 years	AD
38	F	30-39	White British	5-10 years	CD
39	F	16-19	White British	1-5 years	CD
40	F	60-69	White British	5-10 years	AD
41	M	40-49	White British	5-10 years	OI
42	F	20-29	White British	> 10 years	CD

43	M	40-49	White British	1-12 months	OI
44	M	20-29	White Other	< 7 days	OI
45	F	20-29	Other	> 10 years	CD

NB. Data found in this table was taken as it was recorded in medical records, and is not self-reported (excluding 'Pain Chronicity' which was recorded from an interview question). Gaps in data represent gaps in the notes examined. ^a CD = Chronic disorders and related problems; AD = Arthritis related disorders and problems; TD = Tumour related disorders; OI = Other injuries and problems. In the Gender column: M = Male; F = Female.

Part One: Semi-Structured Interview

Themes

Analysis of the qualitative data from the semi-structured interviewed produced a total of eight themes with four subthemes. Together these were grouped under three clusters: (a) How the pain experience was anchored, (b) relationship with painkillers, and (c) relationship with staff. Figure 2 displays a 'map' of the themes and relationships between themes. The themes are explored below, highlighting both similarities and differences between participants. At times, the prevalence of themes or meanings are reported. However, it should be noted that a participant not reporting a theme does not necessarily imply that it is absent from their internal representation of pain. Where direct quotes have been used, ellipses indicate parts of the transcript not reported in order to be succinct. Participants are numbered so that, for example, P22 would indicate Participant 22 from Table 1. *Int* indicates the interviewer.

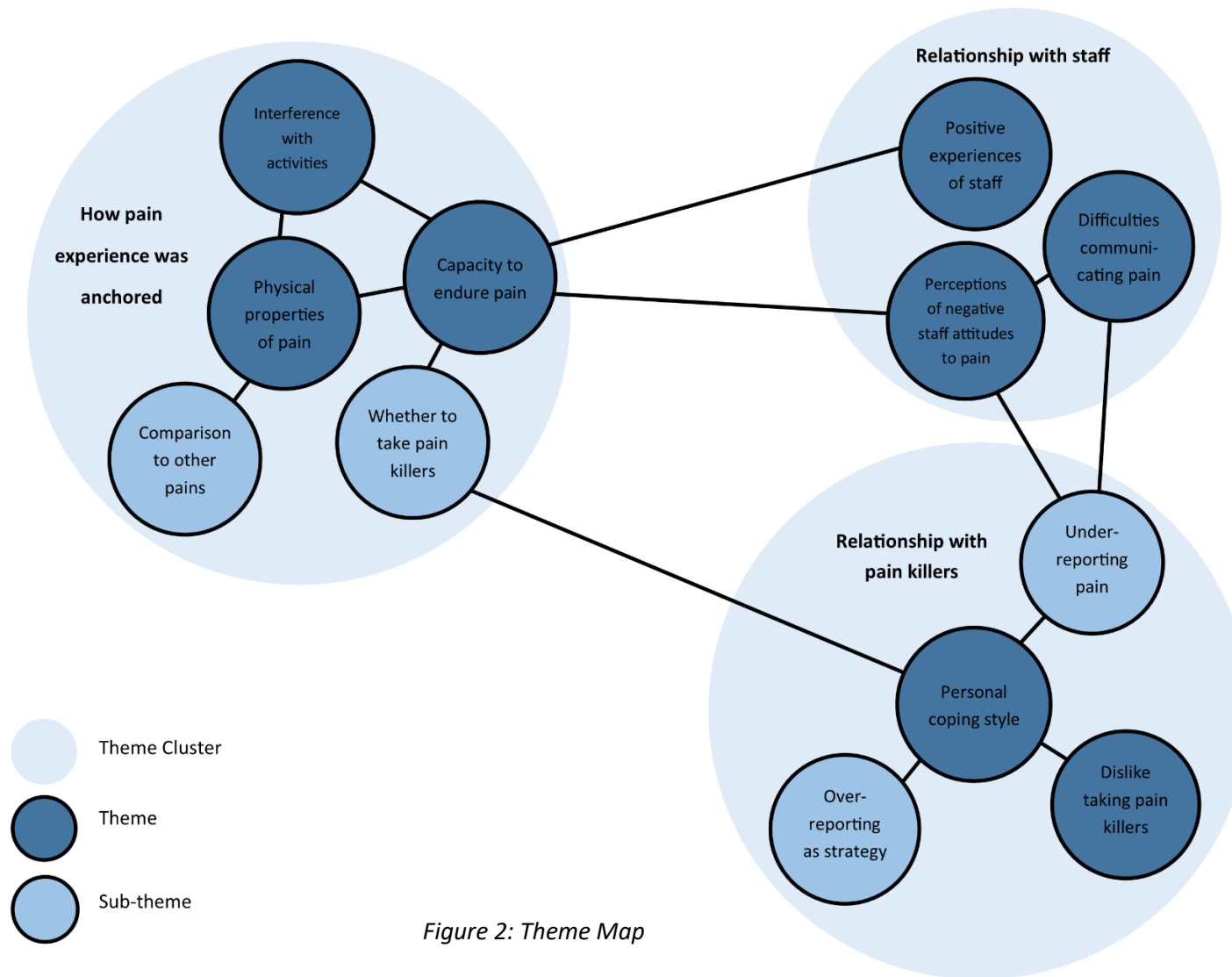


Figure 2: Theme Map

Cluster 1: How the pain experience was anchored

This cluster of themes pertains to how participants described and objectified their pain in order to ground the categories of the VRS. This included the physical properties of pain, how pain impacted on their functioning, their ability to endure pain, and how to cope with pain.

1.1 Physical Properties of Pain

Unsurprisingly, many participants ($n = 25$) made reference to the physical sensations of pain when demarcating categories of the pain measure. This included the amount of pain, number of pains, the longevity, constancy, and quality of pain. Generally, as these properties increased, the reported pain severity worsened. However, the precedence and concatenation of these properties varied across participants. For example, pain longevity and constancy were referenced as sometimes more influential than the amount of pain.

P14: I go back to the comparison with the broken leg and gastritis ... Obviously, that hurt more than that ... But this ultimately hurts more than that did because it's there all the time ...

Similarly, some participants commented on how the number of pains had an additive effect on pain ratings.

P42: ... I don't just think of one pain I think of all my pain... and then amalgamate it according to how much, how much pain I'm in... if only one thing is hurting, then it will be a lower score than if my joints are very sore and I've got my pancreas kicking off, my bowels cramping, for instance...

This additive effect was also related to how they perceived their need for painkillers. Two participants described how new acute pain was understood as 'on top of' pre-existing chronic pains and required a unique intervention.

P41: ... then they realised this is a new injury this injury didn't gravitate itself high above my current status ... But this, this new injury is superseding their limits at their prescribed dosage.

1.1.1 Subtheme: Comparison to Other Pains

Many participants used comparisons with other experiences of pain to ground their pain categories ($n = 17$), this included actual experiences and hypothetical ones. The time frame of these comparisons also varied, from how the current pain compared to the previous day in hospital to historical pain. There were references to what was labelled 'everyday' or 'normal' pains, as well as more exceptional pain from their pasts.

P28: ... I'd compare [the current pain] to my kidney stones, I compare all my pain now to the worst pain I've ever experienced ...

P1: ... I mean you're talking like headache, maybe, I mean, say headache. Erm, I mean, mild to moderate as, as I said is like, just like normal aches and pain ...

P12: ... that would be erm, stabbing pain I think, yeah. I mean I assume what you'd feel if you'd been shot ...

Comparisons to other pains also had emotional consequences. The major difference to the 'Capacity to endure' theme consequences was that favourable comparisons resulted in positive emotions.

P45: ... now like I'm feeling today I'm feeling pretty good ... but I feel a lot better because I was previously in quite severe pain

1.2 Interference with Activities

The majority of participants ($n = 34$), and the most prevalent theme in this cluster, used how pain interfered with what they could do as a reference to describe the severity of pain.

These related to a number of areas, including interference with mental activities, behaviour, sleep, and coping strategies. Participants described both what they could and could not do to delineate the severity of their pain.

P29: ... that's how I associate what my pain is if someone asks me is what am I able to do at the moment ... To be able to say how much pain that I am in.

P44: ... I know [the pain is] there but I can also forget about it and focus on something else ... I know I'm hurting but I know, I can do something else you know read, listen to something the, the pain is not getting in the way of something else that I'm doing, that would be mild for me.

Participants used a wide range of examples of behaviour that was disrupted, such as conversing with others ($n = 7$) and movement ($n = 8$). The mental activities that were disturbed were often the ability to concentrate and maintain attention. Some participants explained that when pain interfered with one activity it also impacted on others.

P2: Mild, I can have a conversation with someone and completely focus on that conversation. Moderate my mind will start focusing slightly on the pain and I will lose the conversation slightly and, or miss parts of what that person is saying, my concentration won't be as good. Severe, I wouldn't be able to have a conversation.

Some participants described how pain affected their ability to sleep ($n = 13$), thus their tolerance for pain at night was lower than during the day.

P6: Well moderate pain is at night, you have to take something to relieve it, otherwise you can't sleep

P13: ...if it's at night time I say yes I want some pain killers ... I want to go to sleep ... what I would tolerate during the day, at night time I won't tolerate ... I'm more

sensitive, that's the word I'm looking for, I'm more sensitive to pain at night time, yeah.

Participants reported using a wide range of coping strategies, the most common being focusing on things aside from pain ($n = 10$), interacting with others ($n = 6$), and physical activities such as going for walks ($n = 6$). With greater pain, participants reported being unable to employ these strategies due to the decrements in physical and mental abilities. As a result, pain ratings rose in order to acquire painkillers, one of the few effective coping strategies for more severe pain.

P42: Normally I'm very good at distraction, mindfulness, that sort of thing ... and if I can't use them and, all I want is my medication.

1.3 Capacity to Endure Pain

In addition to the physical qualities of pain and how it interfered with activities, participants also spoke about the tolerability of pain ($n = 15$). As pain became less bearable, severity of pain ratings increased.

P1: Mild is something you can actually deal with ...

P28: [Moderate pain is] probably stuck in bed but [I] can tolerate it ...

The Very Severe category was often described uniquely compared to the other categories of the VRS. The words used to describe Very Severe often represented the limit of capacity, such as unbearable ($n = 3$), agony ($n = 4$), and excruciating ($n = 1$). Some participants reserved the Very Severe category for only the worst occasions and thus was used rarely ($n = 7$). Three participants related Very Severe to requiring or having surgery, and a separate three participants stated that this is the pain that would bring them into hospital.

P29: Oh very severe is all consuming, you can't think of anything and when it gets like that yes I will, I do start crying and screaming ... it is hell.

P10: ... whilst I'm in [very severe] I actually wish to die which is like, shocked me because normally I never do like, I actually wish to think that death is easier ...

Many participants commented on the emotional impact of being in pain. This included feeling low ($n = 14$), angry ($n = 7$), and anxious ($n = 4$) as a result of pain. The hospital environment also contributed to these emotions, with some participants stating that their usual coping mechanisms were frustrated by the ward environment.

P29: ... the only thing that does get me down is pain. So yeah, it controls everything with my emotions ... When I'm having a bad time it turns me into a nasty, snappy, aggressive, horrible person and that's not who I am, so yeah it's controlling completely.

P9: ... you can never relax with the pain.

Some participants described how emotions also affected how tolerable the pain was. Generally, negative moods exacerbated pain and worsened the person's ability to tolerate pain.

P20: ... if you're having a bad day and the pain is there you just don't want to deal with it so even, and that can be just a day when it's moderate pain and you're feeling emotional you would ask for [medication] ...

P38: ... if you're getting a bit anxious and down with the pain then it's getting up to that severe level and you're having to ask for pain medication ...

1.3.1 Subtheme: Whether to Take Painkillers

The subtheme of this theme reflected whether participants would use painkillers for their

pain ($n = 27$). In this sense, the scale was used as a communication to nurses that they required painkillers. Some participants described how the less tolerable the pain became, the greater the need for painkillers.

P26: I might take something for moderate but I probably wouldn't for mild ... severe I definitely would take something for it ...

Many participants described a threshold at which they would begin to consider painkillers, which tended to be either Moderate ($n = 7$) or Severe ($n = 4$). This also related to the 'Personal Coping Theme' in the 'Relationship to Painkillers' cluster, in that the participant's approach to managing pain affected when they would use painkillers.

P11: ... moderate pain means I'm thinking about I might need something to quell the pain ...

P31: ... moderate pain is something that you kind of live with, erm. Severe pain I guess you'd ring the call bell and say can I have [medication] please.

This subtheme was also mirrored in how some participants described the effects of painkillers, in that pain became more tolerable, bearable, or manageable.

P11: ... [painkillers do] help because it makes it bearable and I'm able to forget it ...

P38: I've always got a pain but [painkillers] will bring it down to a manageable level.

Cluster 2: Relationship to Painkillers

The second cluster pertains to how participants related to painkillers themselves. This relationship was mixed; needing painkillers to cope with pain, but disliking the dependence or long-term effects of using them. How participants viewed themselves in terms of their ability to cope with pain also influenced how painkillers were used. The need for painkillers ultimately reflected how the VRS was used.

2.1 Dislike Taking Painkillers

Many participants spoke about what they disliked about painkillers ($n = 10$), although every person who reported pain said that they took some form of painkiller. The reasons for disliking painkillers varied, but included side-effects, the build-up of tolerance, and fears of long-term damage.

P2: ... I wonder, if everyone actually understood the severity of use, overusing painkillers and what it does to their body, if they would necessarily do that all the time.

For those with chronic pain disorders there was often conflict between managing pain and staying alert enough to live normally.

P8: it may dissociate me from the pain but it doesn't help the pain itself ... and I don't rate dissociation as help because I still want to be able to do what I want to do.

P2: ... it's got rid of my pain but I haven't gained anything from that, I've still lost my day.

Another reason for disliking painkillers came from the fact that they often removed pain completely, meaning that participants were unable to check their pain levels ($n = 3$). These people described periodically stopping or refusing pain killers to review their pain.

P23: ... I need to know how bad the pain is, so if I'm junked up with pain killers I don't know, so they expect me to take eight a day, but I won't take them.

P43: ... I am the type of person who from time-to-time will stop taking pain killers in order just to check [my pain]

2.2 Personal Coping Style

Participants varied on how they approached their pain management and reporting pain levels to staff. Some participants had an uncomplicated approach to reporting their pain,

preferring to give accurate and rational responses. These participants had a straightforward relationship between their pain and the use of painkillers.

P19: When it's there it's there, I always say it ... I won't try to hide it, no point in hiding, no one going to take my pain from me.

P13: I'm in pain and I don't want to have a conversation about it, they're here and they know what to do and that's it ...

Other participants compared their own approach to pain to other patients around them, with some noting that they think they have a 'higher tolerance' for pain ($n = 12$). This was consistently linked to under-reporting pain to staff. This is explored in more detail in the subtheme described below.

P33: ... I am a er, a person who tried to cope with quite severe pain as I do with most things with illness ... it tends to be a case of, oh just pull yourself together and do it, deal with it, don't turn to somebody else all the time to deal with it.

2.2.1 Subtheme: Under-reporting Pain

Pain was under-reported for a multitude of reasons linked to the participant's coping style ($n = 20$). In relation to the perception of having a higher pain tolerance, some participants said they under-reported their pain so as not to appear negative to staff. This included being 'soft', appearing to be a 'nuisance' or a 'wimp'. Two participants described how these attitudes developed from their family of origin.

P11: ... I think potentially it could be cultural or generational as to why I don't think it's the done thing to say that I'm in pain ... I grew up single parent family, mother who was extremely hard working and never complained a day ... so it would for me feel wrong that I'm, I, I feel as though I'm moaning if I'm complaining ...

Some participants described a preference for handling pain using their own coping mechanisms. As a result, they would under-report pain in order to avoid discussions about painkillers.

P8: ... I know that painkillers at that point aren't going to help, and my own techniques are going to be far superior so it's a lot easier to say I'm in no pain and get on with what I do.

2.2.2 Subtheme: Over-reporting Pain

Comparatively, the prevalence of deliberately over-reporting pain was much less frequently reported ($n = 4$). All participants who had done this described how this was goal orientated, most commonly to take control of when and what painkillers they received.

P30: ... because erm by the time they actually go get the pain relief erm they were only going to give me moderate pain relief like, it would have already turned into severe

P42: ... I can feel when my pain is progressing, and I like to pre-empt it before it gets to, before it gets too high. Because when it gets too high, it's then very very difficult to get back down again ... So I might give a slightly higher pain score.

Cluster 3: Relationship with Staff

The themes in this cluster pertain to the measure as a communication tool in an ongoing relationship with staff. Participants discussed the difficulties of communicating their pain as well as the positive effects of attentive staff.

3.1 Perceptions of Negative Staff Attitudes to Pain

Many participants described negative experiences or impressions of staff in regards to their pain ($n = 20$). Many of these experiences were suggestive of a negative attitude towards painkillers or those with pain. For example, participants recounted staff not acting on

requests for painkillers, failing to hand over key information to other staff, or in one case outright refusing to give prescribed painkillers. Several participants also described fears of being negatively evaluated by staff when asking for painkillers.

P26: ... sometimes in the morning the doctors go 'I gather you had a really good night' and you're like well, no, I told them I was in severe pain and that, so I don't think things get passed to the doctors unless they're really serious things.

Int: And do you think pain is taken seriously?

P26: Not really, no ...

Several participants described the problems about the assumptions that staff have about what those in pain look like ($n = 5$). This was particularly prominent for participants with chronic pain problems, who talked about not meeting the expectations of what someone in pain looks like.

P42: [The staff] criteria for severe is in tears, erm, can't really communicate, asking for medication, erm, and being kind of, having a face of, pulling a face ... Making noises, that sort of thing, and if you're completely absent of that and you give an answer of severe then, I've had plenty of times where someone has said, but you look, you don't look like you're in severe pain, or they've kind of raised an eyebrow to sort of say, oh, oh yeah, course ...

P8: You can't have pain if you're smiling, that would be a very good [laughs] assumption if you're doing a crossword and listening to music you can't be in pain, when in fact that's exactly what I do when I am in pain.

Likewise, there was a high prevalence of participants reporting incorrect methods of how staff presented the VRS. This included listing numbers instead of categories, recording their

own estimated pain levels without asking the participant, and being inconsistent with which scale was used.

P42: ... quite often people will write down a score, but they haven't asked you. They haven't asked you what your pain is ... I was finding that I was getting erm, marks of, that said no pain, or moderate pain, or low pain ... which isn't, isn't right

P8: ... my pain [has been] assessed in at least five different ways ... I've been nought to four, one way, and nought to four the other way. Er, one to ten, ten to one, and the mild, moderate, severe but, again, on the ward I've never been asked until you said it if my pain was very severe. That's the first time I realised that was on the scale is when you said it ...

3.2 Difficulties Communicating Pain

Many participants remarked on the difficulties of communicating pain to staff, including when using the VRS ($n = 27$). With regard to the measure itself, some participants struggled to distinguish between adjacent categories ($n = 5$). Participants also explained the difficulty of converting the pain experience into scale categories.

P36: ... how do you quantify? How do you explain it? I don't know.

P14: I would just tell [staff asking on the VRS] I was completely unable to give an answer because I find the entire thing ridiculous ... I don't think you can quantify pain when pain can mean so many different things ...

Two participants reflected on how difficult it was for staff to understand pain from an academic or medical perspective. This echoed other participants' comments about the inadequacy of the scale in portraying pain. However, others recognised the subjective nature of pain and the variability of how people used the pain scale exacerbated the difficulty for staff.

P24: ... I think it's hard because obviously they study in that area but there's still no real concept of what our pain is that we go through ...

P30: ... you think you know what pain is, like from what they teach in University, but it's nothing like that when you experience it yourself.

P28: ... so my pain to someone else's pain is going to be completely different, the way we rate it, so how is a nurse going to then be able to perceive that in terms on prescribing pain medication?

3.3 Positive Experiences of Staff

The final theme of this cluster covers how the positive experiences of the staff-patient relationship altered the way the VRS was used by patients ($n = 10$). Participants described how consistent and responsive care for their pain enabled them to report their pain needs more easily. For a few participants, this helped them 'overcome' the barriers of their stoic coping style, where they needed painkillers but felt unable to ask for them.

P11: ... virtually everybody who I've come into contact with will ask me are you in pain? And they don't just ask are you in pain, they're asking using the scale, so you're getting used to the idea that it's not going to be a shock to say to somebody you're in pain

P15: ... people ask you, they ask very regular er, that come and check on you, and they, they've very positive to you, you know, calling on the bell et cetera so you feel well cared ... I wouldn't feel negative about saying well I am in pain.

Another key positive experience of staff related to the staff's awareness of the participant's pain. These participants described how the staff had knowledge about the non-verbal signs that indicated they were in pain.

P29: But they know me well enough here that they can gauge my pain levels against what I'm doing ...

Two participants described how the attentiveness of staff made them feel more reassured and relaxed, which helped them deal with their pain.

P17: ... I think, that they know exactly what's going on with me, and, you know, where I should be and in a way that I, you know, I've, I've got no idea if this is normal or er, erm, but I feel very sort of calm and relaxed about it ...

Summary of Themes

How the VRS was used varied by participant across three main areas. Participants reified the categories in semantically similar but idiosyncratic ways. This included grounding the category demarcations using physical sensations, impact on functioning, and levels of tolerance. However, these demarcations also interacted with the emotional state and current needs, such as sleep. The main use of the VRS reflected it as a communication tool in asking for painkillers. The participant's relationship to pain and painkillers played a key role in this communication. The experiences of staff, both positive and negative, influenced this communication in the form of either enabling or discouraging participants to communicate their pain needs.

Part Two: Personal Pain Scale Task

This section will first examine how participants placed the original categories of the VRS measure on their scale. This includes the positions on the scale, as well as testing the assumption that there are equal distances between categories. The final section examines the modifications and additions participants made to their scales.

Of the 45 participants interviewed for Part One, 29 (64%) agreed to complete Part Two. Sixteen participants declined or were unable (e.g. due to eyesight problems). Of the 29

participants, 21 recorded all five categories of the original VRS (No Pain, Mild, Moderate, Severe, and Very Severe), or left one end of the scale as an assumed 'No Pain' category where it was not explicitly indicated. Of the eight participants who chose not to include the full scale, two participants decided to completely develop new categories, three participants created scales that reflected that they always experienced some pain, and three participants chose not to use one of the categories (e.g. Very Severe).

Although the 'thinking-out loud' protocol was recorded during the 'Personal Scale Task', the qualitative data are not reported here. This is because they were largely consistent with the themes reported in Figure 1 and did not add any substantial new information.

Category Positions

Twenty-one participants who recorded all five categories were included. The categories were measured from 'No Pain' (i.e. the left end of the line) and recorded in centimetres. Where participants did not indicate the exact position of a category on the line (i.e. they just wrote 'Mild' above an area of the line), the position was calculated by the midpoint of the written word. Due to a printing error, scale lines used by the participants were one of two lengths (26.8cm or 27.6cm). As a result, the positions of categories were transformed into percentages, such that 0% and 100% represent the two ends of the line. For example, a severe category measured to be placed 18cm from the left on a 26.8cm line would be recorded as 67.16%. The means and standard deviations of the categories are displayed in Table 2. Figure 3 displays box plots for all categories.

Table 2: Descriptive statistics of scale category positions

Category	Mean Position (%)	Standard Deviation (%)
Mild	11.73	6.21
Moderate	33.44	11.26
Severe	63.92	14.56
Very Severe	84.58	15.64

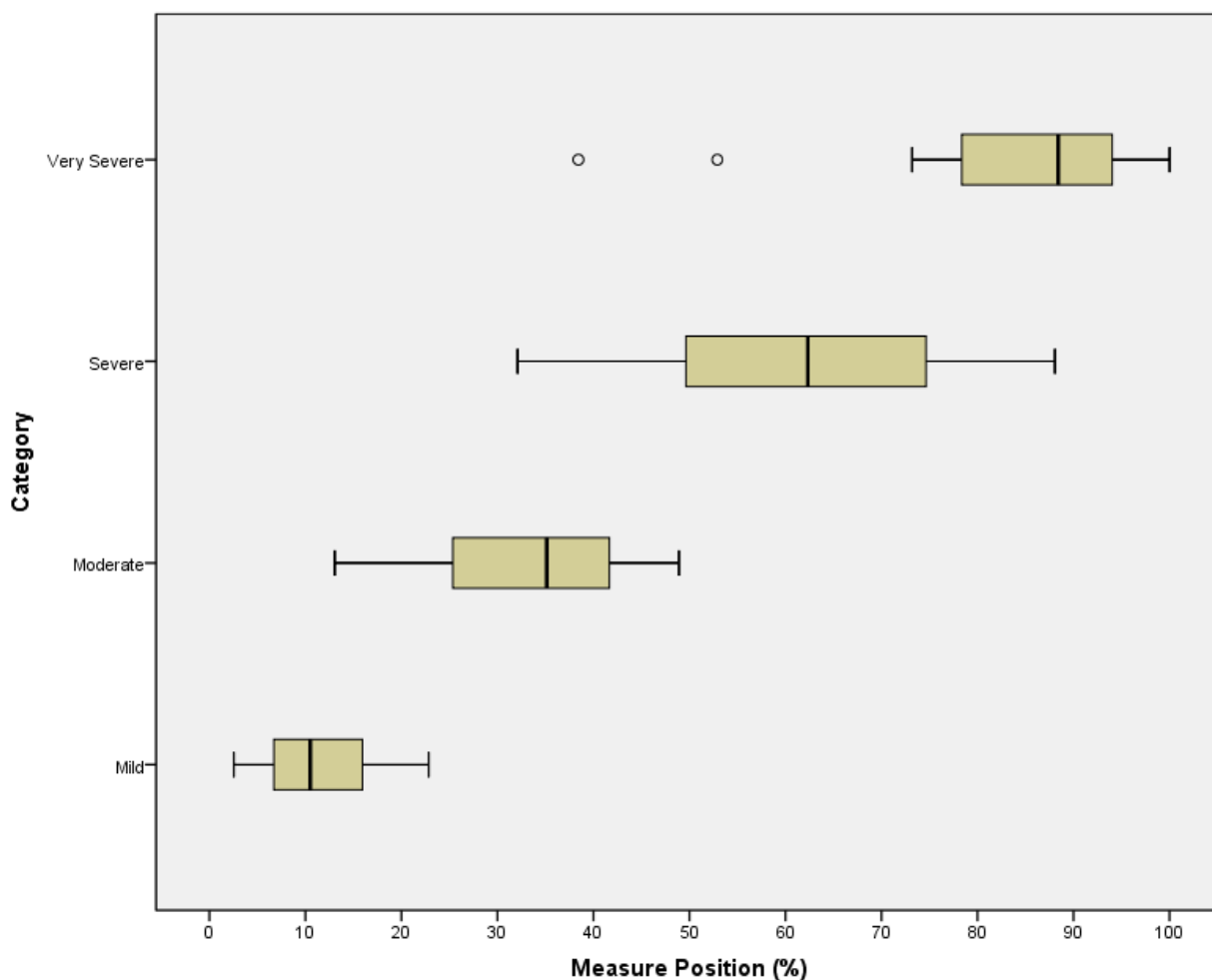


Figure 3: Box plots of each category position

All of the categories except Very Severe met assumptions for a normal distribution. Very Severe was found to be significantly negatively skewed and leptokurtic (skewness z score = -3.34, kurtosis z score = 3.16). Two scores in the Very Severe category were identified as outliers (see Figure 2) with z scores of -2.95 and -2.03. However, as the nature of this study was exploratory and did not assume normal distributions, these scores were retained. As a result, non-parametric tests are reported here. A Kruskal-Wallis test and follow-up planned comparisons of Mann-Whitney tests were conducted to examine whether positions indicated discrete categories. The four categories positions were significantly different, $H(3) = 69.79, p < .001$. Mild was significantly different to Moderate, $U = 20, z = -5.04, p < .001$;

Moderate was significantly different to Severe, $U = 22$, $z = -4.99$, $p < .001$; and Severe was significantly different to Very Severe, $U = 62$, $z = -3.98$, $p < .001$.

Testing Equidistance

The assumption that there were equal distances between the categories of the measure was tested. The distance between each category was calculated for each participant who had recorded all five categories ($n = 21$). This created four categories: No Pain to Mild, Mild to Moderate, Moderate to Severe, and Severe to Very Severe. Distances were calculated as percentage of the measure to simplify comparison. For example, a distance between the categories of mild and moderate of 6.6cm on a scale 26.8cm long would be recorded as 24.63%.

No Pain to Mild had the smallest distances ($M = 11.73$, $SD = 6.21$), while Moderate to Severe had the largest ($M = 30.48$, $SD = 10.09$). Mild to Moderate ($M = 21.71$, $SD = 9.64$), and Severe to Very Severe ($M = 20.65$, $SD = 8.59$) had similar category distances.

All four categories met assumptions for normality so a One-Way ANOVA was conducted to test the hypothesis that there would be no difference in distances between categories (i.e. equal distance). The ANOVA revealed an overall significant difference: $F(3,80) = 16.08$, $p < .001$. All post-hoc comparisons were significant, except for 'Mild-Moderate' and 'Severe-Very Severe' (see Table 3). Overall, the hypothesis that there are equal distances between categories on the VRS is rejected. In particular, there appears to be a large 'jump' between moderate and severe, suggesting that the 'moderate' category covers a larger proportion of the pain experience.

Table 3: Category distance t-test comparisons

Comparison	Statistics (t test, p value, effect size)
'No Pain to Mild' and 'Mild to Moderate' (M = 11.73) (M = 21.71)	t(20) = -3.92, p = .001, r = .66
'No Pain to Mild' and 'Moderate to Severe' (M = 11.73) (M = 30.48)	t(20) = -7.08, p < .001, r = .85
'No Pain to Mild' and 'Severe to Very Severe' (M = 11.73) (M = 20.65)	t(20) = -3.65, p = .002, r = .63
'Mild to Moderate' and 'Moderate to Severe' (M = 21.71) (M = 30.48)	t(20) = -2.81, p = .011, r = .53
'Mild to Moderate' and 'Severe to Very Severe' (M = 21.71) (M = 20.65)	t(20) = .37, p = .714 (ns.)
'Moderate to Severe' and 'Severe to Very Severe' (M = 30.48) (M = 20.65)	t(20) = 3.18, p = .005, r = .58

Additions and Modifications of the Scale

Of the total 29 personal scales that participants developed, four did not include any changes or additions. Four participants chose to expand on the original VRS categories but did not add any new categories. Sixteen participants added their own new categories in addition to the original VRS ones. Two participants chose not to use the original categories and created a completely new set of categories. Three participants made major structural changes to the measure. Overall, every single scale was unique and represented the participant's personal relationship with pain. Some representative examples of each type of change are displayed below, recreated exactly as participants designed them.

P22's scale is displayed in Figure 4. He had a very short experience of pain and had not used the pain scale for long. He chose not to make any additions or changes.



Figure 4: Participant 22's Personal Scale

In contrast, P42 (Figure 5) reported a longer experience of pain and use of the scale over many years. She described having her own personal scale superimposed over the Severe

and Very Severe categories in the form of a numerical system. This was converted back to the VRS terms when answering medical staff.



Figure 5: Participant 42's Personal Scale

P11 (Figure 6) chose to expand on the already existing categories, adding what interventions might be required and how she might experience or evaluate that pain.

Mild	Moderate	Severe	V Severe
No treatment Just go to bed and sleep it off		Hospital. No cause & effect. Serious.	No choice All Consuming. Agony. Unrelenting

Figure 6: Participant 11's Personal Scale

P20 (Figure 7) altered the scale completely by adding a separate dimension on the y axis labelled 'Intensity/Heat'. This represented her nerve pain in that the experience of heat was separate from that of pain, but that they often interacted. She also added that this could be used to map out the different pain locations, as pain often varied across the body.

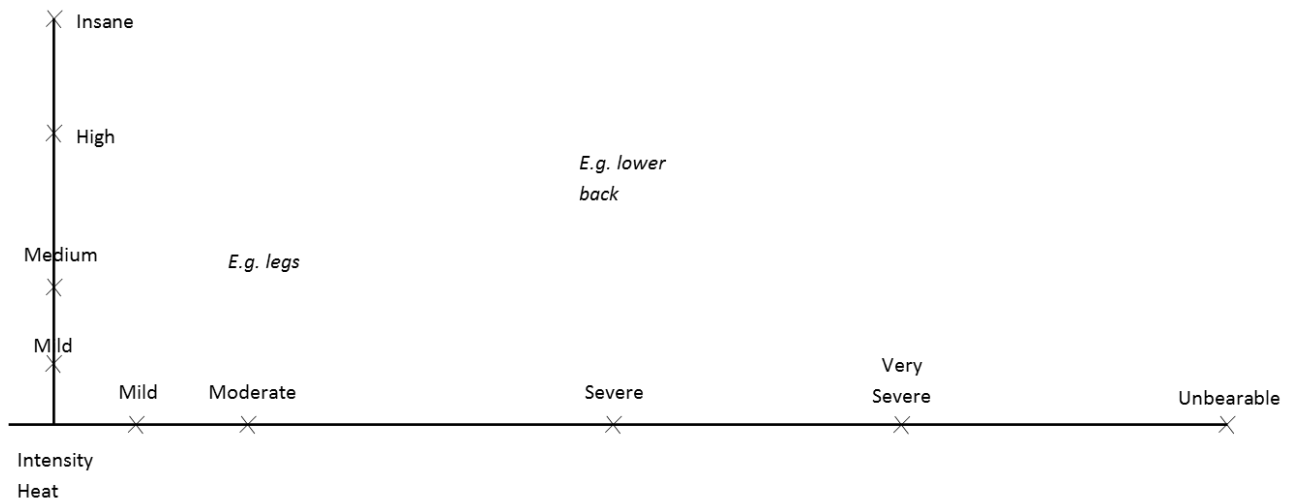


Figure 7: Participant 20's personal scale

P14 (Figure 8) chose not to include any of the original VRS categories as they did not describe her experience of pain. Instead, she chose to list her own personal sequence of feelings and experience as pain increased.

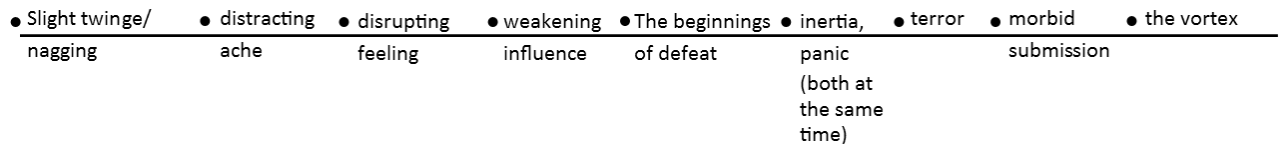


Figure 8: Participant 14's personal scale

Overall, the main similarity shared between the personal scales was that they were all different. Otherwise, end scale categories after Very Severe also had a shared emotional language such as 'unbearable' ($n = 5$), 'extremely severe' ($n = 4$), 'agony' ($n = 3$) and 'excruciating' ($n = 2$).

Discussion

Using a mixed methods approach, this study aimed to explore how inpatients understood and used the VRS, a unidimensional pain scale used routinely in the hospital. This study was unique in that it scrutinised the factors involved in self-reporting pain in an ecologically

valid setting. Participants described idiosyncratic systems of constructing pain within the categories of the VRS. These systems included the physical properties, interference with activities, and ability to endure pain. Otherwise, the use of the VRS reflected it as a tool to communicate the need for painkillers. In this sense, the relationship the participant had with painkillers and previous experiences of staff responses to them influenced their pain ratings.

The 'physical properties of pain' theme was consistent with Jensen and Karoly's (1992) dimensions of pain in that participants described the magnitude, quality, and location of their pain. However, 'pain affect' (the emotional impact or distress occurring with pain) was not as readily described by participants. This topic was, for the most part, only accessed through direct questioning included in the interview protocol. This may reflect the difficulty of reporting or discussing negative emotions in health care (e.g. Gard, Gyllensten, Salford & Ekdahl, 2000). Participants may have also been reluctant to discuss negative emotions as the interview setting lacked confidentiality. Equally, it may be that participants did not consider it as a separate category of experience in their understanding of the VRS.

However, emotions were discussed in relation to the 'tolerability' of pain (i.e. 'capacity to endure pain' theme). In this, negative emotions were detrimental to the ability to bear pain. Previously, the 'tolerability' of pain has been considered a cognitive evaluation (e.g. Melzack, 1975) rather than a dimension of the pain experience.

The 'interference with activities' theme reflected how pain encourages resource conservation and recovery through inactivity (Wall, 1979). The reported activities share many of the same features of 'pain disability' measures, including interference with sleep, mobility, and socialising (e.g. Meenan, Mason, Anderson, Guccione & Kazis, 1992; Fairbank, Couper, Davies & O'Brien, 1980). What was unique to this study was that participants also

explicitly discussed interference with mental activities, such as concentration, and preferred styles of coping.

Overall, participants made sense of their pain in a multitude of ways. They drew on different elements of pain: the physical sensations, history of pain, tolerability, emotional impact, effectiveness of coping strategies, context, and functional impact. Within these elements they combined experiences in unique ways, such as 'additive' pain or the precedence of constancy over intensity. Essentially, participants described individual differences in their pain in accordance with the biopsychosocial model (Hadjistavropoulos et al., 2011; Turk & Okifuji, 2002). The results from this study support assertions that patients combined pain affect with other pain elements in their ratings on unidimensional pain scales (Morone & Weiner, 2013; Sullivan & Ballantyne, 2016). However, in addition to the above, there was the impression that the only reason to report pain was to acquire painkillers. A large proportion of the interviews was spent discussing medication, despite there only being one question in the interview protocol.

Consistent with other research about low adherence to pain management protocols (Chow & Chan, 2014), this study also found participants reported multiple instances of improper use of the pain measure by staff. This may reflect a lack of training or knowledge (e.g. McCaffery & Ferrell, 1997). Alternatively, there may be other features, such as organisational or practical issues, that may have influenced the methods used by staff (Bell & Duffy, 2009). However, this study did not aim to understand the staff processes, so possible explanations for this can only be speculative. Nonetheless, the findings reported here extend the known difficulties with pain management protocols by describing some of the impact these behaviours have on patients. These included a reluctance to report pain due to a fear of being judged as a person and an overall detriment to the care experience of

the patient. However, positive experiences had an opposite effect of feeling 'cared for' and enabling participants to report their pain and, to some extent, manage it themselves.

This study also examined the 'distances' between categories by asking participants to describe the VRS in spatial terms. The findings here corroborate previous suggestions that distances between categories are not equal (Jensen & Karoly, 1992) as assumed of interval scales. In fact, similar to Williams et al. (2000), the pain measure was understood in idiosyncratic ways. As summarised by Rollman (1977), multifaceted decisional processes impacted how pain was reported.

Clinical Implications

There are a number of clinical implications from this study, some of which confirm what is already considered good practice.

Participants reflected their capacity to endure pain in the categories they chose. However, the capacity to endure pain was fluid, varying over time with context and emotional states. Addressing the emotional needs of patients may be a more useful intervention when emotional contexts are making pain difficult to deal with. In particular, feeling low, angry, and anxious were the most frequently reported emotional consequences of pain. At these times, other strategies based on the emotion identified by the patient could be used. For example, those reporting anxiety could be given clear expectations for pain, provided information about pain, or provided reassurance. Likewise, consistent and responsive care by staff helped patients cope with the anxiety provoking nature of pain and the hospital environment.

Similarly, some of the pain behaviour was goal orientated. For example, people reported higher pain levels at night, when pain interfered with sleep, in order to get painkillers. Staff should be aware that if pain is blocking a behaviour or activity, pain levels may be reported

higher than the same pain intensity at a time when a goal is not being blocked. It may be useful to explore this with the patient, especially where other processes may also impact on levels of disability. Equally, the patient being occupied was the most frequent form of coping with pain. Therefore, patients with nothing interesting to do, such as having visitors or using entertainment, will likely report higher pain levels. Ward staff could encourage patients to be proactive in their care by bringing activities.

The scale was also used as a communication tool in asking for painkillers. Considering that many patients described a preference for stoic forms of coping, it may be useful for staff to inform patients that the scale can be used in other ways (e.g. monitoring after surgery; pain as a symptom) to reduce under-reporting pain. Likewise, staff should be encouraged to treat pain reports as separate from a request for painkillers. Generally, it may be useful to give patients 'permission' to report pain and that this can be independent from coping styles and use of analgesics.

Clinicians should be aware that pain ratings from unidimensional pain scales such as the VRS combine multiple elements of the pain experience, including pain affect, disability, coping and magnitude. Therefore painkillers, such as opioid medication, may not be the most appropriate intervention in cases of high pain ratings. High ratings should instead indicate that further exploration is required to determine what intervention might be most helpful.

Participants constructed their pain categories in idiosyncratic ways. However, categories were not equidistant, so changes in pain scores between some categories may represent bigger changes in pain than others, making interval-level scoring inappropriate. Likewise, patients will likely be representing changes that do not necessarily reflect just pain intensity but improvements in other functions such as mobility, sleep, or mood. Sometimes patients

may use terms that are 'beyond' the final Very Severe category, including 'unbearable' or 'agony', which should warrant attention equivalent to, or more than, Very Severe.

Finally, medical and nursing staff should be aware of the appropriate way to present the pain scale. Inconsistency, incorrect instructions and improper recording were all noticed by patients, undermining their confidence in the staff's ability to manage their pain. This also disrupts the relationship that patients can develop with the pain measure over time.

Similarly, staff should be aware of the different ways that pain can be expressed, especially in chronic pain patients, and may not be easily determined from their behaviour or expression. To summarise:

- Pain scale ratings should not be assumed to only represent pain intensity. Staff should enquire further to understand ratings.
- Relatedly, negative affect is not usually reported by patients. Staff should enquire directly about emotions and their impact on the tolerability of pain. Naming negative emotions will provide guidance on the advice or intervention that may be useful (e.g. anxiety/worry would benefit from reassurance or relaxation techniques).
- Painkillers should not be prescribed based only on pain ratings. Instead, higher pain ratings indicate that pain management should be discussed and agreed with the patient. This may include strategies other than painkillers.
- Patients should be educated about using pain scales and their purpose, in order to reduce under and over reporting of pain.
- Pain tolerance varies with context. Being unoccupied, trying to sleep, or feeling distressed will exacerbate reported pain levels. Staff should help patients identify other coping strategies to manage the context contributing to pain where possible.

- The pain scale should be presented correctly and consistently. Staff should not depend on the patient's appearance to gauge either pain levels or whether they need to ask about pain.
- Finally, nurses and other ward staff should be empowered to make enquires about pain ratings and pain management strategies. This could be through training and education, support from management, and, where appropriate, support from other specialised teams.

Limitations

As this study was exploratory, it did not reliably determine the endorsement of themes across participants. Likewise, this study does not provide information about the importance of the different elements participants considered when constructing their VRS categories. Interviews did not take place in a confidential setting, so participants may have been reluctant to fully disclose sensitive issues (e.g. distress from pain).

The participants recruited were identified by the nurse-in-charge as suitable, which may have introduced bias towards more articulate, intelligent or amenable patients, or those more likely to give a good account of their interactions with staff. The participant group were mainly White British and female, and may not fully represent the viewpoints of other ethnic groups or men. This may be particularly relevant in the approach to coping with pain, where culture and gender roles may influence norms and preferences. However, the study has strengths in representing both acute and chronic pain patients, and a wide range of ages and diagnostic groups.

Another issue is related to how the scale was incorrectly presented by staff. The aim of this study was to understand how participants used the VRS; however, many were not regularly asked about their pain, or if they were the VRS was used incorrectly (e.g. asking patients to rate their pain from one to four). The results therefore may not apply specifically to the VRS

and may include hypothetical, rather than ecologically valid, usage. Likewise, as this research was based on using verbal categories it cannot be assumed to apply completely to other unidimensional pain measures, such as the Numerical Rating Scale (NRS) or the Visual Analogue Scale (Jensen & Karoly, 1992). However, the results share similarities to other research that asked patients to elaborate the NRS (Williams et al., 2000) so how patients construct their pain may apply.

Future Directions

There are several directions for the future research. One uncertainty is how important each factor identified in this research is in contributing to a scale category and whether this is a stable relationship both between and within people. This could be studied further by splitting the factors up into separate ratings (i.e. tolerability, interference with activities etc.) and observing how they change with the global scale rating (e.g. mild, moderate etc.) over time. By determining how much each factor contributes to a scale rating, clinicians would be better positioned to understand a patient's pain.

Another avenue of research could relate to how the different pain 'groups' use the pain scale (i.e. acute and chronic pain). I made an anecdotal observation during the study that those with acute and short lasting pain had a simpler and more straight-forward relationship with the pain scale than those with chronic pain. I had considered splitting and comparing the analysis, but I decided to instead describe common factors across all participants rather than group them separately. This could be investigated more thoroughly in the future.

The problems identified with staff behaviours and attitudes are a well-documented problem in regards to pain. There are a wide range of solutions being attempted, such as education and training. This study suggests that including the patient reactions during

interventions that aim to change staff behaviour may give more depth to the impact of these approaches, rather than just reporting variables such as frequency of measurement. Finally, this study did not cover how staff interpret, understand, and act on the patient's responses to the pain scale. Future research could aim to understand this process by, for example, interviewing staff.

Conclusion

In conclusion, participants using the VRS compounded a number of pain elements in idiosyncratic ways, including sensory, affective, cognitive and functional dimensions. Otherwise, the VRS was mainly used as a tool to request painkillers, and scores were adjusted accordingly to the participant's attitude to pain and previous experiences with staff. These results have implications for staff in how they are trained to both deliver the pain scale and interpret scores, and how participants are involved in this process. Pain scale ratings should not be assumed to represent pain intensity and need to be investigated further.

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Part 3: Critical Appraisal

This critical appraisal will cover some of the issues that arose for me during the research project. These issues are divided into three parts. The first part examines my pre-existing attitudes and experiences with pain and how this influenced the direction of the research. I will also describe the assumptions of the research and how these came to be re-examined when considering the credibility checks. The second area will cover some of the practical issues of conducting research in a physical health environment. The third area will briefly discuss some of the difficulties in implementing the clinical implications from the empirical paper.

Assumptions and Methodological Considerations

My interest in reviewing individual differences in those with pain came from my training placement in clinical health psychology. During this time I worked therapeutically with several people who had mental health difficulties in the context of chronic pain. I came to make two observations. Firstly, I noticed just how many people with chronic pain cope exceptionally well despite living with debilitating conditions. I recognised that people whom I saw were actually the minority of people with these conditions. Secondly, I found that a large amount of the material that was being brought to therapy was focused on relationships as opposed to being specifically about pain. The problems with pain also seemed to be entangled with relationships, such as pain flaring up during marital arguments. I found the Cognitive Behavioural Therapy (CBT) models that I was using did not necessarily resonate with patients or their problems. It is likely that my lack of experience influenced this, but I also thought that the explanatory models were missing something. I thought a theory that was both interpersonally focussed and systematically described individual differences would be useful in understanding what I observed. Hence, I decided to look at attachment theory and chronic pain. Ultimately, as the review described, I was disappointed with the lack of a coherent model linking attachment theory and pain.

However, I still held the view that the complexity of pain was ignored in many settings, including pain measurement. I came to this research project wanting to demonstrate how something as simple as choosing one of five categories on a pain scale concealed a complex and multidimensional process. This bias likely influenced how I analysed and interpreted the results. This section will describe in more detail how I came to reconsider and evaluate my assumptions.

One difficulty came from deciding which credibility checks to use for the project. In a similar fashion to quantitative research, these checks aim to improve the validity and reliability of the analysis and results. I decided to opt for two of the methods: inter-rater agreement of themes (comparing with another researcher's analysis of the data) and testimonial validity (checking with original participants). However, the usefulness of these methods in assuring credibility have been questioned in the literature. In regards to inter-rater agreement, it has been argued that due to the epistemology of qualitative research, divergence of codes and themes do not necessarily reflect poor reliability.

In quantitative research, reliability is the quality of measurement in the form of consistency and repeatability, reducing measurement error as far as possible (Field, 2009). Natural sciences, using quantitative methodology, most often uses a positivist epistemology, which states that phenomena can be measured and analysed objectively. However, qualitative research does not necessarily agree with this epistemology, recognising that human and social processes are often not objectively observable. In fact, this study on pain measurement aimed to demonstrate how even something that has a neurobiological basis is still constructed between people. The concept of 'objectivity' is heavily criticised. As a result, in studies using qualitative methods the researcher themselves are explicitly incorporated into the analysis. It is recognised that separating the researcher from the interpretation is not possible, even with 'bracketing' (Smith, Flowers & Larkin, 2009).

Therefore, it is accepted that the analysis represents the researcher's unique perspective on participants' reports of their experience. This is in contrast to claiming to represent the 'truth' of the phenomena (i.e. the participants' experiences). A relativist position, even a critical realist one, recognises that researchers will have unique perspectives and knowledge that influences the analysis and interpretation of results. Therefore, in a credibility check it would be difficult to determine which analysis better describes or represents the participants' experiences. The value of 'agreement' between researchers was doubtful.

Likewise, there is debate in the literature about the value of testimonial validity, often called 'member checks'. Thomas (2017) concluded that member checks used in studies were done in a tokenistic way and seldom improved results. They also argued that studies aiming for generalisation were not appropriate for member checks; it was often difficult for individual participants to comment on the general 'themes' of experiences across the entire sample. However, I realised that being in the position where neither other researchers nor the participants themselves can refute the validity of the analysis was simply unreasonable. I found it helpful to return to the underlying assumptions I made during the project to consider how to integrate meaningful credibility checks.

I assumed that participants experienced 'pain' in a physical and embodied sense. I also assumed that participants constructed and made sense of this physical sense in a multitude of ways. For example, this might have included previous experiences or context dependent knowledge (e.g. 'medical' language). When patients responded to staff on the VRS, I presumed that two processes were occurring; (a) patients were converting this constructed sense into the measure categories, and (b) they were doing this in a social interaction. The interview protocol in the empirical paper aimed to elicit and elucidate these two processes, while also recognising that the interview process itself was a social interaction. The

importance of the latter was important to note as social processes can influence the research discussion, such as social desirability (Bertrand & Mullainathan, 2001). The thematic analysis I conducted was based on a semantic analysis rather than a latent analysis. I aimed to represent participants' explicit experience rather than infer any 'deeper' meaning. This type of thematic analysis came from my personal preferences for pragmatism and applicability.

By re-examining the assumptions of the project and methodology I could decide how I would incorporate the validity checks. As semantic analysis aims to represent explicit experience, a member check would be useful in assessing the 'accuracy' of at least part of the themes, even if the feedback did not agree with all of the themes developed. This incorporated both Thomas's (2017) comments that participants would struggle to comment on experiences outside their own, while also respecting participant feedback. It was also useful to consider what aspects of the experience the themes and feedback were referring to. I found it useful to look again at the participant's transcript and his/her feedback to see which themes he/she would be expected to endorse. This was a slight variation on the 'synthesised member checking' method (Birt, Scott, Cavers, Campbell & Walter, 2016). The assumption I made also influenced the themes I developed, for instance, a theme dedicated to the relationship with staff reflected my perception of the importance of the social interaction in reporting pain. The perspective of another researcher would help challenge and reconsider the assumptions I made. As semantic themes are close to the explicit meaning of the participants, the feedback from another researcher can easily be supported by examples in the data. Therefore inter-rater agreement helped protect against my assumptions overriding what has been expressed by participants. With these points in mind I was then able to make use of both forms of credibility checks.

By considering the assumptions I was also able to identify potential weaknesses in the study. I assumed that participants would be able to articulate the processes of constructing and converting their pain into scale categories, but it could be that these processes are not consciously available for articulation. The interview only may have reflected the participants' attempts to put an implicit experience into words rather than the 'truth' of the phenomena. For example, participants saying what pain interferes with is an easy way to relay to another person the extent of pain, but it does not necessarily describe the embodied nature of pain. A person may say they could 'eat a horse' to express how hungry they are, but this does not describe the physical embodiment of hunger. It could be that in reality this interference is not the basis of pain measurement and I have inferred the results incorrectly.

In addition, focusing only on semantic themes may mean that the social processes are not well captured. The analysis conducted in the empirical paper represents only one potential interpretation of the results. An alternative analysis could have examined the 'latent' themes. For example, the cluster representing how pain was objectified (Cluster 1) could have been interpreted through a cultural lens. Participants' focus on functional impairment may reflect how society values productivity and usefulness in individuals. Likewise, the 'personal coping' theme (Cluster 2) could also be said to represent the Western interpretation of what 'good' coping is, such as stoicism and 'not making a fuss'. These latent interpretations are not considered when conducting a semantic analysis. Ultimately, personal preference and the research question guided the type of analysis I conducted.

Difficulties During the Research

There were several practical challenges I encountered when conducting research in a physical health setting. These included working with staff unfamiliar with research and attempting to navigate a new environment.

As part of the process of gaining ethical approval it was agreed that I would need senior staff approval to both collect data on the day and approach individual patients. One unavoidable and unexpected problem was that there were several infectious outbreaks in the hospital, and I lost weeks before (as non-essential staff) I was allowed freely on the wards again. I was offered the chance to collect data if I wore a full mask to protect patients from infection, but I felt this would not be conducive to the relaxed interview I was hoping to create. A second problem arose from being dependent on staff to identify patients. It is difficult to determine if the patients were representative of the inpatient population at the hospital, or if they were identified because they were friendly, articulate, or generally satisfied with their care. One advantage came from being attached to the Complex Pain Team who were able to tell me a bit about some of the patients if they were also referred to the team. I was surprised to discover that many people who were referred to the team were also identified for me to interview. Likewise, I was surprised that some of these people agreed to be interviewed, as I was told they had conflictual relationships with the Pain Team (mainly around the reduction of opioid medications). This made me realise that people are often keen to talk about their experiences of pain and that perhaps this opportunity is not easily available. However, I still unfortunately had relatively few men and people from ethnic minorities take part in the study. Another side of having someone identify participants for me was that occasionally I found myself talking to someone who I would realise was highly inappropriate for the study, including people who could speak no English or those with a cognitive impairment. This led to slightly awkward positions where I would start to explain the study before attempting to explain why they could not take part. One strength of the study was that it included a variety of pain experiences and conditions. Pain is often divided into 'acute' or 'chronic' based on whether it has persisted for longer than three months. I was able to speak to people who were experiencing post-surgical pain, flare-ups, new conditions developing, or other injuries in the context of both acute and

chronic pain. This variety of hospital newcomers and 'veterans' provided a rich diversity of experiences using the pain scale.

One problem I expected to occur but, to my surprise, did not, was related to what I perceived as my low status in the medical hierarchy as a researcher. Contrary to expectations, I was well respected and experienced few interruptions or obstacles. In part this may have been helped by having an honorary contract with the Complex Pain Team in the hospital. However, I think it is more likely that I began with biased assumptions. I had previously worked as an Assistant Psychologist on a mental health inpatient unit. During my time there I experienced a rigid medical hierarchy where psychology had a low status. In this work environment the staff were highly stressed from a combination of factors, including high levels of local poverty, complexity of patients, and high staff turnover. As a clinician I had to tactically navigate the conflicts between management, medical staff and senior psychologists in order to do the clinical work with patients. I had similar expectations coming to research in a physical health environment. One key difference I noticed between the two inpatient experiences was that while staff had a high workload, the quality of morale was very different. This made my coming onto the ward to conduct research a trivial issue. Barker, Pistrang and Elliott (2002) warns of these practical and political issues, although I now fully appreciate this knowledge for conducting research in the future.

Of all the patients I met during this research project, those with Crohn's disease were the most memorable. Crohn's disease is an inflammatory bowel disease associated with pain, diarrhoea, and tiredness (e.g. Lynch & Spence, 2007). I was struck by how debilitating the condition was, but at the same time I was inspired by the resilience of the people with it. This was due, in part, to most of the people I interviewed with Crohn's disease being a similar age to myself. It made me reflect on how difficult it must be to live with a chronic

health condition whilst facing the usual struggles of life. This left me with a deeper appreciation of what it is like living with a chronic pain condition.

Future Directions

One of the reasons this research was conducted was to reveal the complexity behind answers on seemingly simple unidimensional pain scales. This was against a background of a debate about inappropriate prescriptions of opioid pain medications for patients really reporting pain distress (e.g. Morone & Weiner, 2013). The results from this research support the assertion that pain ratings should not be taken at face value. The conclusions and clinical implications of the empirical paper are essentially to enquire further about high pain ratings. However, whether this is realistic in the current environment of the National Health Service (NHS) is a concern that cannot be ignored. It is widely recognised that demands on staff time are high, and the suggestions here only add to the list of tasks to be performed. Organisational structures have a large influence on the behaviour on staff. Pain management is especially pertinent in the current 'business' environment of health services, such as evaluating services using the 'friends and family' test (e.g. Sizmur, Graham & Walsh, 2015). The problems of this approach to pain management are mirrored in some of the complex pain patients I saw who were in conflict with the Pain Team. The crux of their arguments were with the Pain Team wanting to reduce or stop opioid medications and invasive procedures against the patient's wishes. These patients were very dissatisfied with their care decisions in regards to pain. However, in the long term, where medication overuse actually increases the levels of pain, risks addiction, and causes mild to severe damage to the body, these care decisions are predominantly more beneficial for the patient. In the same way, declining to give patients painkillers because of levels of distress would likely increase dissatisfaction with care, and so the service gets poor ratings. Figuring out the right course of action and then carrying it out is a lengthy process and one for which

many nurses and health care assistants are neither trained nor recognised when they attempt it. Giving painkillers for high ratings is the route that most clinicians would choose in this environment. The suggestions from the results of this study are then perhaps naïve, even if they are correct. However, while acknowledging organisational pressures on staff, the tenets of good practice cannot be ignored.

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Appendices

Appendix A: AXIS Quality Tool

From Downes, Brennan, Williams and Dean (2017).

Table 2 The final AXIS tool following consensus on all components by the Delphi panel

	Yes	No	Do not know/ comment
<i>Introduction</i>			
1			Were the aims/objectives of the study clear?
<i>Methods</i>			
2			Was the study design appropriate for the stated aim(s)?
3			Was the sample size justified?
4			Was the target/reference population clearly defined? (Is it clear who the research was about?)
5			Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
6			Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?
7			Were measures undertaken to address and categorise non-responders?
8			Were the risk factor and outcome variables measured appropriate to the aims of the study?
9			Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?
10			Is it clear what was used to determine statistical significance and/or precision estimates? (eg, p values, CIs)
11			Were the methods (including statistical methods) sufficiently described to enable them to be repeated?
<i>Results</i>			
12			Were the basic data adequately described?
13			Does the response rate raise concerns about non-response bias?
14			If appropriate, was information about non-responders described?
15			Were the results internally consistent?
16			Were the results for the analyses described in the methods, presented?
<i>Discussion</i>			
17			Were the authors' discussions and conclusions justified by the results?
18			Were the limitations of the study discussed?
<i>Other</i>			
19			Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
20			Was ethical approval or consent of participants attained?

TERMS OF PLACEMENT AS HONORARY APPOINTEE

Mr Luke Bosdet

[ADDRESS REDACTED]

Placement Title: Honorary Trainee Clinical Psychologist

Place of Work or Main Base: [REDACTED]

Starting Date of Honorary Appointment: 31st March 2016

Honorary Appointment expires: 30th March 2017

Responsible to: Clare Daniel

FURTHER CONDITIONS

- 1.** This honorary appointment will enable you to undertake your role visiting [REDACTED]
- 2.** Your honorary attachment to the Trust does not constitute employment and you will not be entitled to any form of payment on its cessation. For the avoidance of doubt, this appointment does not constitute an employment relationship.

RESEARCH GOVERNANCE

[REDACTED] Trust manages all research in accordance with the requirements of the Research Governance Framework. All research active appointees must familiarise themselves with the [REDACTED] policies for research governance and be aware of the obligations this places on them. You must comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance. You are reminded that any breach in research governance policy will result in appropriate action. This may include discontinuation of your honorary appointment and cessation of your involvement with all research at [REDACTED].

PROFESSIONAL REGISTRATION

Dependent upon the nature of your role, you may be required to be registered with a relevant professional body eg GMC, NMC, CPSM.

A copy of confirmation of your professional registration should be attached and returned with this document.

A copy of your registration renewal document must also be provided to the Trust.

Failure to be registered with the appropriate professional body, and to maintain professional registration, may result in your honorary appointment being terminated.

PRE-APPOINTMENT HEALTH SCREENING

This honorary appointment is conditional upon confirmation of your medical fitness to undertake the full duties of the honorary appointment.

CRIMINAL RECORDS/CONVICTIONS

This honorary appointment is exempt from the Rehabilitation of Offenders Act 1974. It is therefore essential that you disclose conviction(s), that would otherwise be “spent” under the provisions of the Act, and that you have notified the Trust if you are “bound over”, have received a police caution, warning or reprimand or if you have been charged with a criminal offence that is not yet disposed of.

In cases where the role of the honorary appointment is defined as a “regulated position” under the terms of the Protection of Children Act 1999 (as amended by the Criminal Justice and Court Services Act 2000), checks will be carried out by the Criminal Records Bureau in accordance with the Protection of Children Act 1999. It is an offence for someone who is legally barred from working with children to knowingly apply for, offer to do, accept or do such work. Appointees will be notified if their appointment is designated as a “regulated position” and therefore subject to the above checks.

If you are convicted of a criminal offence whilst an appointee of the Trust, you must inform your manager of the nature of the conviction even if it does not relate to your work. Dependent upon the nature of the conviction and details of the sentence, the continuation of your honorary appointment may not be put at risk. However, the Trust reserves the right to terminate your appointment in relation to any such conviction or sentence.

CONFIDENTIALITY

During the course of your honorary appointment, you will have access to information of a confidential nature including (but not exclusively) patient and staff information. This information must be treated as strictly confidential at all times.

All appointees must familiarise themselves with the UCL Hospitals NHS Trust Information Governance Policy and be aware of the obligations it places on them. A breach of confidentiality will result in appropriate action, which may include discontinuation of your honorary appointment, being taken.

VALUING DIVERSITY

UCL Hospitals NHS Trust undertakes to provide equality of opportunity in its twin role as employer and provider of health services.

All appointees have a personal responsibility towards the public and their colleagues for the implementation of the Equal Opportunities Policy within their duties.

Appointees should familiarise themselves with the Equal Opportunities Policy and be aware of the obligation it places on them and the individual rights extended to them.

HEALTH, SAFETY, FIRE & SECURITY

Occupational Health

Occupational Health aims to make sure that appointees are fit for their work and are not becoming ill because of work. This means promoting the physical and mental health,

safety and welfare of all working in the Trust, both by seeing individuals with problems and by advising management on measures to safeguard staff.

Safety at Work

It is the policy of the Trust to give the greatest importance to the health and safety of appointees, considering this is a management responsibility equal to that of any other managerial task.

Appointees are responsible for following all health, safety and hygiene regulations, as laid down locally from time to time and are required to play their full part in ensuring the safety of others.

In the event of an accident occurring to an appointee in the course of their work, the facts should be immediately reported to your supervisor who will decide on the arrangements for any necessary medical treatment. In the event of an accident, an accident report form must be completed by the injured party and any witnesses and be signed by the supervisor.

It should be noted that Trusts and individuals are not exempt from statutory enforcement procedures and will be subject to prosecution for failure to discharge their duties under the Health & Safety Act 1974. Should appointees not comply with health, safety and hygiene regulations, appropriate action will be taken.

Ionising Radiation (Medical Exposure) Regulations 2000

Under the above Regulations, the Trust is obliged to maintain a register of all persons entitled to act as Practitioners or Operators (ie to justify or to carry out a medical exposure) and to keep records of their training.

If your post includes the responsibilities of either Practitioner or Operator as defined by these regulations, you must provide the Trust with evidence of training. This should include evidence of completion of an approved training course plus details of practical experience.

Please note that if, during the course of your duties, you refer a person for a medical exposure you are obliged to provide sufficient relevant clinical information to the Practitioner who justifies the use of ionising radiation. You are expected to follow any guidelines for such referrals that the Trust provides.

Investigation of Untoward Incidents

All appointees are expected to assist management fully in the investigation of incidents by supplying written statements and, where appropriate, acting as a witness.

Fire Precautions

It is your responsibility to make sure that you are aware of the procedure to be followed on discovering a fire or hearing a fire alarm. Appointees should attend at least one period of fire training each year.

Personal Indemnity

The Trust has Public Liability Insurance which will cover you while you are on Trust premises, on Trust business or working for the benefit of the Trust against accidental injury.

Additionally, the Trust will provide coverage for negligent acts or omissions by you which occur whilst on Trust premises and whilst you are acting in your professional capacity in the course of your honorary appointment with NHS patients of the Trust. This coverage will not apply where your acts are recklessly negligent or criminal, occur outside the course and scope of your honorary position with the Trust or result from contact with non-Trust patients or employees. For this coverage to apply, you must notify the Trust of an incident or occurrence which has resulted in an injury or possible injury to a patient within 48 hours of the incident or occurrence or the date of knowledge or discovery of the incident or occurrence. This coverage does not extend to work which does not fall within the scope of the NHS indemnity for clinical negligence. It does not cover non-NHS and private practice work, for which the Trust would encourage you to ensure that you have adequate and appropriate defence cover to cover you for such work.

Security

The security of property belonging to the Trust, appointees and the public at large is a matter which must be the concern of every member of staff. In this respect, appointees are required to assist management in maintaining and improving security.

Identification Badges

If you are issued with an identity badge, it should be worn visibly all the time you are on duty or on site. If you are issued with an identity badge, it must be returned should you leave the Trust. If you lose the badge at any time, this must be reported to your manager.

Property and Claims for Compensation

You must comply with local regulations with regard to patients' cash/property. You are also asked to ensure that all property of the Trust in your charge is correctly used. Furthermore, it is your duty to report any loss or accidents which may give rise to a claim for compensation to your manager. In addition, you should also report any suspect fraud or theft.

Property Disclaimer

The Trust cannot accept responsibility for money/property lost or damaged on Health Service premises and strongly recommends appointees to consider taking out insurance policies to cover themselves against such a loss. Whilst lockers may be provided, these are intended for the convenience of appointees and no responsibility can be accepted for money, jewellery or similar valuables stolen from these lockers. Appointees providing their own tools or equipment belonging to them should take out their own insurance policies against theft or fire.

INTELLECTUAL PROPERTY (IP)

10.1 Intellectual Property (IP) may be generated during the course of your honorary appointment that may have value in the delivery of better patient care.

10.2 IP can be in the form of inventions, discoveries, surgical techniques or methods, developments, processes, schemes, formulae, specifications, or any other improvements which may give rise to certain rights such as patents, trade marks, service marks, design rights, copyright, know-how, trade or business names and other similar rights (all of the foregoing rights being referred to as “Intellectual Property Rights” or “IPR”)

10.3 Potential IPR means any works, information or other elements from which IPR may derive.

10.4 You and the Trust confirm it is foreseeable that IPR may arise in the course of or in connection with your honorary appointment to the Trust.

10.5 Cases involving IPR and/or Potential IPR will be managed in accordance with the Trust’s management procedures for intellectual property (IP). These procedures have been approved by the Trust Board and are available on request from the Research & Development Directorate and are consistent with the Management Framework for IP of the Department of Health.

10.6 IPR and/or Potential IPR created during the course of your honorary appointment will generally belong to the substantive employer or the Trust, unless agreed otherwise in writing.

10.7 Where you consider that IPR and/or Potential IPR has been created, you shall promptly notify the Research & Development Directorate providing full details.

TERMINATION OF HONORARY PLACEMENT

If your honorary appointment with the Trust arises as a result of your employment by another body (being either an NHS Trust or an academic establishment) should your employment terminate with that NHS Trust or academic establishment, your honorary appointment will terminate immediately. You are required to inform the Trust should such employment be terminated.

If you have any queries regarding the terms of your honorary placement, please contact your manager or Recruitment Services Manager.

Please sign both copies of the Terms of Placement as Honorary Appointee and return one signed copy to the relevant Recruitment Services Department (see below), keeping the remaining copy for yourself.

Signed: [REDACTED]

Date: 30th March 2016

Print Name: [REDACTED]

Job Title: Honorary Contract Co-ordinator

Honorary Contracts Department

I ACKNOWLEDGE RECEIPT OF MY TERMS OF HONORARY PLACEMENT AND ACCEPT THE TERMS AND CONDITIONS SET OUT THEREIN.

Signed: [REDACTED]

Date: 30th March 2016 **Print Name:** Luke Bosdet



Health Research Authority

Yorkshire & The Humber - Leeds West Research Ethics Committee

Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8087

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

28 September 2016

Mr Luke Bosdet

[ADDRESS REDACTED]

Dear Mr Bosdet

Study title: A Mixed Methods Exploration of how Inpatients use the Verbal Rating Scale of Pain
REC reference: 16/YH/0417
IRAS project ID: 209181

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Leeds West Research Ethics Committee reviewed the above application on 22 September 2016.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Assistant, Miss Kirstie Penman at nrescommittee.yorkandhumber-leedswest@nhs.net.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the Sub-Committee gave a **favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ('Participant Identification Centre'), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting (if applicable)

The PR Sub-Committee raised the following queries in email correspondence with you between the 25th and 26th September.

□ **Recruitment arrangements and access to health information, and fair participant selection**

Members queried whether ward staff had agreed to assist with the recruitment for this study, and what wards participants would be recruited from.

You stated that you had edited the IRAS form to make it clear that the Complex Pain

Team worked across all wards at [REDACTED] and that Dr [REDACTED] would liaise with the wards on this issue. The exact wards to be recruited from could not be confirmed until ethics approval was obtained, but this would be managed by the Complex Pain Team.

PR Sub-Committee members concurred that the minimum recruitment age for inclusion into the study should be 16 rather than 18 as defined in the Clinical Trials Regulations.

You informed the PR Sub-Committee that this had been amended.

• **Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

Members sought clarification how the disclosure of sensitive information would be dealt with.

You informed the PR Sub-Committee that you had updated the IRAS form to explain that this information would be passed on to the ward staff and the Complex Pain Team, with Dr [REDACTED] as a point of contact. You added that the student researcher was familiar with the types of issues that would need to be passed on, such as safeguarding issues and risk to self or others.

• **Informed consent process and the adequacy and completeness of participant information**

The PR Sub-Committee agreed that the study, and the Participant Information Sheet in particular, would benefit from input by a Public and Patient Involvement Group and requested that this be arranged.

You confirmed that you had consulted a patient representative on the Participant Information Sheet and Consent Form and had made changes on their recommendation, which were included in version 3 of the Participant Information Sheet.

Members confirmed that the Participant Information Sheet needed to include information to inform the participant that confidentiality may potentially need to be broken if sensitive information was provided that needed to be disclosed to relevant authorities.

You confirmed that you had updated the Participant Information Sheet to this effect.

PR Sub-Committee members noted that the Participant Information Sheet should be amended to explain to participants that direct quotes would be published, and added that the consent form would need to be amended to seek consent for publication.

You confirmed that this had been amended as requested.

□ **Other general comments**

At A35, members agreed that the second option, 'The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant' would be more appropriate and should be selected.

You amended the form as requested.

Members requested confirmation that a home PC would not be used, as temporary files may be stored; a secure PC should be used.

You reassured the PR Sub-Committee that the data would be analysed from secure UCL computers and not stored at home or on personal computers.

The PR Sub-Committee recommended that a Good Clinical Practice course be undertaken.

You informed the PR Sub-Committee that the student researcher was a third year Trainee Clinical Psychologist. This training included extensive clinical training and experience delivering psychological interventions across London. You added that the student researcher would also be supervised by two experienced clinicians and researchers.

The PR Sub-Committee was satisfied with the responses provided.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Contract/Study Agreement [Honorary Contract]	1	30 March 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Confirmation Letter]	1	16 August 2016
Interview schedules or topic guides for participants [Interview Schedule]	1	13 July 2016
IRAS Application Form [IRAS_Form_26092016]		26 September 2016
Other [Hand Written Task Instructions]	1	13 July 2016
Other [Dr Katie Herron CV]	1	12 September 2016
Other [Cover Letter for REC Changes]	1	26 September 2016
Participant consent form [Consent Form - Clean]	3	25 September 2016
Participant consent form [Consent Form]	3	25 September 2016
Participant information sheet (PIS) [Patient Information Sheet - Clean]	3	25 September 2016
Participant information sheet (PIS) [Patient Information Sheet]	3	25 September 2016
Research protocol or project proposal [Study Protocol - Clean]	2	25 September 2016
Research protocol or project proposal [Study Protocol]	2	25 September 2016
Summary CV for Chief Investigator (CI) [CI CV]	1	05 September 2016
Summary CV for student [Researcher Luke Bosdet CV]	1	07 September 2016

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee’s best wishes for the success of this project.

16/YH/0417

Please quote this number on all correspondence

Yours
sincerely pp



Mr Anthony Warnock-Smith Alternate Vice-Chair

Email: nrescommittee.yorkandhumber-leedswest@nhs.net

*Enclosures: List of names and professions of members who took part in the review
'After ethical review – guidance for researchers'*

*Copy to: Mr Onyike Nmaju, University College NHS Foundation Trust
Dr Amanda Williams, University College London*

Yorkshire & The Humber - Leeds West Research Ethics Committee

**Attendance at PRS Sub-Committee of the REC meeting held via
correspondence**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Martin Elliott	Consultant Paediatric Oncologist	Yes	
Ms Sarah Kirkland	Project Manager, Spinal Services at NHS England	Yes	
Mr Anthony Warnock-Smith	Retired solicitor	Yes	Chair of the PR Sub-Committee

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Christie Ord	REC Manager
Miss Kirstie Penman	REC Assistant

Appendix D: Participant Information Sheet

Participant Information Sheet

Study title: A Mixed Methods Exploration of how Inpatients use the Verbal Rating Scale of Pain

R&D ID No: 16/0412

Date: 11th November 2016

Chief Investigator: Dr Amanda Williams, Clinical Psychologist

Researcher: Luke Bosdet, Trainee Clinical Psychologist

Introduction

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

One of our team will go through the information sheet with you and answer any questions you have. We suggest this should take about 10 minutes.

What is the purpose of this study?

We are interested in finding out how patients understand the pain measure used here at University College London Hospital (UCLH). This pain measure is called the 'Verbal Rating Scale' and it asks you to pick your pain levels from a list of adjectives: no pain, mild pain, moderate pain, severe pain, and very severe pain. Research suggests that people answer questions about pain using very different and personal criteria. This can sometimes lead to clinicians using the wrong intervention for pain when an alternative might be more helpful. For this reason, we want to study the criteria people use in greater detail to help us improve the way we help people in pain or maybe how pain is treated.

The first part of the study involves a short interview focused on how you have used the pain measure while an inpatient at UCLH. This involves questions about how you decide what answer to give to nurses and what you expect to help you with your pain in those moments.

The second part of the study involves a short hand written exercise where you draw out how you understand the pain measure and its categories.

In total, we expect the study to last between 20 and 30 minutes.

Do I have to take part?

It is entirely your decision whether to join the study. If you do agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

What are the possible disadvantages of taking part?

Due to practical issues, the interviews will be conducted by your bedside. Therefore we cannot guarantee that others on the ward would not overhear our conversation. However, the questions in the interview and hand written task do not ask about personal or sensitive topics beyond the pain measure and your experiences of pain. Questions about pain may be a difficult topic for you.

What are the possible benefits of taking part?

We cannot promise that the information will help you but the results of the study might help patients in the future.

It may help you see more clearly how you have used the pain measure and that might make it easier for you to explain to ward staff how your pain is affecting you.

Will my taking part be kept confidential?

We cannot guarantee that the interview and hand written task is completely confidential due to being conducted on the ward. However, we do not expect any information too personal or sensitive to be disclosed.

After you have finished both tasks, the information is stored securely on encrypted devices and on secure computer networks at University College London (UCL). Your data will only be identifiable through a unique study code and not your name or other personal information. Research data produced by the study will be stored at UCL for 20 years in line with UCL Records Retention Policy, but note that this is still confidential (you cannot be identified from the data) and secure. The data will then be destroyed. The data will only be accessed by the identified research team: Luke Bosdet and Dr Amanda Williams.

The answers you give during the study, in either recorded or written form, will not form part of your medical notes.

The only time we might break confidentiality is if you say something that makes us worried that there might be risk to you or someone else. In this case we would need to share this information with other health care professionals to make sure that you and others are safe.

What will happen to the result of this study?

Firstly the data will form part of a thesis project submitted for a Doctorate of Clinical Psychology. The data may then be used in articles and sent for publication in peer reviewed scientific journals. These might contain direct quotes of what say during the interview or hand written task during this study. However, all published data is anonymised in such a way that it would be impossible to identify you from it.

What will happen if I don't want to carry on with the study?

You can decide to stop the study at any point during the interview or hand written task without giving a reason. You can withdraw consent for your data in any completed parts of the study at any point, that is, you can request your data to be removed and destroyed at any time.

If for some reason you cannot continue to take part in the study after we have started, then you will be automatically withdrawn from the study. All identifiable data you have provided will be destroyed, and non-identifiable data will be kept and used in the study (unless you specify otherwise).

Taking part in the study or withdrawing from it has no impact on your medical care.

Who has reviewed this study?

This study has been approved by the NHS Ethics board, local Research and Development department, and University College London Hospitals NHS Foundation Trust.

What is there is a problem?

Your researcher is Luke Bosdet (email: [REDACTED]). Please contact him if you have any concerns about any aspect of the study.

Alternatively, you can contact Dr Amanda Williams who is supervising this part of the research (email: [REDACTED] number: [REDACTED]). If you wish to complain about your treatment by members of staff due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, or if you have concern about any about any aspect of this study, you should ask to speak to a member of the study team who will do their best to answer your questions. If you remain unhappy or wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital Patient Advice and Liaison Service.

Contact for further information

You can contact either Luke Bosdet or Dr Amanda Williams at:

Phone number: [REDACTED]

Address: [REDACTED]

Thank you for reading this and taking part in the research.

Appendix E: Consent Form

Consent Form

Project Title: A Mixed Methods Exploration of the Use of Pain Measures

R&D ID No: 16/0412

Name of Researcher: Luke Bosdet, Trainee Clinical Psychologist

Name of Chief Investigator: Dr Amanda Williams, Clinical Psychologist

Please read and initial the box if you agree.

1. I confirm I have read and understood the Participant Information Sheet for the above study. I have had the opportunity to consider the information, ask questions and had these answered satisfactorily.

2. I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and without my medical care being affected.

3. I understand that parts of this study will be audio recorded (by a Dictaphone) and that this recording will be stored securely.

4. I understand that relevant sections of my medical notes and data/information collected during the study, may be looked at by individuals from University College London (UCL), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

5. I understand that direct quotes from me may be published in journal articles and used as part of a thesis research project. I understand that this will be anonymised in such a way that identifying me from it would be impossible.

6. I consent to take part in this study

Name of participant:

Date:

Signature:

For Researcher Use

Do they want to receive a copy of the results? YES / NO

If YES, what is the best contact method (email/postal address):

Appendix F: Interview Schedule

Interview Schedule

Introduction

This section sets the scene for the interview and expectations for the participant. This is based on Smith, Flowers and Larkin (2009).

- 1) Introduce project, enquire about interest and present information and consent forms
- 2) Allow the participant to read forms alone (allow 10 minutes) and return to answer any questions
- 3) If the participant agrees to continue, remind participant of participation rights and discuss confidentiality depending on interview location
- 4) Set up expectations about interview itself by saying something similar to:

Thank you agreeing to take part in this interview. As we have just discussed, we are interested in your own experience and opinions about assessing pain while on the ward. There are no right or wrong answers, and you can elaborate on your answers as much or as little as you like. The conversation may be one sided as I may say very little. Some of the questions may seem obvious as I am trying to get to grips with how you understand things. I might interrupt you at times to keep the interview on track or ask questions about topics that come up that seem important for this research.

Rating pain

During recruitment it is planned that a member of the medical team (referred to as nurse throughout this document) will ask the patient about their pain. This helps make the pain

rating as ecologically valid as possible. If for some reason this does not occur, the interviewer can ask this themselves.

- *If the nurse was to come over to you now and ask you to rate your pain on a verbal scale from no pain, mild pain, moderate pain, severe pain, or very severe pain, what answer would you give?*

X refers to the answer given.

Z refers to answers higher or lower on the rating scale that are used as comparisons during the questions.

Interview Questions

This section outlines the questions to be asked of the participant. It is interested in determining how they use the pain scale and communicate their needs to health care professionals.

- *How did you come to answer X to the nurse?*
- *For you, what are the main differences between X and Z? (This question can be repeated for other points on the verbal scale if it is considered useful) How would you know if you felt Z?*
- *Has there been a time when you felt similar pain to now but gave a different answer? Have you ever given a rating that was higher/lower than you actually felt? Why?*
- *How does the pain affect how you feel emotionally while you're in hospital? Does this affect what pain rating you give to the nurse?*
- *What do you think about the pain scale they use?*
- *What else would you like to tell the nurse or doctor about your pain? What else do you think they would need to know?*

- *In an ideal world, what are all the things that would help your pain while you're in hospital?*
- *Do you think that an analgesic/pain killer would help your pain? In what way/how much?*

Appendix G: Personal Scale Task Instructions

Personal Scale Task Instructions

This section introduces the hand written task. The task is verbally introduced as described in italics below.

Pain is a complex experience, and scales like the one you were asked about earlier (rating pain as mild, moderate, severe or very severe) may not fit for what you want to tell medical and nursing staff about your pain. So this is a chance to show how you would like your pain to be assessed.

Please have a look at this piece of paper (This will be a landscape A4 page with a line running through the centre). As you can see, there is a line running through the middle of the page. You can add your own terms for pain, as well as placing the ones we already use (No pain, Mild Pain, Moderate Pain, Severe Pain, Very Severe Pain) on the scale where you think they belong. I would like you to talk out loud while you do this so I can understand your thinking process.

As an example, if we asked people to make a rating scale for how hot things feel, offering them the terms “very cold, cold, warm, hot” they might place them like this (draw them on the example sheet along with brief ‘thinking out loud’ demonstration). Then we might want to add our own terms (draw freezing, chilling, boiling etc.)

Did you have any questions? (Once participants understand the task then proceed) The rating scales are: no pain, mild pain, moderate pain, severe pain, and very severe pain. Remember to say out loud what you are thinking while you complete the task.

(Once completed) Are there any other terms you want to include on the page?

Thank you very much for your time.

Appendix H: Example Transcribed Interview

I = Interviewer; P = Participant

I: So if a nurse was to come over to you know and ask you to rate your pain from erm no pain, mild, moderate, severe or very severe erm what answer would you give?

P: I'd give probably mild to moderate.

I: Mild to moderate, okay. So how did you come to answer mild to moderate?

P: Just by, I think by erm by virtue of the fact I know where my pain is. I've had my pain for a long time, I know how it's managed and I know how to manage it.

I: Mhmm

P: Er, but the pain is always there.

I: So, there's never no pain?

P: There's never no pain. No.

I: Okay, so for you what would you say the difference is between mild and moderate?

P: Mild and moderate. Well mild is when ouch I've hurt my finger and moderate is I'm a nagging little bee which is locked inside and I can't get out but I want to get out.

I: Sure. And what would be the main difference between moderate and severe then?

P: Moderate and severe is somebody has either, their bees have, has multiplied! Or er, or something else has happened in relation to let's say, well let's say er somebody has decided they need to do er a exploratory because I have a hernia or something of that nature, or I've just come back from theatre because of surgery so

I: and what would be the differences between severe and very severe?

P: Now that's a difficult one, because I could honestly say well for me, the pain I have would never be severe enough to stop me doing what I do, even though I take a strong amount of medication and in terms of how others see my pain and how I see my pain, erm they would erm people would be going "I just couldn't cope if I had the pain like you have the pain!" so

I: Okay, so it sounds like you're using kind of a lot of like comparison of what you've gone through to determine where you are in each category.

P: I think it's the only way you can

I: Hmm

P: Because I think pain is er, very subjective concept and it's how our bodies deal with it I think is the only way forward.

[Transcript continues]

Appendix I: Member Feedback and Responses

Here I present the member feedback provided to me and my response to their feedback in how it has been incorporated into the study. Bolded sentences represent the prompts and questions given to participants. Italicised sentences represent the participants' response.

Participant 8

Feedback for Cluster 1

Do you think that the above themes described how you thought about the categories on the pain measure? (Mild, moderate, severe and very severe)

I think the themes both reflect and indeed corroborate on the categories of the pain measure.

Is there anything that you would add?

Perhaps clarification as to whether the categories are designed to describe acute, chronic or acute on chronic etc pain.

Is there anything you would change?

As per what I would add above.

No.

Feedback for Cluster 2

Do you think the way you approached pain influenced the pain rating you might have gave to nursing staff while you were in hospital?

I don't think the patient's approach to pain influences the rating when using a specific objective scale. A subjective, descriptive 'scale' e.g. Worst pain ever, 'like child birth' would be more prone to influence.

Is there anything that you would add?

What surely matters is the pain being experienced and expressed, regardless of approach?

Is there anything you would change?

No

Feedback for Cluster 3

Do you think your relationship with staff influenced how you reported your pain?

Some staff themselves appeared to have different categories of whether they considered pain 'sufficient' for intervention. Some staff however appreciated the impact of pain and made clear efforts to help e.g. Referral to a relevant pain team.

Is there anything that you would add?

It sometime felt that as a non-demanding patient, in terms of nursing requirements, I was more likely to be listened to regarding pain as compared to a 'trouble maker'.

Is there anything you would change?

No

Any other feedback or reflections about any parts of the results above?

It was great to have an opportunity to talk about pain scales as my subjective experience of pain has been a feature of all of my hospital admissions.

Researcher's Response: The participant feedback suggests that they agree with the category groundings and divisions. They make the distinction between 'objective' and 'subjective' pain measures, noting that the way the question is worded will influence how the way it is answered. This interesting point agrees with research elsewhere, but for now I am hoping that this variation is captured in Cluster 1. They make other good points about the attitudes of the nurses, and the interaction between the nurse's attitudes and the patient's behaviour. I am hoping that this is captured in Cluster 3 and the experiences of staff and expressions of pain. However, I have emphasised this connection in the discussion section.

Participant 35

Feedback for Cluster 1: How the pain experience was anchored

Yes, the themes you have described about the categories on the pain measure are a true recording of how I would think of mild, moderate, severe and very severe.

There is nothing further I would like to add.

Nor is there anything I wish to change.

Feedback for Cluster 2: Relationship to painkillers

Yes, my approach to pain going into hospital before surgery was very different, prior surgery the pain was severe, after surgery the pain diminished to a surgical pain and one that could be tolerated.

There is nothing I would like to add.

Nothing to change.

Feedback for Cluster 3: Relationship with staff

Yes, every opportunity was given to me to feel comfortable and pain free.

Yes I would like to add, that whilst in hospital it wasn't a given that painkillers were administered without consultation between patient and nursing staff. Your views were taken into consideration.

I have nothing I would like to change or further add.

Researcher's Response: The participant is largely in agreement with the themes and clusters presented. The participant interestingly describes pain post-surgery as 'surgical'

pain and is thus easier to tolerate. This evaluation of pain and the relationship between tolerability and evaluations are expanded upon in the discussion section.

Participant 4

I have read through the paper. While I don't think much of what you said applied to me directly I do agree with one participant's point that if you smile that staff don't perceive you could be in pain. I think it goes back to what I was trying to say that people deal with pain in very different ways and if you try to deal with it in a positive headspace then my pain is not perceived in the same way as someone who is in a negative headspace. Likewise the mood of the staff can impact how we feel. If you are approached by a staff member who is kind and caring (my experience) then you are less frustrated by the pain. If you are approached by someone who is tired, annoyed (in a negative space) then that transmits to you and enhances your pain.

Researcher's Response: The participant comments expand on what is described in the 'Personal Coping' and 'Positive Experiences of Staff' themes. However, they do add a new dimension in that negative moods of staff make it more difficult to cope with pain.