Diagnostic uncertainty and recall bias in chronic low back pain

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1. INTRODUCTION

The identification of sub-groups of people with low back pain (LBP) has been outlined as a priority, in order to modify interventions to match patients' obstacles to recovery [5]. Patients' beliefs and expectations about their pain have been shown to predict prognosis [13; 15; 17]. Amongst these beliefs, catastrophic thinking appears to be particularly important [24]. A related emerging area of research focuses on perceived diagnostic uncertainty, and the impact that such uncertainty could have on subsequent beliefs, behaviours, and outcomes. Precise causes and diagnostic labels can only be found in around 5-10% of patients with LBP [16]. In the absence of a clear diagnosis, practitioners are expected to provide explanations [17]. There is evidence from qualitative studies that the absence of a clear diagnosis and explanation are associated with negative social, cognitive and emotional functioning [25; 29]. Patients who are uncertain about their condition continue searching for a diagnosis [29]; this may place an extra burden on health services and prevent patients from directing their attention to other aspects of life.

Better understanding of the mechanisms underlying the relationship between beliefs and outcomes is needed. One method to study this is through quasi-experiments observing cognitive processes, such as attention and recall for specific types of stimuli. This method has the advantage of being relatively free of self-awareness and demand characteristics. There is evidence that pain patients selectively recall pain and illness-related information in preference to other types of stimuli when compared with control groups [20]. Additionally, in spite of early mixed evidence [20] recent meta-analyses [4; 28] suggest that pain patients also selectively attend to pain words. These biases reflect underlying pain and illness

schemas and are associated with disability [12; 20] and higher health care costs [21]. Although interrelated, pain schemas contain immediate properties and features of pain, whereas illness schemas incorporate the consequences of illness relevant to patient's self-image, and have been hypothesized as evidence for poor coping [20]. To date, there has been no direct comparison between recall bias in people with LBP who perceived their condition to be unexplained and undiagnosed, and those who perceived their condition to have an acceptable diagnostic label. Previous research has demonstrated that recall bias towards illness-related stimuli is also associated with high rates of depression [22]. Because of the proposition that uncertainty leads not only to preoccupation with illness, but also to increases in depression, we included a set of stimuli related to depression.

The current study aimed to compare recall of specific stimuli sets in two groups of patients with LBP: Those who perceive themselves to have a clear and acceptable diagnosis, and those who believe that their pain is due to an undiagnosed problem. We hypothesised that both groups would replicate previous findings for a bias towards pain stimuli, but that only the group of patients high in uncertainty would selectively recall words related to illness, reflecting these patients' preoccupation with the meaning and consequences of their pain.

2. METHOD

2.1 Design

The research design was a 2 (between-group, levels of certainty about diagnosis) x 4 (within-group, word type) mixed factorial design. In the primary analysis the two groups were a priori categorised on the basis of participants' self-report answers to the following question: "I think there is something else happening with my back which the doctors have not found out about yet (yes/no)". In a secondary sensitivity analysis groups were categorised on the basis of participants' self-report answers to the following questions: a) ''I have been given a clear label/diagnosis for my back pain (yes/no)'', b) ''I have been given a clear explanation about why I have back pain (yes/no)''. The four levels of the within-group factor were word category (i.e., pain, illness, depression and neutral).

The primary outcome measure was the number of words recalled for each word category by each participant. In addition, we measured the number of words endorsed as self-descriptors for each word category and mean reaction time (measured in milliseconds) for each word category. Additional measures were pain intensity, disability, depression and anxiety self-report scores.

Sample size calculation using G*Power[8] ($a = 0.05$, $\beta = 0.80$) was set to achieve a medium effect size and it resulted in a minimum sample size of 62.The sample size in the present study was in excess of this value and therefore satisfied this criteria. Our assumption of a medium effect size was based on other studies of recall bias in pain populations [20]. These were not identical to our study in design, but in the absence of studies in cognitive bias that compared groups for diagnostic certainty; this appeared the most informed assumption.

2.2 Participants

A total of 80 participants with mechanical chronic low back pain (CLBP) were recruited from the pain management services in two UK urban hospitals. Inclusion criteria were that participants be between ages of 18-65, speak fluent English and have musculoskeletal CLBP with pain duration of at least 3 months. Participants with back pain due to ankylosing spondylitis, osteoporosis, cancer and inflammatory conditions such as rheumatoid arthritis were excluded. These inclusion criteria were checked for each participant by their clinician before they were invited to participate in the study. However, it was not possible to keep a record of how many patients were approached, and how many refused to take part in the study; therefore response rates could not be calculated. The study received ethical approval from an NHS (National Health Service) ethics committee and the university research ethics committee.

2.3 Materials and Procedure

Participants were first given a screening questionnaire which included demographic questions and questions about their pain, other conditions and diagnosis. The testing began with a computer-based task. The task was created and delivered using DMDX software programme [10] and it included 32 words (all adjectives): 8 depression related (describe salient aspects of depression, e.g. guilty, withdrawn, unlovable), 8 illness related (describe the consequences of illness, e.g. suffering, disabled, dependent), 8 pain related (describe immediate properties of pain, e.g. pounding, sore, pricking) and 8 neutral (e.g. nosey, obnoxious, crude). The complete word stimuli are reported elsewhere [33] and are available from the authors. Depression and neutral adjectives were taken from previous research

[11; 22; 23], where the adjectives had been matched for social desirability, word frequency, and length. Illness and pain adjectives were taken from previous recall bias studies in chronic pain patients [22; 23].

The words were presented in white letters (font type: Times New Roman; font size: 36) against a black background on a laptop computer (12.1 in.; 1280 x 800-pixel resolution) positioned approximately 50 cm in front of seated participants. Right and left shift keys were labelled with 'yes' and 'no' respectively. The task was preceded by written instructions on the screen, which participants were asked to read and then these were rephrased by the investigator in order to ensure that the instructions were clear and understood:

> *You will be presented with some words that may describe you or your pain. Before each word is presented, the following question will appear on the screen: "Does the following word describe you/your pain? ". Press the right SHIFT button if YES, that is if this word describes you or your pain. Press the left SHIFT button if NO, that is if the word does NOT describe you or your pain. Please respond as quickly as possible, the first response that comes to your mind is probably the most accurate. You will be presented with some practice questions first. Press SPACEBAR to start practice questions.*

Words were presented on the computer screen in a random order (different for each participant), with the restriction that no two words from the same category were presented in succession. Preceding each 'pain' word was the cue question, ''Does the following word describe your pain?'' Preceding all other words was the cue question, ''Does the following word describe you?'' The cue question facilitated encoding of the words in relation to the self. It was presented for three seconds, followed by a delay of 500 milliseconds, before the

appearance of the target word [22]. The participants were expected to respond to the target word by answering 'yes' or 'no' as quickly as they could, by pressing either right or left shit key on the keyboard. As soon as a response has been made or after 3500ms, the next cue question was presented. The 32 words were preceded by 6 practise trials at the beginning, in order to familiarise participants with the procedure. Following the practise trials an additional three adjectives were presented to control for primacy effects, as well as three adjectives at the end to control for recency memory effects [22].

On completion of the computer task, participants were asked to complete a filler task [22] for two minutes in which they were presented with two nearly identical images and were asked to identify differences between them. The filer task was used to avoid short term memory effects and prevent participants from rehearsing the information. Participants then recalled as many of the previously presented words in a surprise recall test. No time limit was imposed on the recall task. Finally, they were asked to fill in the questionnaire containing the following measures:

Demographics and pain details - Participants were asked to supply details about age, gender, duration of their back pain, and other health-related problems.

Diagnostic status questions – The following questions were constructed from a qualitative study investigating the impact of diagnostic uncertainty in people with CLBP [29]:

1. "I think there is something else happening with my back which the doctors have not found out about yet (yes/no)".
2. Two additional questions were asked:
    a. ''I have been given a clear label/diagnosis for my back pain (yes/no)''

b. ‘‘I have been given a clear explanation about why I have back pain (yes/no)’’.

If participants answered ‘yes’ to either of the last two questions we also asked them if they agreed with the diagnosis/explanation given or not, and what diagnosis they were given.

Pain intensity **-** Pain intensity was measured using a numeric scale of 0 (‘no pain’) to 10 (‘pain as bad as you can imagine’) [26] .

Anxiety and Depression **-** The Hospital Anxiety and Depression Scale (HADS) [34] consists of 14 items which evaluate the severity of anxiety and depression (7 items relating to anxiety; 7 items relating to depression) . Scores range from 0 to 21 for each scale; higher scores indicate greater likelihood of depression or anxiety. Recommended cutoffs are: 8-10: mild cases, 11-15: moderate cases and 16 or above: severe cases. The measure of anxiety is included in the study to describe the sample characteristics. The HADS has been widely used in studies of depression and anxiety in medical populations.

Disability **-** Roland Disability Questionnaire (RDQ) [27] was used to measure back pain related disability. It is composed of 24 yes/no questions where 0 = no disability to 24 = maximum disability. This is a widely used and reliable measure of disability related to LBP[32].

2.4 Planned Analysis

After data screening for outliers and inspecting parametric assumptions, we planned the following analyses:

First, patients’ groups would be compared on measures of pain intensity, disability, depression and anxiety.

For our main (primary) analysis we planned to conduct a two-way mixed analysis of variance (ANOVA) with Simple planned contrasts, to test the two a-priori hypotheses relating to recall of the four word types in two groups of CLBP patients.

Two sensitivity analyses were also planned to investigate if the findings from the primary ANOVA can be confirmed, first by grouping participants by diagnosis received, and then grouping them again by explanation received.

There is evidence [20] suggesting that concurrent depression biases recall toward self-referent illness stimuli. Depressed mood is also associated with greater disability [21]. This warrants the inclusion of depression and disability as covariates in order to control for their effects; and to this end, an analysis of covariance (ANCOVA) was planned on recall data and using grouping by diagnostic certainty (which is our primary grouping and analysis).

Secondary two-way mixed analysis of variance would also be carried out on reaction time and endorsement data. This is to test for the possible confounding effects of group differences on these factors, and if significant, these measures would also be entered as covariates in the ANCOVA analysis, together with depression and disability measures.

When the assumption of sphericity was violated, we planned to apply Greenhouse-Geisser correction of degrees of freedom in all analyses of variance and covariance. Finally, we planned to conduct bivariate correlations between pain intensity, disability, depression, anxiety and word recall to examine associations between these variables. We planned to conduct all analyses using SPSS statistical package, version 19.0 [14].

3. RESULTS

3.1 Data preparation

We recruited 80 participants with mechanical CLBP. In the recall analysis, data for three participants was incomplete. On the inspection of outliers, further nine participants' recall scores (> 5% of the sample) were > 2 standard deviations above the group mean [9] and were excluded from the recall analysis. The final sample size for the recall analysis was 68. In the reaction time and word endorsement analyses, data was incomplete for three and four participants respectively. Further five participants who had > 3 (>10%, [1; 18]) 3500ms responses, and/or > 2 3500ms responses within the same word category were excluded from the reaction time and endorsement analyses. No further outliers had to be removed [9]. The final sample size for the reaction time and endorsement analyses was 72 and 71 respectively.

3.2 Sample characteristics

Participants' characteristics are reported in Table 1. No significant differences were found for gender, age, pain duration and comorbidity between the two groups. Participants' responses to the diagnostic status questions are summarised in Table 2. Over 40% of participants who reported thinking that there was something else, undiscovered, going on with their back, also reported having received a clear diagnosis and clear explanation for their pain. All participants were screened by practitioners who excluded diagnoses other than mechanical LBP. In spite of this, the diagnostic labels that participants reported being given varied, and included simple descriptions of their symptoms and concrete diagnostic labels, including several that had in fact been excluded.

Insert Table 1 about here

Insert Table 2 about here

Independent samples t tests were carried out to compare the two groups on measures of pain intensity, disability, depression and anxiety (see Table 1). No outliers had to be removed [9] and data were normally distributed. The only significant differences were found on measures of depression and disability; participants who were uncertain about their diagnosis were more depressed and disabled than those who were certain about their diagnosis.

3.3 Analysis of variance on recall data (primary analysis)

Homogeneity of variance was met; however data were not normally distributed for all variables. As the majority of assumptions were met and ANOVA is regarded as a fairly robust statistical method [30] we proceeded with this analysis. A 2 x 4 mixed ANOVA revealed that there was a significant main effect of word type ($F(2.38, 157.1) = 24.2$, $p < .001$, $\eta_p^2 = .27$). Simple planned contrasts showed that more pain words were recalled than illness words ($F(1, 66) = 25.6$, $p < .001$, $\eta_p^2 =. 28$), depression words ($F(1, 66) = 31.2$, $p = .001$, $\eta_p^2 = .32$), and neutral words ($F(1, 66) = 57.6$, $p = .001$. $\eta_p^2 = 47$). There was no significant main effect of group ($F(1, 66) = 3.30$, $p = .074$). There was a significant interaction between word type and group ($F(3, 198) = 5.34$, $p = .001$, $\eta_p^2 = .075$), indicating that the recall for the four types of words differed between the two groups.

We examined this interaction further within each group and using participants' recall for neutral words as a comparison baseline. A repeated measures ANOVA showed that in the group with diagnostic certainty there was a significant main effect of word type ($F(2.16, 75.51) = 22.39$, $p < .001$, $\eta_p^2 = .39$). Simple planned contrasts showed that more pain words were recalled than neutral words ($F(1, 35) = 32.13$, $p < .001$, $\eta_p^2 = .48$); however there was not a significant difference between the recall for neutral and illness words ($F(1, 35) = .093$, $p = .76$) and between neutral and depression words ($F(1, 35) = 1$, $p = .32$), indicating that participants in this group selectively recalled pain words only.

In the group with diagnostic uncertainty there was also a significant main effect of word type ($F(2.29, 71.11) = 6.25$, $p = .002$, $\eta_p^2 = .17$). Simple planned contrasts showed that more pain words were recalled than neutral words ($F(1, 31) = 33.70$, $p < .001$, $\eta_p^2 = .52$), and more illness words were recalled than neutral words ($F(1, 31) = 7.01$, $p = .013$, $\eta_p^2 = .18$); however there was not a significant difference between the recall for neutral and depression words ($F(1, 31) = 3.93$ $p = .056$). Therefore, participants in this group selectively recalled both pain and illness words. Descriptive statistics are reported in Table 3.

Insert Table 3 about here

Sensitivity analyses using grouping by diagnosis received and explanation received

Sensitivity analysis was carried out by repeating the analysis of variance using group categorization according to diagnosis received, and explanation received. The sample size in the groups reporting that they did not receive a diagnosis (N=20) or an explanation (N=24)

was very small. Nonetheless, the pattern of results confirmed the main findings in the primary analysis of variance.

3.4 Secondary analyses of variance on reaction time and endorsement data

Analyses of variance on reaction times revealed a significant main effect for word type ($F(2.72, 210) = 19.1$, $p < .001$, $\eta_p^2 = .22$). Simple planned contrasts revealed that reaction times were slower for pain words than for illness, depression and neutral words. Main effect for group was significant ($F(1, 70) = 5.38$, $p = .023$, $\eta_p^2 = .071$), showing that the group with diagnostic uncertainty responded slower than the certain about diagnosis group. The interaction was not significant.

Analyses of variance on endorsement data showed a significant main effect for word type ($F(3, 207) = 6.32$, $p < .001$, $\eta_p^2 = .084$). Simple planned contrasts revealed that participants endorsed fewer pain words than illness and depression words. Main effect for group was significant ($F(1, 69) = 12.4$, $p = .001$, $\eta_p^2 = .15$), the group with diagnostic uncertainty endorsed more words across the four word types. The interaction was not significant. Descriptive statistics for word endorsement are reported in Table 3.

As the interaction was not significant in both analyses (there were no differences between the groups on their pattern of endorsement and reaction times) it was not necessary to use endorsement and reaction time variables as covariates in the ANCOVA analysis.

3.5 Analysis of covariance on the primary analysis

A 2 x 4 ANCOVA was conducted on recall data and using grouping by diagnostic certainty (see the primary ANOVA analysis) with the total depression and disability scores entered together as covariates. Both covariates were non-significant: depression ($F(1, 63) = .065$, $p = .80$); disability ($F(1, 63) = .29$, $p = .59$). The inclusion of these covariates did not change the pattern of results.

3.6 Correlations between pain intensity, disability, depression and anxiety and word recall

Bivariate correlations between measures of pain intensity, disability, depression and anxiety and word recall were all non-significant for both groups of patients.

4. DISCUSSION

4.1 Main findings

The objective of this research was to examine the relationship between diagnostic uncertainty and recall bias among patients with CLBP. The study hypotheses were supported: both groups displayed a recall bias for pain stimuli, but only the group with diagnostic uncertainty additionally selectively recalled illness-related stimuli. These biases remained after adjusting for depression and disability, and were not found in endorsement or reaction time data. Secondary analyses using grouping by diagnosis/ explanation received were in line with the primary analysis findings, supporting the link between diagnostic uncertainty and recall bias. The group with diagnostic uncertainty had higher levels of depression and disability than the comparative group, but levels of pain intensity did not differ between the groups. The group with diagnostic uncertainty recalled fewer pain words than the certain about diagnosis group (although this was not tested explicitly to avoid multiple post-hoc testing). One explanation is that these patients allocate their memory resources more equally between pain and illness stimuli than patients with diagnostic certainty whose cognitions seem to be primarily pain focused. Overall, the results demonstrate an association between diagnostic uncertainty and recall bias towards negative health-related stimuli, which has been conceptualised as evidence for the presence of maladaptive schemas and poor coping [20] (see below). The findings provide a plausible explanation for the association between diagnostic uncertainty and poorer prognosis.

The findings suggest that patients can hold seemingly contradictory perceptions of their diagnostic status simultaneously- thus, over 40 % who thought there was something else

going on with their back which was not found yet, also reported having received a clear diagnosis. This may be a function of unwillingness to contradict health professionals; might refer to patients' belief that the diagnosis is correct but does not capture the true severity of their condition; or perhaps it represents a belief that the diagnosis is correct, but that it fails to capture something else that is going on, in addition to the diagnosis. This is supported by other studies [19; 29] which suggest that improved doctor-patient communication, clear explanations, and manageable expectations might influence patients' beliefs, and subsequent behaviours. Additionally, mistrust and poor relationships with the doctor increase likelihood of non-adherence [2; 35]. However, offering reassurance may be difficult in the context of uncertainty about aetiology and prognosis [18]; chronic pain patients rarely receive labels that precisely explicate the causes of their condition [3]. The current study does not provide information on the most acceptable explanations or labels. In fact, the accuracy or clarity of such 'diagnoses' appears to matter little. All the patients in the current study had been seen by practitioners who excluded diagnoses other than mechanical LBP. Nevertheless, exploration of the 'diagnoses' that patients reported revealed high variability, ranging from very simple descriptions of patients' symptoms (e.g. 'problem with spine') to more concrete (but often incorrect) labels (e.g. 'slipped disc').

It should also be noted that the significance for the difference between the recall for neutral and depression words in the uncertain about diagnosis group was $p=.056$; suggesting that the inference that the recall bias in this groups is specific to illness words only is perhaps premature and requires further testing.

4.2 Fit with previous research

These results are in line with findings from qualitative studies [25; 29], which showed that diagnostic uncertainty matters, and that it appears to be related to negative emotional, cognitive and social functioning. The current findings support this proposition by providing evidence that diagnostic uncertainty is associated with reports of higher disability and depression. The recall bias towards pain and illness words is in line with previous evidence that depressed pain patients selectively process pain and illness-related information [20].

The only previous study [33] that examined the effect of diagnostic certainty on recall bias found significant different patterns of results between diagnosed and undiagnosed chronic pain patients. In this study, however, the pattern suggested that perceived diagnostic certainty was associated with a reduction in the recall of depression-related words. Although the pattern of results is different, the conclusion stated by the authors is in line with the current study: diagnostic certainty is associated with healthier cognitive processes.

Surprisingly, correlations between recall of pain, depression and illness stimuli and measures of depression and disability were not significant. Recall bias has been shown to be related to disability [12; 20] and depression [22] in most previous studies, but it is not without precedent [7].

The findings also support the self-enmeshment model of pain [20], which proposes that in the presence of chronic pain schemas of illness, pain and depression become enmeshed with self-schema. More specifically, the model suggests that biases towards pain-related information in pain patients might be a normal adaptation to pain, while biases towards

illness or depressed stimuli are reflective of maladaptive schemas and poor adjustment to illness. Such biases may maintain distress and indicate that illness information is enmeshed with the self-schema [20]. Whether a change in patients' diagnosis related beliefs could reduce the degree of the enmeshment is an important question for future research.

The findings also fit within the context of models that include other aspects of cognitive biases, such as the fear avoidance model [31]. The extent to which recall bias is associated with, and potentially dependent on, other biases is poorly understood. For instance, pain patients may interpret ambiguous stimuli as pain-related, selectively attend to them and subsequently recall them later. Future research should study how cognitive biases interact.

4.3 Implications for clinical practice and research

The findings reveal that many patients with CLBP think there is something else going on with their backs. The distinct recall pattern between those certain and uncertain about their diagnosis may reflect patients' preoccupation with the meanings and repercussions of their pain. Even though these findings cannot provide evidence for a causal link between diagnostic uncertainty and maladaptive cognitions (or subsequent poor prognosis), they provide tentative evidence for the hypothesis that greater certainty may help patients to shift their attention to non-pain and non-illness aspects of life. However, how to provide acceptable explanations to decrease uncertainty in these patients remains unknown: diagnostic uncertainty does not appear to be linked to what patients think they were told about their pain and condition; instead it might be a product of their communication with practitioners and their prior beliefs and experiences.

A key implication of these findings is the need to prioritise the study of effective reassurance in the absence of a concrete diagnosis. Screening for diagnostic uncertainty might also be a valid and relatively easy method to establish if a patient needs to be reassured further.

4.4 Strengths and limitations

One strength of the current study is that it used a clear and precise inclusion and exclusion criteria; clinicians explicitly excluded alternative diagnoses which contributed to the validity of our categorisation of patients into groups. The use of an experimental procedure enabled an insight into the information processing in CLBP patients and their pain-related cognitions uncontaminated by biases commonly found in self-report data. Additionally, the sample size was sufficiently large to find significant differences.

The study also has some limitations. The choice of stimuli was adapted from previous research, and might not have captured the specific qualities of participants' individual pain [20]. There is also evidence of this in attentional bias [6; 26]. This limitation might have influenced the endorsement results; we asked participants to endorse pain words as self-referent or not and found that patients' endorsement of pain words was unexpectedly low, suggesting that some pain words might have been irrelevant. Additionally, no differences were found between the groups on their pattern of endorsement. Matching pain words to participants' descriptions of pain might have improved the validity of the stimuli used. Additionally, although the cues differed between pain words ('Does the following word

describe your pain?') and other three types of words ('Does the following word describe you?'), in line with past research [22], encoding was identical between groups and should not have affected results.

In addition, the findings are applicable to CLBP patients who actively seek treatment; the extent to which these findings apply to other CLBP subgroups (such as those not seeking active treatment and/or primary care patients) is not known. In the absence of a control group the inference that only CLBP patients with diagnostic uncertainty show a bias towards illness words cannot be conclusively established. Lastly, the study was only powered to find medium effect sizes [8]; a larger sample size might have allowed for small effect sizes to be detected.

Conclusions

Overall, these findings suggest that uncertainty about diagnosis in LBP is associated with recall bias towards pain and illness stimuli. Although the findings provide evidence of a relationship between diagnostic uncertainty and recall bias, the cross-sectional design of this study means that causality cannot be inferred. Future research should focus on the development and consequences of patients' beliefs about their diagnosis.

Conflict of interest statement

The authors report no conflict of interest.

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LEGENDS

Table 1: Sample characteristics

Table 2: Participants' responses to diagnostic status questions

Table 3: Means and standard deviations for word recall and endorsement