

# Chasing the ghosts: The impact of diagnostic labelling on self-management and pain-related guilt in chronic low back pain patients

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## Abstract

In the majority of chronic low back pain (CLBP) patients a clear diagnosis cannot be established; as a result patients are given labels such as non-specific low back pain. There is some evidence to suggest that lack of a clear diagnosis is associated with negative psychological, clinical and behavioural outcomes. The main aim of this study was to examine CLBP patients' understanding, feelings and behaviour in response to their diagnostic labels. Semi-structured interviews were conducted with twenty CLBP patients who were recruited from one osteopathic and one pain management clinic in the UK. Sampling, data collection and analysis were driven by a grounded theory approach. Data were analysed through four stages of coding: open, selective, axial and theoretical coding. Data collection and coding continued until data achieved saturation. Results indicated that lack of a clear diagnosis is associated with distress, further treatment seeking and uncertainty. It also influenced participants' perception of their social relationships; having visible evidence and a clear diagnosis gave patients' pain more social credibility. Participants reported feeling guilty about the consequences of their pain to themselves and others, and for failing to recover. Overall, participants' narratives suggest that at least for some, absence of a clear diagnosis has considerable negative implications. The goal of the study was to inform clinicians and policy makers about the impact of diagnosis on CLBP patients' adjustment and emotional burden; findings suggest that legitimising the pain experience is of prime importance to CLBP patients.

**Keywords:** Chronic low back pain, diagnosis, pain-related guilt

## Introduction

Low back pain (LBP) affects about 80% of the adult population over a life span (1), has considerable impact on individuals and accounts for substantial socioeconomic costs (2). When a definitive cause and

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a clear diagnosis cannot be established patients are often given labels such as non-specific LBP (3). Diagnosis is defined as the ‘identification of a disease or condition by a scientific evaluation of physical signs, symptoms, history, laboratory test results, and procedures’(4). However, non-specific LBP is diagnosed by exclusion and is defined as non-specific or musculoskeletal back pain where underlying pathology cannot be found (2). It is often understood as a symptom or a syndrome rather than a diagnosis (5). Diagnostic labelling is defined as ‘the act of classifying a patient according to a diagnostic category’ (4). In the case of non-specific LBP labelling can be problematic and misleading because non-specific LBP is not a single diagnostic category; it represents a number of different subtypes of back pain (6). Non-specific LBP represents the majority of LBP patients as only in about 5-10% of cases precise causes of back pain can be identified (2).

In the absence of clear physical evidence the meaning of diagnosis becomes ambiguous, and it becomes questionable whether non-specific LBP should be seen as a diagnosis or not. As there is no consensus and clear guidelines in the literature on this issue, but there is sufficient evidence to indicate that the non-specific LBP label is problematic and ambiguous, in this paper we will refer to it as an unclear diagnosis/diagnostic label.

Having no clear physical evidence means that some patients feel that their pain is delegitimised and disbelieved (7). Some patients who lack clear physical evidence to justify their pain experiences also report feeling guilty (7). However, to our knowledge there are no studies specifically investigating pain-related guilt in CLBP patients and no instruments have yet been developed to measure it. Therefore, a secondary aim of this study was to explore pain-related feelings of guilt in CLBP patients, especially in relation to unclear diagnosis. Guilt is a type of emotional distress that is founded on the likelihood that we may be in the wrong, or that others may perceive us that way (8). Guilt is often found to be a feature of depression, and it is recognised that many depressive symptoms are prevalent in chronic pain disorders (9) such as CLBP. It is therefore important to explore if pain- and diagnosis-related guilt is present in CLBP patients.

## Methods

Sampling, data collection and data analysis were driven by grounded theory, which is considered a suitable methodology to understand participants’ experiences and to produce a theory that explains the phenomenon under study (10). Grounded theory was selected because its systematic and precise procedures for data sampling, collection and analysis should contribute to validity and reliability of findings. We based our theory on the premise (constructivist grounded theory) that multiple and socially constructed realities exist, and concepts are created rather than discovered from data (11).

### *Recruitment and sample*

Grounded theory employs a theoretical purposive sampling which is aimed towards theory construction and data saturation rather than population representativeness. Therefore, we continued with data collection and analysis until saturation was achieved (10). Inclusion criteria were LBP patients seeking treatment, aged over 18 and with a pain duration of at least 3 months (2). Exclusion criteria consisted of any conditions other than musculoskeletal back pain (e.g., rheumatoid arthritis, ankylosing spondylitis, cancer) ascertained by self-report and by examining patients’ medical notes with practitioners. Participants were recruited from two clinics in London, UK: a private pain management institution and an osteopathic clinic, selected to achieve a diverse sample with a range of disability levels. Information about participants’ diagnosis was obtained from their medical notes and by consulting with practitioners in the participating centres. An information sheet with a short screening questionnaire and opt-in slip were handed out to patients. Patients who fulfilled the inclusion criteria were contacted by the researcher to arrange an interview. Two measures of participants functioning were collected to allow full description of participants’ characteristics: (i) Roland Disability Questionnaire (RDQ) (12), which is a reliable measure of low back disability (6); and (ii) Hospital Anxiety and Depression Scale (HADS) (13), which has been widely used in studies of depression and anxiety in medical populations.

### *Data collection*

Semi-structured interviews were based on a schedule including exploration of participants' condition, their understanding of their diagnostic labels, their response to diagnostic labelling, their coping with CLBP and their relationships with others. Because of sensitivity attached to the terminology of guilt we opted not to ask about this directly in the first instance, but it was used as a probe.

All the interviews were conducted by the first author in the participating clinics. Interviews were tape recorded and later transcribed. Length of interview ranged from 9.02 to 34.58 minutes, the average length was 24.45 minutes. This study was approved by the University's Ethics Committee.

### *Data analysis*

Data collection and analysis were carried out simultaneously. All coding was completed by hand. Comparisons of statements and incidents were made within the same interview and then compared with statements and incidents in other interviews. Categories were supported by verbatim quotes from interview transcripts (14, 15).

We combined elements of coding from Glaser (14) and Strauss and Corbin (15) grounded theory in the following way: all interviews were coded, first by using open coding; each transcript was analysed line by line in order to identify key words, phrases and eventually codes (14). Selective coding (14) followed: we selected and employed the most significant and recurrent categories to code large amounts of data. However, Glaser's (14) selective coding does not provide specific procedures for studying relationships between categories and subcategories, for this reason axial coding (15) was also employed. Theoretical coding (14) was the final stage of coding; this was used to bring related categories together. Theoretical categories were intergraded into an interpretative theoretical framework (15), which explains the studied phenomenon by showing how these categories are related (see Figure 1).

### *Data triangulation*

Observer triangulation was achieved by the second author coding 10% of the interviews (blind to the first author's coding); and then by examining codes and categories (against interview transcripts) developed by the first author; this was done throughout the coding process. Additionally, observer triangulation was achieved by an independent auditor, a health psychologist with considerable experience in qualitative research inspecting the coding process and categories developed against the interview transcripts. Theory validity was achieved by: (i) returning to already analysed data to check if any instances could be found that contradict the emerging theory, and (ii) collecting new data (10): five participants with a clear diagnosis were interviewed, four of these five participants experienced a prolonged period of being undiagnosed (between several months and eight years) prior to being given a diagnosis. These cases enabled a direct comparison between absence and presence of a clear diagnosis.

## **Results**

We excluded one participant due to insufficient proficiency in English. Therefore, 20 participants' data were included in the analysis: 12 participants were from an osteopathic clinic, 7 were on a pain management course and 1 pilot participant who fulfilled the inclusion criteria.

The characteristics of the participants are summarised in Table 1. Fifteen out of 20 participants had mechanical non-specific LBP, and the remaining 5 participants had a clear diagnosis (e.g., prolapsed disc). The information from these participants was analysed alongside the remaining 15 participants' data as part of theory triangulation. Four out of these five participants experienced a prolonged period of being undiagnosed (between several months and eight years) prior to being given a clear diagnosis and overall there were no apparent differences in their emerging themes. On a few occasions they were asked to make a direct comparison between undiagnosed and diagnosed state; these instances are clearly flagged in the findings.

**Table 1. Characteristics of the participants**

		Osteopathic* Clinic	Pain Management Clinic	Pilot	Total
N		12	7	1	20
Male (N)		4	2		6
Female (N)		8	5	1	14
Age (Mean & SD)		50.5 (16.9)	41.1 (8.4)	33	46.4 (14.7)
Pain intensity (Mean & SD) on a scale: 0-10		6.1 (2.6)	6.3 (1.8)	3	6 (2.3)
Pain duration (N)	1-2 years	1	1		2
	2-3 years	1			1
	4-5 years	2	3		5
	5+ years	2	1		3
	10+ years	6	2	1	9
HADS (Mean & SD)	Anxiety	7.9 (4.8)	9.4 (5.0)	8	8.5 (4.7)
	Depression	4.1 (1.7)	8.3 (6.9)	7	5.9 (4.8)
RDQ (Mean & SD)		7.1 (4.4)	10.4 (6.2)	3	8.2 (5.3)

Abbreviations: N-number of participants; SD-standard deviation; HADS- Hospital Anxiety and Depression Scale; RDQ- Roland Disability Questionnaire.

\*Two patients from the osteopathic clinic did not complete HADS & RDQ.

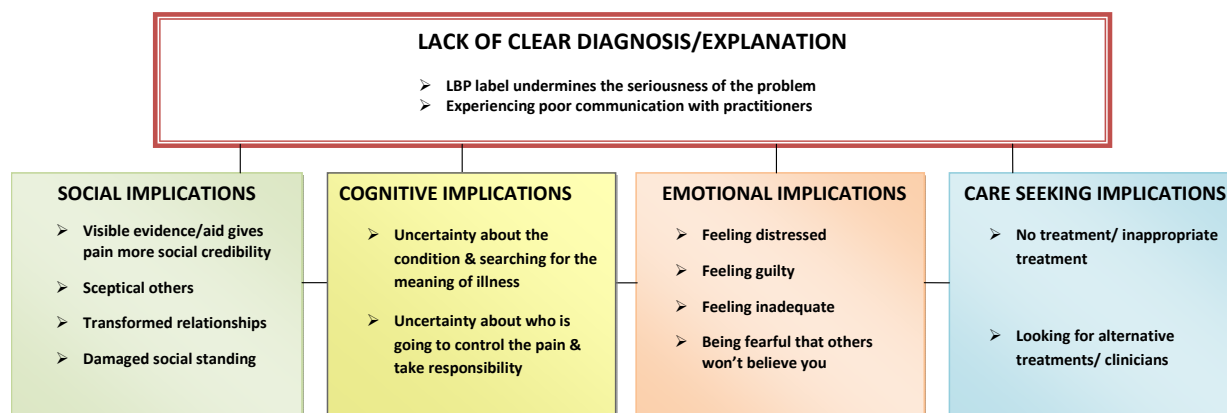


Figure 1. Theoretical framework to represent the implications of lack of clear diagnosis on CLBP patients. (Lines that connect theoretical categories indicate that all of them are related to each other; however the nature and direction of these relationships cannot be established by the use of qualitative methodology).

*Structure and characteristics of the theoretical framework*

The theoretical framework (see Figure 1) consists of five theoretical categories: Lack of clear diagnosis and explanation about the back pain, Social implications of lack of clear diagnosis, Cognitive implications of lack of clear diagnosis, Emotional

implications of lack of clear diagnosis and Implications of lack of clear diagnosis on care seeking. Our findings indicate that all categories are related; however the nature and direction of these relationships cannot be established using qualitative methodology.

Theoretical categories consist of two or more first order categories. Theoretical categories are more abstract than first order categories and are used to

conceptualise how the categories may be related and amalgamated into the theory (14). We included participant's gender (M-male, F-female) and age with each quotation.

### *Theoretical categories*

#### ***Lack of clear diagnosis and explanation about the back pain***

Interviews with the participants revealed that the meaning of not having a clear diagnosis can be understood as a prolonged state that impacts on how participants cope with back pain, how they perceive themselves and how they think they are perceived by others. This state does not normally come to existence in a single point of time in which the doctor is either able or unable to deliver a diagnosis to the patient; our findings showed that this is a process characterised by a prolonged search for a diagnosis and an understanding of the experienced symptoms. This theoretical category consists of two first order categories: 'experiencing poor communication with practitioners' and 'LBP label undermines the seriousness of the problem'.

Participants reported several problems relating to their communication with practitioners, such as being given very little advice:

'And I think I've seen about four different consultants by now, not one of them has offered any advice' [F39].

Practitioners want clear and simple explanation from patients about their symptoms; however patients are not always able to produce one, due to the complexity of their symptoms:

'... I mean it wasn't like how are you feeling and how are you coping...It was more like: 'okay so where does the pain go and is it piercing'...a lot of, not technical, but stuff that I didn't really understand, and I tried my best to explain it, considering the pain changed a lot, and it moved around a lot. I just felt pretty stupid because I couldn't pin point and describe my pain very well' [F33].

Participants reported that practitioners use technical and complicated jargon so they are often left puzzled:

'...so they tend to say there is nothing to see, it's obviously mechanical, that's what they always say; what mechanical means you see, I don't know' [F46].

Most participants used the LBP label or just back pain to describe their condition. Participants' accounts indicate that the LBP label undermines the seriousness of the problem, and that it is puzzling to practitioners:

'...cause I know the doctors and GPs and everyone kind of scoffs then, when you say those words [back pain], it means oh well we don't really know' [F33].

It is also assumed to be a short duration problem:

'I know they [new people she meets] won't understand because everybody at some time has back pain and they think it's over in days or weeks, but with mine it hasn't gone away ever; it's always there. I get varying degrees of it' [F39].

This indicates that in general people misunderstand LBP and that they are not sufficiently informed about it:

'... because it's the whole system, it does not lead you to kind of, um...to have this kind of very accurate understanding of it [back pain]' [F35].

#### ***Social implications of lack of clear diagnosis***

Participants believed that visible evidence and having a more concrete label would give them more credibility, tolerance and sympathy:

'...but if you had something more concrete [in terms of diagnosis] for them to go on, they'd look at you in a completely different light, like oh my God... so if I could say this is a back problem of some proportion, or whatever, then yeah, I would be quite happy to have that'[F39].

Other forms of visible evidence such as carrying a stick, telling others about being on painkillers and having positive results from medical tests is another way of emphasising the seriousness of the condition and gives participants' pain more social credibility. One participant did not receive a clear diagnosis until an MRI scan (eight years later) showed three

prolapsed discs. When asked whether having a clear diagnosis now has made any difference, she said:

‘Yes, I think so...they have an idea of what that is, so at least it helps in that sense rather than just: ‘ohh I’ve got a bad back’...I feel better for the fact that it sounds awful even though it isn’t necessarily that bad, it’s kind of stupid’ [F46].

Lack of physical evidence and clear diagnosis presents a problem when participants need to justify their pain; participants reported feeling inadequate and being disbelieved by others, especially by managers and work colleagues:

‘Yeah, there was no point [in explaining to work colleagues and managers the problem], absolutely no point because everybody else around you wants a diagnosis and when you can’t give one you feel like you’re a failure yourself’ [F39].

The majority of participants acknowledged that they felt, rather than experienced direct scepticism:

‘He [the manager] said: ‘oh, all you can do is go and see another specialist and see if you can get some kind of firm diagnosis for it’...I don’t actually think they believed me in the beginning...I think they just thought I wanted some time off...They didn’t turn around and say: ‘no, we think you’re faking it’; and you know...but you can tell by the way they behave towards you, that they don’t believe you’ [M54].

Almost all participants reported that they get understanding and support from family members; but their relationships with friends are more problematic. Several participants said that a shift occurs in how friends and other people perceive them and some participants said that having a clear diagnosis would change these perceptions. Participants also reported that these perceptions influenced and changed their relationships with other people and impacted negatively on their social standing:

‘It would be brilliant if they had one [diagnosis]...and it would mean my friends would know that I’m not being a rubbish friend...I’d be taken a lot more seriously in many ways’ [F33].

### ***Cognitive implications of lack of clear diagnosis***

Uncertainty about the condition and searching for its meaning was a prominent category in the study. Managing patients’ expectations about what is possible to achieve through consultations with health care practitioners appears to be one way to address this uncertainty. For instance, being informed about the non-specificity of LBP at early stages of the problem may help patients to have more realistic expectations:

‘... there’s a massive area in there where patients don’t initially understand, so I think it should be made clear to patients, right out from the outset. So there is no big expectation that’s then dropped through the hole in the middle. So...to start off with, and say: ‘look it can’t always be diagnosed specifically’...reduce their expectation level...and I think that’ll help. Because you’re not chasing these ghosts’ [M54].

Feeling uncertain about one’s condition contributed to feeling helpless:

‘I want answers, it can’t be right to be in this position for so long, and there must be something that you can do to help me’ [F39].

It also contributed to the level of distress:

‘It was very, very tough [being in so much pain and not being able to explain to herself and other people what really caused it], it was very depressing; I ended up extremely depressed’ [F46].

Participants needed a label that will represent and give a meaning to their experiences:

‘I’d rather have an explanation than all this...and I felt the unknown sort of thing, I wasn’t very happy with that’ [F36].

Having a clear diagnosis would contribute to their wellbeing and self-concept:

‘...cause all I wanted was somebody to say this is it, this is what’s wrong with you...and just for my own wellbeing, just to sort of confirm this is it, this is the problem’ [F39].

However, for some participants having received adequate explanation regardless of being given a diagnosis made them feel reassured:

‘He [the doctor] did not know exactly what it was but it still did not matter because he was showing me, he was explaining a lot more...Yeah I had some sort of reassurance as to say, this is what you’ve got but we can sort it out, sort of thing; or we can go through procedures...he made me feel better’ [F35].

Participants also expressed uncertainty about who is going to take responsibility and control the pain. Having a clear diagnosis and/or understanding of the condition would mean that practitioners may be able to control the pain:

‘...so it would be nice to just have one diagnosis and say this is what we think it is, and this is what they’re going to do to relieve the pain or to help you’ [F38].

Practitioners would also take responsibility for it:

‘So you know you’ve got this problem and this is how they’re gonna fix it. That’s what’s in your mind...you know, who’s gonna take responsibility for it, if you like, who’s gonna put it in the correct direction’ [M54].

### ***Emotional implications of lack of clear diagnosis***

Participants reported feeling distressed, feeling inadequate and being fearful that others will not believe their symptoms. These feelings are associated and have been reported with above categories; here we focus specifically on feelings of guilt.

Feelings of guilt were grouped into three subcategories: feeling guilty towards other people, feeling guilty towards yourself and feeling guilty for not getting better.

Feelings of guilt towards other people can be split further into: (i) feeling guilty for what you have done:

‘Guilt, always saying sorry to everybody as if it’s my fault, you know, didn’t know what to say or do, just felt I was just apologising all the time...for my actions...’ [M39].

(ii) Feeling guilty for what you cannot do, such as not being able to help and do things with family and friends:

‘You feel like you’re letting people down, like when you should be able...to be a good friend or be a good

employee, then you feel guilty ‘cause you can’t and it sucks’ [F33].

A number of different situations were mentioned from not being able to cook a meal for the family, attend birthdays to not being able to care and provide for children:

‘...but I’m not working, I can’t do...I feel very guilty with my children’ [M34].

Some participants said they were feeling guilty towards their colleagues at work, for instance for not being able to go to work due to back pain:

‘...and the pressure on my colleagues and you know you can see the stress in their faces. They have recruited a temp...that’s relieved my guilt actually’ [F28].

Participants also reported feeling guilty for not meeting friends’ expectations and disappointing them:

‘Why do you feel guilty for like you should be there but you can’t? Also they don’t believe that your excuse is real. You feel like you’d done something wrong and you haven’t’ [F28].

They also said that friends expect them to be the same type of person as before back pain started, and they do not understand that the back pain has brought a change. When friends do understand, for some participants the guilt does not disappear, they reported feeling guilty because others are trying to make allowances and be helpful:

‘But then that has a knock down effect as well, that makes me feel guilty as well because they [friends] are making allowances’ [F36].

How do participants deal with feelings of guilt related to other people? Some participants reported distancing themselves from other people because they cannot understand their situation.

This seemed to be common behaviour by a number of participants in the study, not only as a reaction to feelings of guilt but to other emotional and social factors discussed above. Other participants tried to say ‘no’ more often and not feel bad about it, or they simply built a resistance towards guilty feelings over the years:

‘...I’ve kind of given up on guilt...I think just because I got my head into a space where I just don’t buy guilt any more. I’ve spent a lot of my life feeling guilty about one thing or another...and umm...it’s just useless so I really don’t go there’ [M44].

Not all participants reported feeling guilty. About one third of them said they did not experience feelings of guilt. Various reasons were put forward such as experiencing a different kind of feeling instead of guilt, for instance feeling frustrated and anxious rather than guilty, to living alone/not having a family:

‘...maybe because I live alone, you know, I don’t need to, you know, to do things for other people’ [F35].

Some participants also reported feeling guilty towards themselves (personal guilt). Back pain impacts on participants’ level of involvement in daily activities and this seems to be related to how they feel about themselves. Participants reported feeling guilty for not living up to their own potential, expectations and values:

‘When I had these two crises, I couldn’t do anything, even to myself, I couldn’t go down to the shops, I couldn’t do my work, and I had deadlines to follow...I felt guilty because I wasn’t doing what I was supposed to be doing’ [F35].

Not being able to provide for themselves appears to be a problem too:

‘The guilt is big when it comes to money, and not being able to work, that’s really bad, that’s horrendous’ [F33].

Some participants reported feeling guilty for not getting better and for not being able to give a specific reason for their pain:

‘I’ve beaten myself up on a regular basis, why I can’t ...why it’s not better, why am I still getting episodes of pain, why hasn’t it gone...I feel guilty that I can’t tell anybody something concrete, that I cannot give a specific reason. I would have loved the doctor just to have gone ‘that’s what’s wrong with you’, and be happy, because then I’ve got something more concrete to say to everybody’ [F39].

However, the fact that the back pain was caused by uncontrollable circumstances made some participants feel less guilty:

‘...but if any relief [from guilty feelings], because it’s always been put down to my caesarean section. I always say it wasn’t like I was just bungee jumping somewhere and then hurt my back’ [F38].

### ***Implications of lack of clear diagnosis on care seeking***

In many instances participants made links between inappropriate treatment or absence of treatment and absence of physical evidence and clear diagnosis:

‘Well you have nothing too serious [GP said], there is no need for physiotherapy...and things like that...but you know, at the time it was really needed’ [F35].

Participants also reported waiting for too long for treatment:

‘[GP] didn’t really explain why I was in so much pain, and he just said I’d have to go on a waiting list which should take about two months to get physiotherapy, and he didn’t have any immediate help’ [F33].

Several participants expressed confusion about their treatment, and in a number of instances this could be linked to a lack of information and poor communication with practitioners:

‘I didn’t feel like I was able to ask about the other therapy options...so it’s been like confusion I think in terms of what is best for my body, and no-one knows’ [F28].

When current treatment does not work many participants reported looking for alternative treatments and seeing private clinicians. This patient explained why she came to see an osteopath:

‘When I go to an osteopath I get looked at...it incorporates not just that specific pain, but you know your lifestyle...’ [F62].



## Discussion

The findings suggest that lack of clear diagnosis and lack of understanding about one's condition affect participants' social, cognitive and emotional functioning. Participants spent much time and effort trying to understand their diagnosis and condition; they invested themselves in this process.

Our findings indicate that uncertainty and a perceptual search for the meaning of the condition are important aspects of LBP, at least for some patients. The ability to find meaning is an important cognitive process and is an essential component of psychological recovery from stressful health related events (16). For the majority of participants, their label provided a poor fit with their experience of the condition and they stated that the LBP label undermined the seriousness of the problem. This is important, because such a fit is necessary for acceptance of the diagnosis (17) and consequent adherence and care seeking. Additionally, it can be difficult to direct attention to non-pain aspects of life if one does not accept the presence of pain. Acceptance of pain is characterised by a willingness to have pain, or other uncomfortable private experiences and it has been linked to better function in several studies (18). The question these findings pose and that needs further investigation is whether acceptance of pain is possible in the absence of an acceptable diagnosis or explanation, and before the very identity of the pain and its causes is accepted?

Participants consistently reported that having visible evidence, such as magnetic resonance imaging (MRI) scan or x-ray positive results, actually serve as a long awaited proof of their symptoms. However, in most cases such tests are negative, and most guidelines now recommend that clinicians should not carry out testing for non-specific LBP. Research on diagnostic approaches for CLBP that has centred on finding biological causes has been recently scrutinised. For instance, the use of early MRI scans has been employed as a means of providing earlier diagnosis and treatment, or reassuring CLBP patients. However, it appears that this leads to an increase in unnecessary surgery and perceptions of poor health (19). In fact, radiological evidence does not support a link between observable disc changes and LBP (20), and the National Institute for Health and Clinical

Excellence (NICE) guidelines for CLBP in the UK now recommend against carrying out x-ray and MRI tests in these populations (21). This also means that many patients are simply told that there is nothing wrong with their back, but instead of reassuring them, such statements can result, at least in some patients, in heightened anxiety, seeking further care and examinations and mistrust in clinicians (22). Our findings support these findings.

Findings from this study suggest that the information participants received from practitioners was often conflicting, and this added to the confusion and uncertainty about their condition. This supports findings from other studies, such as McIntosh and Shaw's qualitative study (23), who found that many LBP patients were dissatisfied with the information they received from their GPs about their diagnosis and treatment. Our findings also showed that in the absence of a clear diagnostic label participants put in immense effort in justifying their pain experiences and convincing practitioners and other people (especially work colleagues and managers) that they were not malingering. Patients' perception that others think they malingering is in line with findings from other research, for instance a study (7) explored the meaning of diagnostic tests for people with LBP and found that in the absence of positive test results many patients felt that practitioners did not believe their accounts of pain. Overall, our findings suggest a misunderstanding and lack of communication between patients and practitioners, and that to an extent managing patients' expectations from the onset may help to solve this problem. Participants said that practitioners should provide much clearer and more detailed explanations, and warn patients that a definitive cause and diagnosis may not be possible to establish.

The participants struggle with their pain and they reported that their distress and suffering impact on their relationships with other people, for instance they said they experienced resentment, a sense of isolation and guilt. It also appears that feelings of guilt are closely linked to disbelief and stigma associated with non-specific LBP. For instance, some participants reported feeling guilty for not getting better and for not being able to give a specific reason for their pain. This suggests a link between pain-related guilt and unknown aetiology/lack of physical evidence, but this

should be confirmed by comparing reported guilt in pain populations with a clear diagnosis and physical evidence.

While trying to cope with the social and emotional consequences of a lack of clear diagnosis participants appeared to be exposed to uncertainty and confusion about what their symptoms mean, why they persists, and how they should be treated. Overall, our findings seem to suggest that a lack of clear diagnosis impacts on participants' self-management of their back pain. However, this cannot be concluded based on qualitative methodology alone and further research is needed.

### *Strengths and limitations*

To our knowledge, this is the first study that explored pain- and diagnosis-related guilt in CLBP patients. Considering that in the majority of LBP patients clear physical evidence cannot be found, and consequently no clear diagnosis can be given, it is crucial to understand associated emotional states in this group of patients.

A methodological strength of the study is that a great degree of care was taken to carefully tailor and justify every step of the analysis according to already well developed strands of grounded theory. However, several limitations are also indicated.

As the inclusion into the study was limited to persons on the pain management programme and undergoing osteopathy treatment, the findings may not generalise to other LBP populations. In addition, the small sample of volunteers who agreed to be interviewed may have been subject to other biases. Future research should test the developed theory in large and diverse samples of CLBP patients. We acknowledge that participants' accounts may be constructed through social processes and demands of the situation, although we tried to minimise these as much as possible. Most importantly, our findings are limited to patients' perception and their own interpretation of their experiences. Exploring any link, especially causal, between receiving and accepting diagnostic labels and subsequent clinical status and health-related behaviours must be explored quantitatively and prospectively in appropriately large samples.

### *Implications for patients and clinicians*

The findings could be interpreted to suggest that there is a need for a clearer labelling system for musculoskeletal conditions with no apparent biological origin, and for a label that will give a new meaning to CLBP and distance it from the current stereotypical view. However, the labelling issue is clearly problematic; for instance it has been debated whether providing labels which indicate biological origins for conditions that do not seem to have one may strengthen the individual's belief that s/he is ill and encourage disability (24).

In addition, it is important to search for more helpful interactions between practitioners and patients that do not depend on the presence or absence of visible evidence (25). The findings of this study provide supporting evidence to this view and encourage practitioners to consider the importance of diagnosis and labels in CLBP, and better and more acceptable explanations. However, this may present a challenge to practitioners as currently there is no consistency and no clear guidelines for delivering diagnosis, explanation and reassurance for LBP.

Many participants reported feeling guilty and further research should examine if pain- and diagnosis-related guilt is associated with depressive mood. This may have implications for refining therapies, such as cognitive behavioural therapy (CBT) by targeting specific emotional states and cognitive processes. Refining CBT to suit specific groups of patients is one of the most important and urgent priorities (9).

### **Conclusion**

The findings indicate that at least some LBP patients invest heavily in a search for biological causes of their condition, as such causes can rarely be found. Participants reported that they do not want to be classed as psychological cases and that they keep looking for evidence of biological or biomechanical malfunction. Their narratives suggested that many participants experienced difficulties as a result of the lack of understanding and acknowledgement of their suffering by practitioners and other people. Participants identified that these difficulties were

linked to a lack of clear diagnostic label; the label that would justify their pain experiences. This poses a challenge to clinicians in the context of uncertainty and further emphasises the importance of clear, acceptable explanations that may replace diagnoses based on physical evidence.

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