

# Managing constraint: the experience of people with chronic pain

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## Abstract

This study describes the experience of people with chronic pain. Using the method of grounded theory, 29 chronic pain sufferers were interviewed at an outpatient pain clinic. A model depicting the basic social psychological process of maintaining a normal life through constraint was developed. This process revolved around people's perception of the constraints imposed by pain: bodily constraint (constraint on the body and its relationship to the environment); activity constraint (the constraint on what people could do); and identity constraint (the constraint on what people could be). The degree to which pain had challenged what people had previously accepted as 'normal' was illustrated through their evaluation of the impact of pain. The conclusion of this process of evaluation reflected how people coped with the constraints of pain—whether they were assimilated, accommodated, confronted or subverted. In assimilation, the constraints were absorbed and normal life maintained. In accommodation, the constraints were accepted and normal life re-defined. In confrontation, the constraints were rejected and pre-pain identities and activities pursued despite leading to increased pain levels. In subversion, attempts were made to retain pre-pain identities, and although pain levels were minimized, activities were altered to a significant degree.

The limitations imposed by pain often form the focus of people's coping efforts, rather than the pain per se. The desire to retain pre-pain 'normal' lifestyles may underlie people's use of coping strategies that exacerbate pain intensity and pain-related disability. Future research needs to explore both the relationship between adjustment to pain and adjustment to the restrictions associated with ageing, and the role of body techniques and identity management in adjustment to pain in order to understand factors which may promote pain acceptance.

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## Introduction

The difficulties associated with chronic pain are considerable. Chronic pain can prevent people from

doing a range of activities (Gamsa 1994a, b; Kerns, Turk, & Rudy, 1985), upset their sense of identity (Johansson, Hamberg, Westman, & Lindgren, 1999; Osbourne & Smith, 1998), and challenge aspects of their world that are usually taken for granted (Jackson, 1994; Morris, 1991). Whilst any chronic illness may pose similar difficulties, one distinctive (and problematic) attribute of chronic pain is its resistance to objectification (Kleinman, Brodwin, Good, & DelVecchio Good, 1992).

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The absence of objective indices to validate and confirm people's subjective experience presents sufferers with a crisis of legitimation. Without an identifiable cause, the claims of the sufferer that they are in pain are undermined, and questions are raised about the extent to which the sufferer is responsible for their pain. For example, causal attributions of pain have been shown to vary systematically between pain sufferers, physiotherapists and doctors, with neither group accepting responsibility for the pain, but blaming sources other than themselves (Eccleston, Williams, & Rogers, 1997). Such mutual suspicion can lead to considerable tension between patients and health-care professionals (Jackson, 1992; Lillrank, 2003) but having unexplained pain also causes problems beyond the medical sphere and affects interactions between patients and their wider social circle. In a study of women with 'undefined musculoskeletal pain', Johansson et al. (1999) found attempts to fulfil family roles clashed with having a genuine illness that prevented them from doing paid work. Hence, one of the consequences of having pain was a tension between wanting to do things whilst maintaining their status as 'sick'. Similar difficulties have been reported in the work of Osbourne and Smith (1998) who observed that people often used social withdrawal as a way of coping with disability in the absence of a recognised illness. Unsurprisingly, the need to find a legitimate cause has been highlighted as a key reason for seeking a diagnosis (Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999) and the main cause of repeated treatment seeking in chronic back pain sufferers (McPhillips-Tangum, Cherkin, Rhodes, & Markham, 1998) because finding a 'cause' would provide a quick and easy solution to such problems.

The issue of the unexplained and invisible nature of pain has attracted a great deal of research interest. This emphasis is particularly evident within qualitative analyses, where a good deal of the work has focused on understanding what it is like to live with unexplained pain (Johansson et al., 1999; Lillrank, 2003; Osbourne & Smith, 1998). In contrast, relatively little work has examined the difficulties faced both by those who know the cause of their pain and those who do not. In addition, although previous qualitative work has outlined the many problems that can accompany chronic pain, the discussion around 'coping', or how these problems are dealt with, has often centred solely on how people cope with pain per se. This may reflect the fact pain comes to dominate people's experience (Hallberg & Carlsson, 2000), but may also reflect the predominance of thematic analysis, which lays out multiple themes rather than describing the inter-relationship among themes. Hence, the problems associated with chronic pain may be described in detail, but may not necessarily be integrated with descriptions of how such difficulties are dealt with.

The present study therefore aimed to develop a grounded theory whereby emerging themes are integrated into a theory that delineates a 'basic social psychological process', i.e. a theory that encapsulates the main 'problem' of people with pain and how they attempt to resolve it. This was done to both offer insight into the experience of having pain and provide a framework for future investigation through the presentation of a set of interrelated theoretical concepts that can form hypotheses for future testing.

## Methods

### *Materials*

#### *Pain measures*

- (i) Four 101-point Visual Analogue Scales of pain intensity were used to assess present pain, average pain over the last week, worst pain over the last week, and least pain over the last week. They were anchored 'No pain'/'Worst pain imaginable'.
- (ii) Details of whether the pain was continuous or intermittent, its chronicity in years, its location, and whether medication was taken for the pain or for depression were also noted.

### *Sample*

Twenty-nine people with chronic pain took part in this study, which was conducted in an Outpatient Pain Clinic in an NHS Hospital in Middlesex, England. People were attending a follow-up appointment to see a Consultant Anaesthetist for routine medical management, and had attended the Pain Clinic at least once before. Chronic pain was defined as present if it was linked to a benign condition, was ongoing, and had persisted for more than 3 months despite medical treatment. The other inclusion criteria were (i) no visual and/or auditory problems, (ii) an ability to read and write English, and (iii) aged over 18 years. People were invited to participate in the study by the clinic nurse, following their medical appointment. The study was approved by the Harrow Research Ethics Committee and all participants gave written, informed consent.

Twenty of the participants were women, nine were men. The average age of participants was 55.6 years (SD = 17.6; range 21–84), 79% were taking pain relieving medication for their pain, the average pain chronicity was 12.5 years ranging from just over 1 year to 59 years. The average reported present pain intensity on a 101-point scale (from 0 to 100) was 59.1 (SD = 29.9), and the present pain intensity was 46.1 (SD = 29.3). Eighty-three percent reported that their

pain was present all the time with the remainder having pain intermittently.

Thirty-eight percent identified their primary pain site as the lower back or lower back and legs, 28% had pain located in the legs (not back), 21% mentioned more than two main sites of pain, 7% had head pain, 3% neck pain and 3% chest pain. Twenty-one percent said the cause of their pain was unknown and a further 7% described it as due to 'wear and tear'.

### *Data collection and analysis*

The aim of grounded theory is to develop concepts from people's accounts, i.e. to develop a set of 'second-order constructs' from people's descriptions of their experiences (termed 'first-order constructs'). Whilst the original aim of this approach was to 'discover' aspects of the social world which could then inform social-psychological theory, the theory-independence of observations has been criticized (Chalmers, 1982) and the interpretive nature of grounded theory acknowledged (Charmaz, 1990).

Consistent with grounded theory methodology, the present study was conducted with no predetermined interview schedule or topics to be covered. The study therefore began with open-ended interviews in which each patient was asked "Can you tell me about your experience of having pain?" Topics raised by participants were followed up in subsequent interviews with new participants (theoretical sampling), hence data collection and interpretation proceeded in parallel, so emerging themes could be explored in future interviews.

The interviews and data analysis were conducted by the first author. The average length of the interviews was 46 min and ranged in length from 29 min to 1 h 34 min. The interviews took place in the pain clinic and it was made clear to participants that, while the clinic supported the research, the interview bore no relation to the treatment they were receiving at the clinic and that all information gained in the interview was confidential and anonymous and would not be passed on to the clinic doctor at any time.

The interview data were audio-taped and transcribed. Data were analysed using the grounded theory described by Glaser (1978), facilitated by ATLAS/ti version 4.1 for Windows. Interviews were initially coded to capture their substance using the technique of 'open coding'. This involves comparing statements both within and across interviews to look for common themes, which are then assigned codes. This method is termed constant comparative analysis. In this way, codes indicating a shared, super-ordinate category were grouped together. Category characteristics were developed and the relationship between categories determined using theoretical sampling which guided data collection in order to clarify

and expand on the themes thereby helping to 'saturate' the emerging categories by continuing until no new meanings emerged (Glaser, 1978). In the present study, theoretical sampling was used to expand the categories developed using both more directive data collection, through seeking out interviews with a wide range of participants who might be expected to give different accounts from those already collected (e.g. those with explained and unexplained pain, different treatment histories, men and women, and people of varying ages), and through more focused questioning around the concepts as they emerged. Memos were used as part of the analytic process of the development of categories and their inter-relationships.

The conceptual categories that are developed in grounded theory seek to describe a basic social psychological problem and how this problem is resolved. A key problem that emerged for participants in this study was the *inability to do the things they wanted to do*. Hence, activity restriction was initially viewed as a potential core category. However, it did not sufficiently capture the challenge to the taken-for-granted things of life, or the effect it had on people's ability to 'be' who they wanted to be, which also emerged in people's accounts. Hence the more abstract concept of 'constraint' was developed as this more adequately encompassed all of the above. Furthermore, the focus of this constraint was on the ability, to conduct a normal life, as this concept encapsulated both the key problem and the way people coped with it. The core category *maintaining a 'normal' life through the constraint of pain* reflected re-occurring themes in the data, linked the data and explained variations in pain sufferers' interpretation of the effects of pain and their coping efforts.

## **Results**

The eight categories that form the theory are shown in Fig. 1.

### *Categories 1–3: Constraint*

#### *Category 1: Bodily constraint*

The effect of pain on the ability to perform larger scale activities such as work and social activities is well-documented. However, in the present study, the complaint that pain affected people's ability to do things that were often described as 'simple', or things they would not previously have had to think about, was notable. The restrictions caused by pain included fundamental changes in the way people could move and physically interact with their environment. This form of 'bodily constraint' affected some people's view of themselves, their place in the social world around

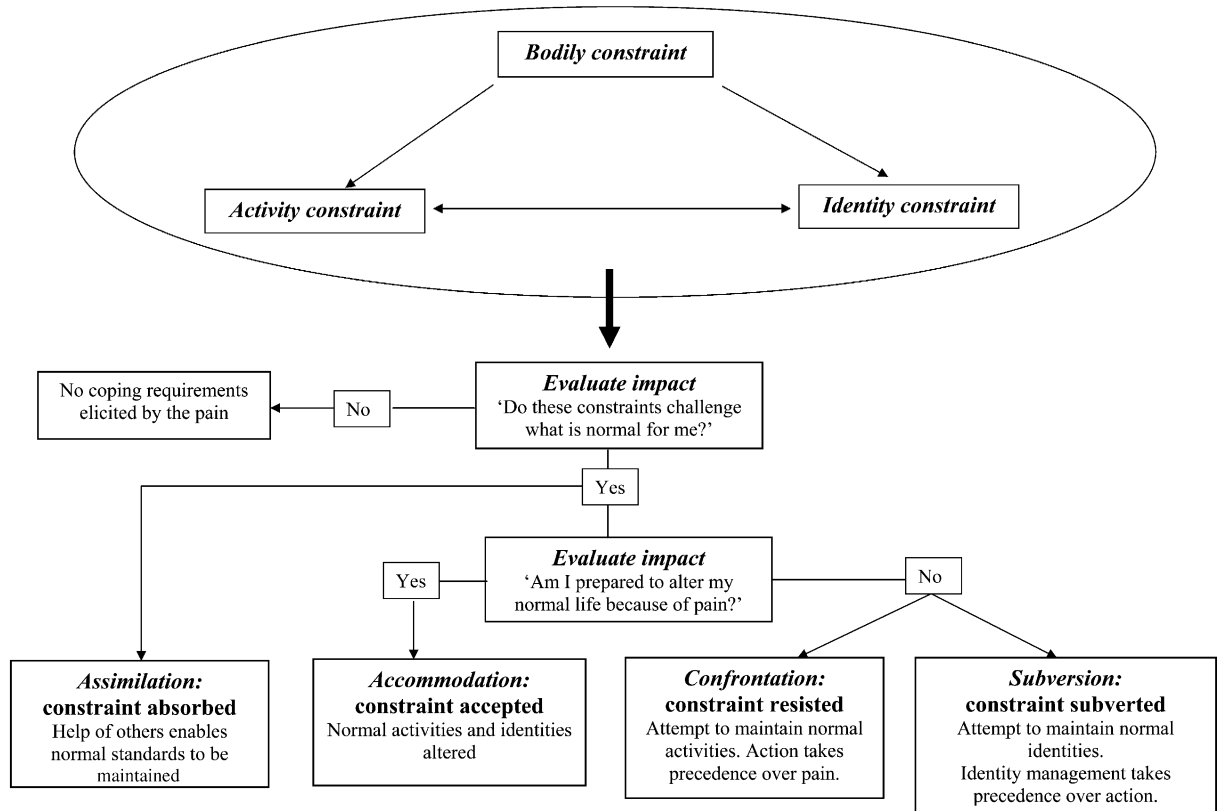


Fig. 1. Diagram showing the relationship between constraint, perceived impact and coping.

them, and their sense of difference from other people. The following four principal themes emerged.

*Speed at which things could be done.* Activities could often be accomplished only if they were done more slowly than usual, to prevent pain from increasing or from flaring up later. This slowing down was often communicated through feelings of occupying a different sort of world, but most commonly by a feeling of getting older.

You do just slow down basically, you know where, it's a bit like going on holiday, you go somewhere down on the coast and the lifestyle is a lot slower. You come back to London and you feel like everything's going past you at 90 miles an hour. So I mean it, it is the same feeling that where I've been going along doing what I would normally do, I've had to come down to sort of being down the coast and go slowly like. It does make you sometimes feel old (S1; 39 year old male).

Such slowing down often meant that people could no longer engage in social and/or family events in the same way as before, with people around them automatically

engaging in activities at a pace faster than the person with pain could manage. Hence these changes could contribute to a sense of isolation and exclusion.

...my children will sort of say 'oh we can do this and that' and I don't keep up with them when they walk. I'm the one lagging behind shouting at them saying what's the point of me coming with you if you're not going to wait (S8; 52 year old female).

*The contracting social world.* Travelling of any kind became problematic. The social spaces that people could gain easy and unconstrained access to became limited, from going shopping to sitting out in the garden. As a result, opportunities for informal socializing with friends and neighbours often became reduced and all these changes resulted in a contracting social world, with people reporting a sense of social isolation, boredom and depression as a result of their inability to move about.

So now, as I explain to people, I live in a box. I can't get out unless somebody comes with a car to take me because I can't walk far enough. I get out of my box

three times a day to get my meals... You never get any air, you never, I mean I knew such a lot of people round where I live, I never see them anymore (S13; 84 year old woman).

*The split between mind and body.* Pain presented a challenge to the performance of simple everyday activities and opened up a distinction between the mind and the body. As one lady put it:

In here (points to chest) I want to do it, here I want to do it (points to head) but down here it (points to legs) doesn't let you do it anymore and I resent it (S6; 54 year old woman).

Because activity often resulted in pain flare-ups, actions suddenly had to be thought through in advance. Whereas before the pain, action largely proceeded automatically, i.e. without any conscious detailed planning, such automaticity became challenged. This in itself was viewed by some as a fundamental shift in their way of life.

Whatever I do I have to very be careful how I do it, what I do and how I do it. Sitting down, stand up, walking, anything I do I have to think first, then act. Like before you act first then think later but now I have to think first, how am I going to do it, then do it. It's like completely, my life is reversed, completely set back like I'm starting to live my life again trying to learn to live again just like I'm on a training programme (S7; 41 year old woman).

In addition, this could result in a loss of spontaneity that could also contribute to feelings of ageing.

*The loss of comfort.* A number of interviewees noted their inability to get comfortable. This inhibited their ability to sleep and relax, and also contributed to their inability to do certain activities, or do them for long:

... I can't sit down for long, not at home in an armchair, or on the settee, I have to find some position to make myself comfortable, quite often I end up on the floor (S15; 77 year old woman).

### *Category 2: Activity restriction*

All those interviewed said that the pain had resulted in some degree of restriction on their activities. The pain could affect particular 'domains' of activity, such as work, or activity within certain environments, such as shopping centres:

When you walk round shops and things like that you take it for granted but when you can't do it, it's hard work (S9; 65 year old man).

Even getting in and out of the car I have to get in and out differently, I can't just sort of throw myself in like

I would normally, I have to lift one leg at a time or something and get myself comfortable with a cushion or something (S22; 26 year old woman).

### *Category 3: Challenge to identity*

For some, being unable to do things, or do them to the same degree of proficiency, posed a challenge to their identity. Following Strauss (1997), identity is understood here as connected to appraisals of oneself. Strauss argues that people see themselves in the mirror of others' judgements, and that in response to this people may choose to project a certain image, i.e. wear a particular 'mask'. Hence, a dynamic relationship is seen to exist between the image one attempts to project (one's 'mask'), and one's sense of identity as reflected back in the judgements of others (one's 'mirrors'). Consequently, people may alter the 'masks' they project in response to the 'mirrors' they see.

People's challenge to identity was viewed in the present study as being mirrored, or reflected back in a variety of ways (people's 'masks' are documented in the section 'subversion' in *Coping with constraint*):

*Actions and judgements of other people.* The reactions of other people, such as their comments on the pain sufferer's actions or offers of help were seen as reflecting undesirable identities:

I suppose I feel it's got a bit of a, not a shameful stigma but it's obviously got a stigma to it ... perhaps it looks like you need help when you don't want help... You see even in my job, we come across some disabled children who are in the normal system. And we say to the able children don't do too much for them they don't like it. Because they don't and I feel that's the category they're going over themselves to help you, you don't want it and you don't ever want to be in that category (S8).

*One's own ability to do things.* For some, the ability to do things to a certain standard was seen as fundamental to their identity.

I haven't done my dusting since the 19th of December ... that isn't me at all (S6).

However, standards could also be more generic, such as those of a person of a particular age:

If it is damp and I'm sitting in the car, I find it embarrassing getting out, because I'm very stiff, mainly on my right side and I feel as if I must look 70, not sort of in my early 50s, and I've got a young child there and I'm sort of hobbling along (S8).

*Physical changes.* The inability to do things also had an effect on people's ability to maintain their usual body size. For some the problem was weight gain:

Well the pain and the immobility caused me to put on weight ... it has affected my image in that I feel fat, you know and I've put on two dress sizes ... I feel suddenly self-conscious and I will only wear long skirts or trousers (S20; 49 year old woman).

Whereas for others (often men) it was loss of muscle:

Once I had big strong legs hairy, blonde hairy legs, ... and my legs have just shrunk away to nothing ... I ain't the same as I was. I ain't fit, I suppose I've lost weight (S9).

*Surrounding environment.* While some of the things that 'reflect back' identity may be relatively stable across situations, such as weight gain, some only emerged in particular environments.

I would like to join my wife say in a simple shopping spree which I can't unless I'm prepared to take a walking stick and sit down every 10 or 15min, ... (but) you'd be surprised at how many shops haven't got a chair. You'd be surprised at how many places just don't cater for anybody that might want to sit down (S5; 64 year old man).

#### *Category 4: Evaluating the impact of pain*

The process of comparing oneself to others and to one's former self was a salient feature of people's accounts of their experience of pain. The negative aspects of their lives were usually emphasised by comparing themselves with those better off:

I also get ... very irritable and this is where the resentment starts because I think why can't I be like the others 'cos I see my sister-in-law who's 67, she's digging her garden, she's coming round taking me shopping, she's running here she's running there... and I think, she's able to do that, why aren't I able to do that? (S6).

And the positive aspects by comparing themselves to people worse off:

... there's two or three blind people I see trying to get across the road and I think oh God it must be awful not to be able to see. I can read, I can see the television. I can see the garden (S13).

People also compared themselves to broader standards of normality, such as behaviour changes that might be expected with age. One man, when asked how he felt about the impact pain had had on his social life, answered:

If I was 30 I'd be shattered, but at this age I would accept it (S5).

However, whether people accepted certain changes as age-appropriate depended to some extent more on how youthful they perceived themselves to be, rather than on their actual age. Hence another reflected:

Well it's affected my life, let's go back to 1995, I was very happy, outgoing, sociable, dancing singing, entertaining, everything, not like a 50 year old at all much younger sort of person ... Whereas I would be standing up at the bar (laughs) or standing along wherever, you know, and it feels awful that people have to squash along to make way for me (laughs). You're treated like this old infirm person and you don't wanna be an old infirm person, before the time's, before I think the time's ready for it (S6).

A key comparison was with themselves as they had been before the pain and hence their own standards of 'normality':

from being someone that was so active to have to do things and sit down at a desk it is, it is just soul destroying you know because my whole personality revolves round sport, with being physical, ... I'm not the kind of person that sits behind a desk (S19; 39 year old woman).

Whilst social comparisons can have a number of functions, they are viewed here as conveying the significance of the constraints of pain, and providing answers to the questions 'has the pain changed what is normal (for me)?' and 'am I prepared to alter my life because I have pain?'. The conclusion of this process played a key role in how interviewees responded to the constraints imposed by pain.

#### *Categories 5–8: Coping with constraint*

People's coping responses centred on their perception of the constraints of pain and their willingness to accept them (see Fig. 2).

#### *Category 5: Assimilation*

Assimilation was characterised by the ability to maintain a pre-pain way of life to a large extent. 'Normal' life was seen as unchallenged, activity constraints were relatively minor, and little challenge to identity was perceived. Any activity restrictions were dealt with either by making minor lifestyle changes, or by accepting support from others (who effectively *absorbed* these constraints by taking on the person's responsibilities and roles). The former involved finding ways round the obstacles presented by pain, while engaging in essentially the same sorts of activities:

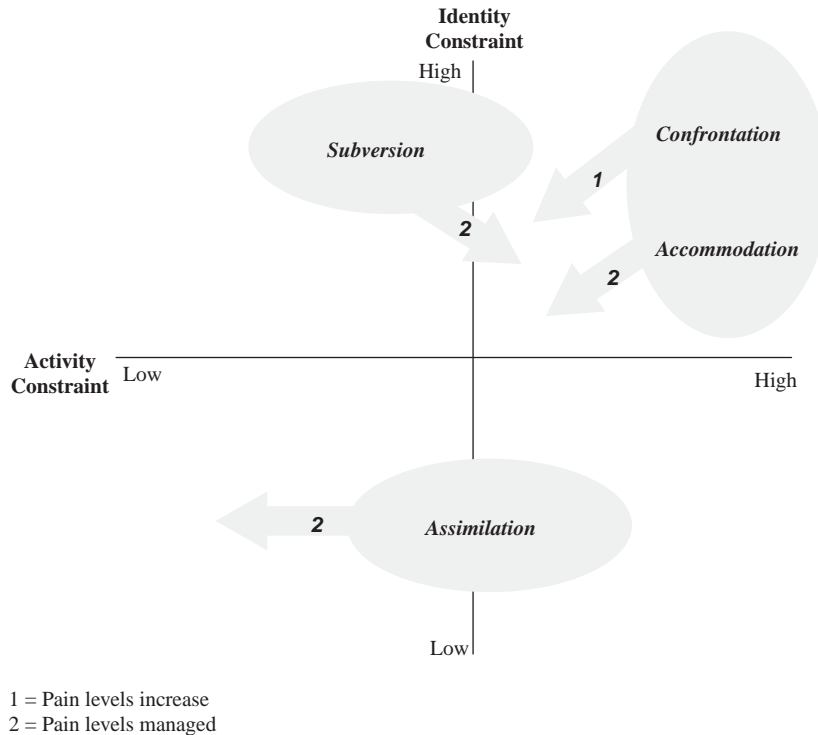


Fig. 2. Diagram showing the interrelationship between levels of constraint, coping responses and pain severity.

Same as going on holidays isn't it, you just have to, instead of going to the mountains you have to go to the valley don't you. You know it's the same thing. Even though you enjoy going for a walk you just have to do it on the level don't you (S14; 39 year old man).

#### Category 6: Accommodation

For others, the pain was seen as demanding more radical life changes. People who adopted accommodative coping acknowledged that certain things could no longer be done and shifted what they considered to be 'normal' life.

Some people normalised the life changes they made, seeing them as part of an ageing process that would have occurred or was occurring anyway:

But it's life isn't it. You have to expect that things go wrong as, in particular as you get older, I don't think there is a person who hasn't got anything wrong as you get older, or very, very few (S15).

Others saw it more as an ongoing daily battle:

Well I get angry and then it subsides because I have to doctor my movements and my activities in that parameter, ... but not angry to making me be morose and ill, it's angry and I sit and talk to myself and say you've got to just work within those lines hopefully something can be done (S5).

Or something that had only come after several years experience:

But you do, you know, you just you do adapt... I've had four years to sort of slow the whole system down and sort of think about it whereas someone's that's probably going through the first stage of what I've been through would be finding it very hard to, to adapt and tearing out there lifting things and ending up in pain (S1).

This form of coping balanced activity levels with pain intensity so as to achieve as much activity as possible with minimal pain.

#### Category 7: Subversion

This strategy reflected a non-acceptance of the constraints associated with pain and an attempt to find a non-confrontational way around them. In contrast to the method of coping outlined below, this was *without* increasing pain levels. *Subversion* centred principally on keeping the appearance of life as normal as possible whilst altering activities to a significant degree. Underlying this response was a desire to return to or retain a pre-pain life, particularly pre-pain identities. So whilst the intended consequence of this style of coping was to 'appear' to be the same person as before as much as possible, an unintended consequence was that the pain actually caused greater activity constraint than it need

have done. In addition, this style of coping was frequently accompanied by a refusal to accept help or to use visible props, such as cushions, to help ease the pain. Moreover, particular environments and people were avoided if there was a danger they would highlight unwanted identities. Hence, people tried to reduce any perceived stigma by choosing their environments and audiences carefully.

It completely changes your lifestyle because you're looking to ways to avoid it, where you're not going to be noticed ... It hasn't actually lost my confidence because I try to avoid places which will show that I'm not confident... at the moment I've given up swimming and things like that ... as I say anywhere where there's a lot of activity, walking, or even if I take my young one to the playground and there are other parents there ... It's just so it's not exposed (S8). there's a film exhibition on in town somewhere that one of my daughters went to see last week and she knows that I'd love it, and her friend said well why doesn't your dad come and she says he can't walk and ... I'm not going to go in a wheelchair. I really am not, not yet. (I feel) angry and realizing my age because part of it's probably age and I do not like to feel I'm getting older this is what bugs me ... it makes me feel as if old age is coming in too fast, not gracefully (S5).

#### Category 8: Confrontation

*Confrontation* was characterized by a focus on doing things even though they may lead to increased pain. This response differed from 'subversion' in that the main aim was to do as much as possible, regardless of the pain.

I mean like I love amusement rides and stuff like that you know... once you get that adrenalin rush you know that I'd then let myself go and I've done it a couple of times you know when I've gone on rides you know and I've started to run and you know you start, you just get so excited especially when you've got the kids beside you. You know and by the end of the day you know, you know you've done too much, you know that you shouldn't have done it and you get up the following morning and you get really angry with yourself, you know, and then you get rebellious because you think to yourself hey fuck it you know I've done this you know I mean I don't give a shit if I done it and you get very very rebellious (S19).

I'll do my normal chores I have to do, and I'll stick to that which I've been sticking to all my life, regardless of the pain like I'll do my prayers for about 20, 25 min which I must sit down and do it to get up after I've sat down it's worse... but I'll still do it, I'll still do it the same position as I used to do because changing the pattern is only giving in, to me it's giving in so I will not change (S2; 55 year old woman).

## Discussion

The basic problem that emerged for patients with chronic pain was 'constraint' and the way this challenge was perceived and met formed the core category. The three principal types of constraint—body, activity and identity—were seen as indicators of a broader restriction: on leading a 'normal' life.

In the present study bodily constraint was considered fundamental. It affected people's relationship with their body and their environment, and led to constraints on activity (what people could do) and identity (what people could be). Activity and identity constraints are widely documented in the chronic pain literature (Gamsa 1994a, b; Henriksson, 1995a, b; Kerns et al., 1985; Johanssen et al., 1999; Osbourne & Smith, 1998), so will not be discussed in detail here. In contrast, the concept of 'bodily constraint',<sup>1</sup> has been largely neglected outside of philosophy and anthropology (e.g. Leder, 1990; Turner, 1992) and is perhaps best understood by drawing on the work of Leder.

In his book entitled *The Absent Body* Leder argues that the body is rarely the 'thematic object of experience' and is 'essentially characterised by absence' (Leder 1990, p. 1). He describes the normal orientation of the body as 'ecstatic' whereby action and perception are directed out from the body. As a result, Leder argues, the body is typically experienced as 'that *from which* I perceive and act' (p. 58; emphasis added).

The results of our study show that chronic pain challenged this outward orientation. The body became limited in its ability to act—speed of movement, spontaneous action, and the spaces that could be reached, became restricted. In addition, people's action and perceptual focus moved away from the external world towards the body: the body became a source of discomfort and something that had to be thought about. Consequently, the body became the object of action, rather than simply the means through which action was achieved, and these changes had profound effects.

Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at times of dysfunction, we then experience the body as the very absence of a desired of ordinary state, and as a force that stands opposed to the self. (Leder 1990, p. 4)

Leder's observation that the body can become a force opposed to the self resonates with the findings of the present study where people's main complaint was of 'not being able to do what they wanted to'.

<sup>1</sup>One exception is the research of Henriksson who describes 'limitation in motor performance' in their study of fibromyalgia.



The constraints outlined in the present study also relate to the distinctions discussed by Turner of ‘having a body’, ‘doing a body’, and ‘being a body’. ‘Having a body’ refers to the body when experienced or dealt with as an ‘object’; ‘doing a body’ describes the ‘normal’ orientation of the body, a body over which we have sovereign control; and ‘being a body’ describes the idea of body techniques—namely the body as a collection of practices over which we might have certain mastery. Pain disrupts the normal emphasis each of these has in people’s lives. ‘Having a body’ comes to dominate experience more. In contrast, both ‘doing a body’ and ‘being a body’ become compromised: sovereign control over the body becomes reduced as pain comes to dictate some of the actions people can take, and mastery over body techniques diminishes. The reduction in sovereign control over the body is evident in people’s descriptions of their pain. Previous research has noted that pain is often described as having ‘agency’, as taking over or ‘invading’ the body (Good 1992; Johansson et al., 1999), and in the present study the reduction in mastery over body techniques was reflected in people’s complaints that the pain prevented them from being able to do activities in the way they would like; hence, people complained that they could not walk like a ‘young person’ or swim to a high standard.

The constraint on leading a normal life was identified as the main problem of chronic pain because it formed a super-ordinate category (encompassing body, activity and identity constraints) and also because the ways in which normal standards were altered or maintained played a key role in differentiating people’s responses to the constraints of pain (see Fig. 2). In *assimilation* little change to normality was perceived. The constraints of pain were either minimal or dealt with by accepting support from others (who effectively absorbed these constraints by taking on the person’s responsibilities and roles) (see Fig. 2). In *accommodation*, activity and identity constraints were severe, but these constraints were accepted to some degree, and reduced through re-conceptualising what normal life was. The ‘reduction’ in activity and identity constraint illustrated in Fig. 2 is therefore more perceived than real, and the focus of people’s coping efforts centred on managing pain severity. In *confrontation* the constraints on activity and identity were severe, but attempts were made to maintain normal life by engaging in pre-pain activities and not accommodating the pain, leading to increased pain severity. In *subversion*, identity constraint was higher than activity constraint and greater effort was put into maintaining normal identities. While this style of coping often kept pain levels down, activities were often curtailed to a significant degree. The latter highlights the point that, while restricted activity is often the direct and unavoidable consequence of having severe pain, such as sciatica, restrictions in activity often reflect ways of coping with circumstances in which people feel stigmatised.

The four coping categories outlined here describe two modes of acceptance and two modes of resistance to the limitations of pain. Recent work on understanding adjustment to pain has drawn a similar distinction between ‘acceptance versus struggle’ (McCracken & Eccleston, 2003; Henriksson, 1995b), and a call has been made for research to move towards understanding how people may come to accept their pain, rather than fight against it (McCracken & Eccleston, 2003). As part of this agenda, Risdon, Eccleston, Crombez, and McCracken (2003) have outlined different methods of acceptance (e.g. accepting loss of self and acknowledging limitations), in order to understand the process of pain-acceptance. Facilitating this is clearly quite a challenge, but the present study may offer some pointers.

There are clear parallels between coping with the restrictions of pain and coping with the restrictions associated with ageing. Both people with pain and people who get old find themselves unable to do certain activities, and this parallel was explicit in the present study in people’s descriptions of feeling old as a result of their pain. Brandtstädter and Renner (1990), and Brandtstädter and Rothermund (1994) have suggested that coping with the restrictions brought about by ageing reflect a trait-like ability to be flexible in the face of constraints, and their model has been shown to fit chronic pain: flexibility in the face of obstacles has been shown to significantly attenuate the impact of pain (Schmitz, Saile, & Nilges, 1996). Future work in the area of understanding pain acceptance may benefit from fuller consideration of the literature on adjustment to ageing and developmental change.

The other issue that emerged was the role identity played in resistance to the constraints of pain. People whose identity rested primarily on performance and body techniques found it considerably harder to adjust to their pain, and such people often went to great lengths to protect their identity by limiting activities and avoiding situations where unwanted identities might emerge. The observation that the social self is presented through bodily performance is not new (e.g. Goffman, 1971) but performance and face-work have been under-emphasized in work on chronic pain, particularly in work aimed at understanding pain-adjustment. Research on understanding people’s relationship with their body might provide some clues as to how new identities which are still grounded in a relationship with the body might be developed.

#### Limitations of the study

This study was based on interviews with people attending an outpatient pain management clinic. A strength of sampling from such a clinic was the wide

range of lifestyle impact that was reported by interviewees, and included those with high levels of distress and disability as well as those with relatively little. However, it clearly omits those with pain who do not actively seek medical treatment for their pain and such a group may articulate different concerns.

## Summary

The present study illustrates that a central problem of chronic pain is constraint. This is revealed as much through the disruption of small-scale activities, such as reaching out for something, as through the disruption of larger-scale ones, such as going shopping. The small-scale changes often indicate a fundamental challenge to people's everyday reality, through altering taken-for-granted aspects of their world. There was a clear sense that the constraints of pain represented, for some, their first experience of exclusion from certain environments, from particular roles and hobbies, and also from a world where the body is largely 'absent' and enabling. However, not all those interviewed felt the pain had challenged their sense of normality. Whilst some people normalised these changes by conceptualising them within socially accepted life changes (such as growing older), others remained unable to accept the pain, and their coping efforts were focused either on maintaining pre-pain activities at the expense of increased pain, or on maintaining pre-pain identities at the expense of greater activity restriction. Research into coping with the constraints of pain needs to assess the role of goals such as identity management and body techniques in pain-related disability if we are to fully understand the ways in which people respond to chronic pain.

## Reference

- Brandtstädter, J., & Renner, G. (1990). Tenacious goal pursuit and flexible goal adjustment: explication and age-related analysis of assimilative and accommodative strategies of coping. *Psychology & Ageing*, 5, 58–67.
- Brandtstädter, J., & Rothermund, K. (1994). Self-percepts of control in middle and later adulthood: buffering losses by rescaling goals. *Psychology & Ageing*, 9, 265–273.
- Chalmers, A. F. (1982). *What is this thing called science?*. Milton Keynes: Open University Press.
- Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine*, 30, 1161–1172.
- Eccleston, C., Williams, A. C., & Rogers, W. S. (1997). Patients' and professionals' understandings of the causes of chronic pain: blame, responsibility and identity protection. *Social Science & Medicine*, 45, 699–709.
- Gamsa, A. (1994a). The role of psychological factors in chronic pain. I. *A half century of study. Pain*, 57, 5–15.
- Gamsa, A. (1994b). The role of psychological factors in chronic pain. II. A critical appraisal. *Pain*, 57, 17–29.
- Glaser, B. G. (1978). *Theoretical sensitivity: advances in the methodology of grounded theory*. California: Sociology Press.
- Goffman, E. (1971). *The presentation of self in everyday life*. London: Penguin books.
- Good, B. J. (1992). A body in pain—The making of a world of chronic pain. In M.-J. DelVecchio Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience: an anthropological perspective*. Berkeley: University of California Press (Chapter 2).
- Hallberg, L. R., & Carlsson, S. G. (2000). Coping with fibromyalgia. *A qualitative study. Scandinavian Journal of Caring Sciences*, 14, 29–36.
- Henriksson, C. M. (1995a). Living with continuous muscular pain—patient perspectives. Part I: Encounters and consequences. *Scandinavian Journal of Caring Sciences*, 9, 67–76.
- Henriksson, C. M. (1995b). Living with continuous muscular pain—patient perspectives. Part II: Strategies for daily life. *Scandinavian Journal of Caring Sciences*, 9, 77–86.
- Jackson, J. E. (1994). Chronic pain and the tension between the body as subject and object. In T. J. Csordas (Ed.), *Embodiment and experience: the existential ground of culture and self*. Cambridge: Cambridge University Press (Chapter 9).
- Jackson, J. E. (1992). After a while no one believes you: real and unreal pain. In M.-J. DelVecchio Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience: an anthropological perspective*. Berkeley: University of California Press (Chapter 6).
- Johansson, E. E., Hamberg, K., Westman, G., & Lindgren, G. (1999). The meanings of pain: an exploration of women's descriptions of symptoms. *Social Science & Medicine*, 48, 1791–1802.
- Kerns, R. D., Turk, D. C., & Rudy, T. E. (1985). The West Haven-Yale multidimensional pain inventory (WHYMPI). *Pain*, 23, 345–356.
- Kleinman, A., Brodwin, P. E., Good, B. J., & DelVecchio Good, M.-J. (1992). Pain as human experience: an introduction. In M.-J. DelVecchio Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience: an anthropological perspective*. Berkeley: University of California Press (Chapter 1).
- Leder, D. (1990). *The absent body*. Chicago: University of Chicago Press.
- Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science & Medicine*, 57, 1045–1054.
- McCracken, L. M., & Eccleston, C. (2003). Coping or acceptance: what to do about chronic pain? *Pain*, 105, 197–204.
- McPhillips-Tangum, C. A., Cherkin, D. C., Rhodes, L. A., & Markham, C. (1998). Reasons for repeated medical visits among patients with chronic back pain. *Journal of General Internal Medicine*, 13, 289–295.
- Morris, D. B. (1991). *The culture of pain*. California: University of California Press.
- Osbourne, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: an interpretative

- phenomenological analysis. *British Journal of Health Psychology*, 3, 65–83.
- Rhodes, L. A., McPhillips-Tangum, C. A., Markham, C., & Klenk, R. (1999). The power of the visible: the meaning of diagnostic tests in chronic back pain. *Social Science & Medicine*, 48, 1189–1203.
- Risdon, A., Eccleston, C., Crombez, G., & McCracken, L. (2003). How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Social Science & Medicine*, 56, 375–386.
- Schmitz, U., Saile, H., & Nilges, P. (1996). Coping with chronic pain: flexible goal adjustment as an interactive buffer against pain-related distress. *Pain*, 67, 41–51.
- Strauss, A. L. (1997). *Mirrors and masks: the search for identity*. Transaction Publishers: New Brunswick.
- Turner, B. S. (1992). *Regulating bodies: essays in medical sociology*. London: Routledge.