



Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain

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Abstract

Interpretative phenomenological analysis (IPA) is a qualitative approach which aims to provide detailed examinations of personal lived experience. It produces an account of lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions and it recognises that this is an interpretative endeavour as humans are sense-making organisms. It is explicitly idiographic in its commitment to examining the detailed experience of each case in turn, prior to the move to more general claims. IPA is a particularly useful methodology for examining topics which are complex, ambiguous and emotionally laden. Pain is a prime exemplar of such a phenomenon: elusive, involving complex psycho-somatic interactions and difficult to articulate. In addition to the 1998 article, published in this Special Issue, two further papers are suggested that the interested reader might wish to look out for.

Keywords

Back pain, chronic pain, pain, intractable, pain clinics, pain perception

It is 16 years since our article on the experience of pain first appeared in the *British Journal of Health Psychology*. We are delighted to see it reprinted here, taking this as an indication of its ongoing resonance. We wish to take the opportunity to say a little on how we think interpretative phenomenological analysis (IPA) can make a valuable contribution to research on pain.

IPA is a qualitative approach which aims to provide detailed examinations of personal lived experience (Smith et al.¹). It has three primary theoretical underpinnings. Phenomenology is a philosophical approach, initially articulated by Husserl, which aims to produce an account of lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions. IPA recognises that this is an interpretative endeavour because humans are sense-making organisms. In IPA, therefore, the researcher is trying to make sense of the participant trying to make sense of what is happening to them. Finally, IPA is idiographic in its commitment to examining the detailed experience of each case in turn, prior to the move to more general claims.

There is now a very large corpus of research studies applying IPA in psychology and also in cognate disciplines. Much of this research is on the patients' perspective on illness, and it includes a number of papers on the experience of pain. There are a number of reasons why IPA is a particularly useful methodology for examining pain. First, IPA is especially valuable when examining topics which are complex, ambiguous and emotionally laden. And pain is a prime exemplar of such a phenomenon: elusive, involving complex psycho-somatic interactions and difficult to articulate. IPA

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is helpful here because of the painstaking attention it gives to enabling the participant to recount as full an account as possible of their experience. This requires a high level of skill on the part of the interviewer – a combination of strong empathic engagement and highly attuned antennae ready to probe further into interesting and important aspects. The small sample size of most IPA studies then enables the micro-level reading of the participants' accounts, which offers the possibility of some entry into the understanding of this elusive condition. And the inquiry is sharpened by IPA's inductive, interpretive analysis, providing an illumination of what is presented but importantly grounding that firmly in a close examination of what the participant has said.

We offer here suggestions of two further papers the interested reader might wish to look out for. The article by us reprinted in this Special Issue acted as a reconnaissance of the terrain of the lived experience of pain. Something which particularly interested us was the impact of pain on identity which was beginning to emerge as a theme in that article. We therefore decided to explore this in more detail, and the resultant study appears in Smith and Osborn.² Analysing interviews with six adults with long-standing severe back pain, we detail the corrosive effect of the pain on participants' sense of identity. Patients present pejorative descriptions of their current self: 'miserable git, cow, this monster' and contrast this *tainted self* with a *truer self* from the past. The article focuses on the dynamic interplay between these different self-perceptions.

A second article exemplifies the ability of a good IPA study to access and illuminate a difficult or sensitive subject. Marriott and Thompson³ interviewed eight women who had vulval pain. A key consequence of this

condition for the women lies in its impact on their sexuality and relationships. As part of this, the women judge themselves as failing in their role as a loving partner. The article is a well crafted, careful and intimate account of how the women's lives are affected by the vulval pain.

For the future, we hope to see more IPA work on the lived experience of pain because, as we have suggested, we see a close fit between what the methodology can offer and some of the issues that warrant further examination.

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3. Marriott C and Thompson AR. Managing threats to femininity: personal and interpersonal experience of living with vulval pain. *Psychol Health* 2008; 23: 243–258.

Useful links

IPA at Birkbeck homepage: <http://www.bbk.ac.uk/psychology/ipa>

Main IPA website: <http://www.ipa.bbk.ac.uk>

The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis

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Objectives. Chronic low back pain is a major health problem and one where pain, physical impairment and biological pathology are only very loosely correlated). It is considered that the experience of pain, its distress and disability is mediated by its meaning to the sufferer. The intention of this study was to explore the sufferers' personal experience of their pain.

Design. Qualitative research is often recommended to complement the quantitative work on chronic pain that has been published to date. Interpretative phenomenological analysis was employed in an in-depth study of a small sample of chronic pain patients.

Method. Semi-structured interviews were carried out with nine women pain patients. The verbatim transcripts of those interviews served as the data for an interpretative phenomenological analysis.

Results. Four themes emerged which are described under the broad headings: searching for an explanation; comparing this self with other selves; not being believed; and withdrawing from others.

Conclusions. The participants shared an inability to explain the persistent presence of their pain or to reconstruct any contemporary self-regard. While they used social comparisons to try and help them make sense of their situation, these comparisons proved equivocal in their outcome. Participants were unable to establish the legitimacy of the chronic nature of their pain and in certain situations felt obliged to appear ill to conform to the expectations of others. By default, participants treated their own pain as a stigma and tended to withdraw from social contact. They felt confused, afraid for their future and vulnerable to shame.

Chronic lower back pain is a major health problem and produces a demand on the medical health services which cannot be satisfied as 85 per cent of cases are not amenable to a diagnosis requiring the attention of a medical consultant (Clabber Moffat, Richardson,

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Sheldon & Maynard, 1995). Rather, in chronic lower back pain, psychological factors are of prime importance in the determination of a patient's disability (Waddell, 1987).

Bonica (1974) described chronic pain as exclusively 'malefic', as he felt it was powerfully destructive of the physical and psychological well-being of individual, family and associates and had no redeeming features. However, there is a considerable variability in the individual response to chronic pain according to its context and meaning to the sufferer (Hanson & Gerber, 1990; Holzman & Turk, 1986; Turk & Flor, 1984). The challenge is to understand the relationship between pain, distress and disability, which is neither linear nor causal, but dynamic and multidimensional (Waddell, 1987).

Behavioural approaches view chronic pain in two ways. Firstly, it is suggested that it can arise as the result of secondary muscular hypertension induced by a fear of pain, causing muscle spasm, ischaemia and exaggerated pain perception (Flor, Turk & Birbaumer, 1985). Secondly, it is seen as a behaviour maintained by secondary gain, where external reinforcement contingencies prompt the development and maintenance of a chronic problem (Fordyce, 1976).

According to cognitive theorists, distorted evaluations of the sensation of pain are considered to lead to feelings of hopelessness, low self-efficacy, and a lack of control and turn an acute problem into a chronic one (Härkäpää, Järvikoski & Vakkari, 1996; Holzman & Turk, 1986; Keefe, Dunsmore & Burnett, 1992; Turk & Flor, 1984; Turk & Rudy, 1992). Lefebvre (1981) found that the cognitive distortions of chronic low back pain patients were similar to those of clinically depressed patients. Catastrophization, frustration, pessimism, self-criticism and pain preoccupation have each been associated with distress in the sufferer.

Pain-specific beliefs are also important. The fear-avoidance of pain (Slade, Troup, Lethem & Bentley, 1983) is rooted in the incorrect assumption that the sensation of chronic pain signals the presence of an ongoing disease process and damage (Riley, Ahern & Follick, 1988) and dictates the need to rest. Rest is contraindicated in chronic pain and fear-avoidance has been shown to be predictive of the development of a chronic pain career (Waddell, Newton, Henderson, Somerville & Main, 1993).

Studies directed explicitly at exploring the personal meaning of chronic pain are rare in the psychology literature, although such an approach is consistent with the social cognition paradigm in clinical health psychology (Skevington, 1995; Taylor, 1983). Hubner (1984), in his clinical observations, placed pain at the heart of the individual's experience of their lives:

Pain had posed the ultimate question of meaning; that is, dominated by pain, and distracted by nothing, what did these patients live for? What gave their lives meaning? (p. 446).

Hubner considered that pain challenged the sufferers' meanings about their life and in so doing isolated them from those around them. To be in pain, involved 'being separated, being alone. At no time are we more alone than when we are in the grip of pain' (p. 447).

LeShan (1964) worked with patients in severe pain of long duration and he described the relationship between chronic pain and meaning as problematic. He felt their chronic pain was typified by 'utter senselessness' and 'meaningless'. The attempt to gain control and understanding of what is senseless prompted LeShan to compare chronic pain with a nightmare, its only adequate expression—a scream.

The impact of a chronic disabling condition such as pain on the individual, is described by Bury (1982) as a 'biographical disruption'. Here, the chronic illness calls into question both the sufferer's past and future, and requires him or her to rethink each one. Williams (1984) also argued along similar lines that chronic illness could prompt a 'narrative reconstruction'. In the absence of other facts, this draws on the individual's lay beliefs to account for the onset of their illness but again demands that they reconfigure their biography, past and present. More recent studies emphasize the impact of chronic illness on the sufferer's self-concept and the contrast within that between private sense of self and public social identity (e.g. Kelly, 1992; Yoshida, 1993).

Empirical research to date has clarified and classified the chronic pain phenomenon (Turk & Flor, 1984; Jamison, Rudy, Penzien & Mosley, 1994; Jensen, Turner, Romano & Lawler, 1994). However, although in each case the researchers have identified important constructs and patient profiles that are characteristic of chronic pain, they have been unable to address how or why such behaviours and beliefs are formed or maintained. Further research is often recommended in order to gain a greater awareness of the personal meaning of pain to the sufferer (Craig, 1984; Holzman & Turk, 1986). Leventhal (1993) considered the need for meaning to be given a central focus in the study of pain because:

It has long been clear that the meaning given a somatic (pain) experience will play a crucial role in the activation of the emotional-motivational component of the pain system (p. 142).

Pain is now both defined and recognized as a subjective experience and this has had important implications in its study enabling a greater focus to be directed towards phenomenological and contextual influences (Anand & Craig, 1996; Encandela, 1993). Despite such recommendations, the number of published empirical studies on the personal meaning of pain is limited, and research is most often to be found within the medical sociology literature (e.g. Baszanger, 1992; Bendelow & Williams, 1995; Bury, 1988). This study is concerned with and aims to explore explicitly the psychological processes which determine and maintain the dynamic relationship between the participants' chronic pain, distress and disability. It therefore adopts a phenomenological, 'insider's perspective' (Conrad, 1987). At the same time the paper is neither a first-hand personal account nor a second-hand clinical case report. The specific methodological approach adopted is interpretative phenomenological analysis (IPA) (Smith, 1996a). IPA is committed to understanding and foregrounding the patient's perspective but recognizes that this is only possible through the interpretative analytic work of the investigator. The published report can therefore be considered as a co-construction between participant and analyst in that it emerges from the analyst's engagement with the data in the form of the participant's account. IPA is an idiographic qualitative methodology which involves the analysis of verbatim transcript derived from in-depth semi-structured interviews with participants (Smith, 1995). If the meaning of pain to the patient is to be fully explored then we would argue such an intensive qualitative approach is required.

Method

The data set for this study consists of transcribed semi-structured interviews with nine women who attend a hospital out-patient back pain clinic.

Each participant attended the clinic following a referral from her general practitioner and was considered on assessment to have chronic back pain with no treatable organic pathology but with excessive distress and

disability. Their pain behaviours and symptoms and signs were 'inappropriate' according to the criteria described by Waddell & Main (1984) and were recognized to be an index of their distress (Waddell, 1987). They are part of a particular group of chronic pain patients who report high scores of distress and disability with little peripheral organic pathology.

The participants' names along with other identifying information have been changed to preserve their anonymity and guarantee confidentiality. Their ages ranged between 25 and 55 years and in each case they had endured their pain for at least five years.

The semi-structured interview procedure followed that described by Smith (1995). It involved the construction of an interview schedule—outlining the areas of interest to be discussed during the interview. However the schedule is not intended to be prescriptive—it acts as a guide for the interview but does not dictate its exact course. During the interview, questions are adapted to the specific context and interesting issues which arise are probed. The aim is to facilitate the participant telling her own pain story, not to check the investigator's preconceptions of pain. The verbatim transcripts of the interviews served as the raw data to be analysed using an interpretative phenomenological method described below (Smith, 1995). Participants were not regarded as exemplars of the 'chronic pain patient' or expected to speak explicitly for their peers but rather to provide specific instantiations of the psychological experience of chronic pain.

The analytic process proceeded as follows:

1. Interview transcripts were read, and reread a number of times, to ensure a general sense was obtained of the whole nature of the participant's accounts. During this stage notes were made of potential themes and the process was informed by the researcher's experience of the interview itself.
2. Returning to the beginning, the text was reread and any emergent themes identified and organized tentatively.
3. Attention was then focused on the themes themselves to define them in more detail and establish their interrelationships. The focus was on the psychological content of the phenomenon under study and the data were now being condensed.
4. The shared themes were organized to make consistent and meaningful statements which contributed to an account of the meaning and essence of the participants' experience grounded in their own words.

Thus the analysis which follows is organized around themes which emerged from the transcripts, rather than constructs predicted in advance. Consonant with the phenomenological approach these themes are then considered in relation to the extant literature in the Discussion section.

Validity

Validity, and the exercise of sufficient rigour to establish the credibility of qualitative study is considered to be no less essential than in any other form of research but it is important that the criteria by which it is judged are appropriate as qualitative inquiry has different epistemological roots to quantitative methodology (Smith, Harré & Van Langenhove, 1995a, b). A number of authors have attempted to explicate alternative ways in which the validity of qualitative research can be assessed (Conrad, 1990; Lincoln & Guba, 1985; Smith, 1996b; Stiles, 1993). Conrad (1990) makes a distinction between the assumptions of qualitative and quantitative research in regard to generalizability suggesting that when considering a qualitative study, rather than looking at sample size, statistical power or participant selection the work should be measured by the applicability of the concepts. For example, how would the concept of 'uncertainty', which is referred to in this study help articulate aspects of the chronic pain experience in other situations.

Smith (1996b) suggested several criteria to assess the internal validity and reliability of qualitative research. Two important ones are: internal coherence and the presentation of evidence. Internal coherence refers to the need to concentrate on whether the argument presented in the study is internally consistent and justified by the data. In addition Smith proposes that sufficient verbatim evidence from the participants should be presented in the paper to allow the reader to interrogate the interpretation.

As a check on the analysis, the first three transcripts were looked at independently by the second author. After this the two authors discussed their readings of these interviews and came to an agreement on the theme categories before analysis proceeded onto the subsequent transcripts. At every stage of the project the second author acted as a check on the emergent analytic account.

It is important to note that these procedures—both on the part of the analysts and of the paper's readers—are not intended to produce a single definitive reading: e.g. the two investigators were not aiming to produce

a satisfactory inter-rater reliability score but rather to verify that the particular analysis presented has been systematically achieved and is supported by the data. Thus the aim of validity checks on qualitative work is to ensure that the particular account presented is a sound one warrantable from the data, not to prescribe the singular true account of the material.

Analysis

This section presents the four superordinate themes that emerged from the analysis, which were: searching for an explanation, comparing this self with other selves, not being believed and withdrawing from others.

The first theme, 'searching for an explanation', sets the scene for those which follow as it articulates the participants' attempts to understand what is happening to them and is a prerequisite for the subsequent self-reflection. Because such questioning recurs throughout the analysis, it is only presented briefly at the outset.

Searching for an explanation

Participants were not asked specific, closed questions but simply to describe their pain and the various ways it had affected them. They showed a strong motivation to understand and explain their situation, to know 'why?':

I just keep asking myself why the pain is there and I haven't got an answer. I don't know how I should feel really it's just that I don't think it should be there why should I have it? I would have thought that after all this time it should have eased up and gone away but it hasn't (Linda).

Participants regularly stated they simply could not 'believe' that nothing more could be done to relieve their pain. There was a marked contrast between their preoccupation with their pain and their inability to account for its chronic presence. Despite their long history of pain and extensive contact with the health service they neither felt informed about their condition, nor able to influence it. Their pain was often felt to act of its own volition. 'It just comes and goes when it wants really (Alice)'.

Linda's account of her situation suggested that despite wanting to understand why she had chronic pain, she could not; to her it was 'unbelievable really'. This was not a simple account of ignorance but a profound state of bewilderment as she failed consistently to understand why she should be suffering. As the best efforts of others had failed, she felt she could only blame herself:

I'm sort of mad at myself I start banging things and getting so aerated with myself that it's there and I can't get it to go away.

Becky also had no answer as to why her pain remained, except to imagine the presence of physical damage or deterioration:

Well I always thought you had pain to tell you when there was something wrong.

Participants could not explain the persistence of their pain in any manner which was meaningful to them beyond the notion that 'there was something wrong', something biomedical which demanded attention. Their disbelief and bewilderment prompted frustration, anger and, in Becky's case, despair:

But I don't know why you have to keep suffering it and suffering it and suffering it for ever and ever.

Each participant rejected the judgment that the pain was 'unreal' but could not explain its reality in a manner that was meaningful to her. Their accounts revealed their attempts to cope with their pain despite a profound lack of either understanding or information. This uncertainty and ambiguity pervades their experience and will continue to appear as an important factor in each of the following three sections.

Comparing this self with other selves

As participants described their pain, they compared themselves with other people and with themselves both in the past and projected into the future. This creative process of comparison captured the pernicious impact of their pain. One participant, Linda, appeared to reach out to what she saw and, by comparing her present situation with selected events she had witnessed, used those comparisons as benchmarks:

I'm only 50 and I should be doing this that and the other cos they say life begins at 40 but I can't and I s'pose it does bother me, it's frustrating that people of my own age are you can see them flying their kite and you feel as if you can't.

Linda could not do the things she felt she 'should' be able to do like other women of her age who were active and enjoying life. Her comparison was not just of reduced mobility but of the denial of pleasure in activity. Others her age could enjoy their life and celebrate it free from pain, 'you can see them flying their kite', and this emphasized her feelings of loss. In one passage, Linda recalls a description of her pain-free self, set amidst her immediate family:

I just think I'm the fittest because there are 3 girls and I'm the middle one and I thought well I'm the fittest and I used to work like a horse and I thought I was the strongest and then all of a sudden it's just been cut down and I can't do half of what I used to do.

Linda's description of her loss was exacerbated by the recall of an idealized past where she was not only fit, but the 'fittest', and worked not just hard, but 'like a horse'. As she anticipated the future, Linda was afraid that she could only worsen progressively. She could not predict her future and emphasized her pessimism by her comparisons with two people, her mother and a school friend, who both died in distressing circumstances. She admitted that neither of them had chronic pain but could not guarantee that she would not share their fate:

She was a school mate and she was 15 month older than me and it was last year she started, I don't know what she died of she was getting these aches and pains I just don't want it to be any worse as I don't want to be pushed round in a wheel chair.

The same uncertainty described earlier is what leads Linda to have such a gloomy perception of a possible future. Gail also described her situation as one where continual pain had eroded her mobility but responded differently to the comparisons she made with others:

When I see all of my friends, I saw one running for the bus the other day I thought Oh my God it's ages since I had a good run or a good walk, you know. So for about 5 minutes I felt sorry for myself, and then I saw somebody else in a wheelchair so you know, I'm not quite as bad as that.

Through comparison, participants often ranked themselves against others and this served to highlight their loss or disability. Linda felt demoted within her family whilst, for Gail, although she felt better off than someone in a wheelchair she became embarrassed when considered alongside her 81-year-old mother-in-law:

You think oh well can I make it over there or shall I say no we'll leave it for another day. I feel so stupid especially when my mother-in-law is 81 and she's trotting about and I am hobbling.

Other participants related similar comparisons. Their social order had been disturbed and in attempting to re-establish their personal status, participants, like Gail, often took refuge in thinking of those in a worse situation than themselves:

I try to tell myself I'm luckier than a lot of people, you know I haven't got cancer (Ruth).

However, the use of others as an aid to resisting the sense of decline and loss that pain provided was equivocal and in some cases detrimental, serving only to exacerbate and define their distress. Participants' uncertainty in their prognosis handicapped any compensation that a 'worse world' offered. When Linda witnessed those more disabled than her she felt she may be looking at herself in the future. 'I just don't want it to be any worse as I don't want to be pushed round in a wheel chair'. Dottie also admitted that, although she looked at others in a worse position it could not compensate for her own sense of deterioration and only increased her fear for the future:

I've done heaps more things than other people have done so I think well, I would, you always think well there's loads of people far worse off than you you know so you try to think of other people who are permanently in wheelchairs, and it's supposed to make you feel better which in a way it does but basically its frightening.

This comparison with others who were more unfortunate was intended or considered as a strategy for enhancing self-esteem but often turned into a reinforcer of despair. Chronic pain promoted distress in each participant when they recalled how they were before it began and a sense of grief pervaded their accounts. Although a few took pride in their ability to cope, they often defined themselves as bereaved.

Nelly believed she had lost everything, her comparisons were global and catastrophic, whilst Mary-Ann was more operational and explicit about the change she had experienced and revealed how her pain frustrated her personally:

It's stopped everything, it's stopped my life completely (Nelly).

I can't do what I used to do I'm not one for staying in house if I can get away with it I go out I don't like stopping in house (Mary-Ann).

As we have already seen with Linda, when participants reflected on their situation they often recalled a better time, a nostalgic time associated with a better sense of self. Memories were recalled to help maintain some morale in the present:

When you don't feel you have a future, you live in the past. (Rachael).

Participants often referred to a past where they were as they had always wished to be, fit, active, able to stay slim, interesting, and sociable. Alice grieved for her personality; she wanted to be the 'old Alice', the Alice who could exercise regularly to keep her weight

down, do and eat what she liked, and feel confident and happy:

Well my personality's gone, I used to be right bubbly and lively and you know, but it's, that's gone, and even my mum says that I've changed, she never really says in what way, she says I've got more snappy and more nasty. You want the old Alice back but you can't.

The nostalgic recall of the past provided some comfort but was again a comparison that proved to be equivocal. The idealized accounts of the past served as a painful index of what had been lost, and what now had to be endured on a daily basis, rather than as a haven of reassurance and source of self-regard. The strength of their loss was accentuated by the fact that the past-self was often considered to represent the real self, replaced irrevocably by a new false persona:

You feel like just not particularly giving up but *you don't feel the person that you are* [author's emphasis] that you're capable of feeling or capable of doing basically. It makes you feel a bit down and a bit miserable (Dottie).

'The person that you are' is the person Dottie was in the past, the person without pain. Through their selective use of social and personal comparison participants highlighted the impact of their pain on their self-regard and the equivocal nature of their attempts to cope with its imposition. Pain denied them the chance to be who they once were and preferred still to be. Their contemporary self-regard contrasted with a nostalgic recall of their past and those around them, and their comparisons served almost inevitably as an index of their sense of threat and loss. Attempts to buttress self-esteem by comparison with those more unfortunate often proved counterproductive and served only to remind participants of their own gloomy prognosis.

Not being believed

Apart from their behaviour, the participants' condition revealed no visible signs that would give credence to any of their claims to suffering or disability. The participants, who themselves endured a profound sense of uncertainty regarding the aetiology or legitimacy of their pain, felt vulnerable to the judgments of those around them:

It's like anger building up in you. It's like if you're talking to people you're forever, its as though you've got to try and convince them that there's something wrong with you, that get's you down (Alice).

The participants felt a continual need to justify their pain as 'real', that is not in any way psychogenic which was synonymous with 'mad or bad':

It's quite embarrassing because its not something that you can see and I do feel guilty, I know that my back really does hurt and I'm not making it up and I feel sort of angry that I can't do it and I think well I wish I could just prove to them that my back really is bad and that I really must not do it, because if I do I put myself back weeks (Dottie).

In the absence of any recognition that their pain could persist, participants were by default required to be defensive about their condition, but were unable to make use of any credible explanatory story and as a consequence were often frustrated:

You feel as though no-one believes you, unless people who have got bad backs, it's only them who'd believe you (Alice).

Pain had caused a shift in the participants' social roles and relationships and denied them the opportunity to be the kind of daughter, grandmother, or lover that they, or others, might wish them to be. Ruth and Gail were well aware of the potential problems of being misunderstood by their lovers and parents:

I mean you don't look ill, you're not flat on your back, so you know, is it an excuse, oh I've got a headache, do you know what I mean [not to have sex with her husband] (Ruth).¹

She [mother-in-law] wanted her house decorating the other week. I said I can't even do my own and I feel guilty that she's going to have to pay somebody to do it (Gail).

Each participant's account exposed her awareness of the threat of rejection, not just because she was a burden and unproductive but because she might be disbelieved. In Gail's case, the lack of credible evidence prompted a feeling of guilt that others suffered too.

Mary-Ann was concerned with being judged as 'useless' because she could not look after her family. This was a judgment she endorsed herself as, in common with Nelly and other participants, she felt uncomfortable at being the recipient of care, unable to reciprocate:

I know I am ill, but I think well why should I have to put that on to somebody else's shoulders I don't want people to look after me and I know they love me but I don't want it. It's degrading (Nelly).

The difficulties of feeling believed had a paradoxical effect on the behaviour of participants as a healthy appearance was considered by those around them to be incompatible with any claims of chronic pain, suffering or disability:

If I went round with no make-up and bags hanging down my face or something and just look really badly they'd probably think well yes, but you can't see pain so they don't know do they so they automatically assume that there's nowt wrong with you (Alice).

Appearing healthy or mobile whilst remaining in pain was problematic and participants felt obliged to appear ill and disabled to satisfy the requirements of others. Unfortunately, appearing ill left them feeling equally as prey to the consequences of pity and condemnation. Pity to Nelly was a stigma. It degraded her, challenged her place in her social world and was incompatible with how she wanted to view herself, or be seen by others:

I just want to say 'hello', you know, 'how are you' and I go 'alright thanks'. Not look at me as though I'm a cripple. I'm not a cripple.

The ambiguity of pain behaviour and the lack of understanding in others left the participants feeling vulnerable to being misjudged or rejected. The suspicion they felt they were under often drove them to appear more in pain than they needed to and in each case they felt their pain denied them the opportunity to relate to others free of its influence.

Withdrawing from others

Rather than endure their chronic pain and continue to meet the demands of their social

¹ Any text held within brackets represents clarificatory information supplied by the authors from the wider transcript to assist the reader.

world, the participants tended to withdraw from public view:

I just want to be on my own. I can't stand anybody, I'm mardy and I'm mardy with everyone else. You know what I mean. I'd rather just take off upstairs (Mary-Ann).

They felt a burden to other people and there appeared to be no agreed way of relating to others that they could employ. It was easier for them to conceal their condition than to rely on the understanding of others. For Gail, rather than explain that it was her pain that caused her to avoid social events, she found it easier to lie and risk appearing unsociable:

If anyone asks me if I am going anywhere, come on, no. Rather than tell them why [the discomfort of pain] I just say I can't be bothered they probably think I'm a bit of a misery it's better than going out with them and spoiling their fun.

Misery and being boring with little to talk about except pain was felt by the participants to be unacceptable in company and they withdrew from social contact to avoid the potential for any embarrassment or rejection:

But I mean we just don't go, we won't go anywhere now because of that I get too embarrassed and I just hate being in company and you always get onto that subject [pain]. And if you're out for social evening the last thing people want to hear is what your misery is, so I just, that's why we don't go out that often (Becky).

There was a tension between the participants' need to withdraw from other people and their fear that this would leave them isolated or abandoned. They felt their relationships were at risk and were aware of the limits of others' compassion. Ruth admitted how before her pain she used to avoid anyone who appeared unwell as she could not tolerate their misery, and she now hides her own distress so as not to prompt others to reject her:

I've been around poorly people all my life and I think I get a little bit naffed off myself and I cross the road cos I've thought, oh gosh, I can't stand Mrs so and so today and she may be a really poorly woman, this is why I don't want to burden anybody else because they must feel just the same as I do.

When in public, Linda not only felt easily irritable but also conspicuous and now preferred not to go out. Her social world could not accommodate people who had chronic pain and required supportive chairs or who needed to move constantly or lie down if necessary. Her disability was in part mediated by social acceptability and appearances:

I didn't even go out Christmas or New Year because I knew what it would be like, there'd be no sitting down because it would be all packed and there's no way I'd like to stand up and if there were a seat I'd have to get back up so I can't remember the last time we went out.

Participants felt that when in public they could neither afford to show their distress, nor appear healthy and mobile. Their social world which, prior to their pain, they recalled nostalgically was now transformed from a sanctuary and supportive network to something aversive and threatening. Regard and respect had been replaced by a perception of disgust or pity. Participants felt trapped, unable to secure the understanding of others and retreated to the safety of their own company, effectively cutting themselves off from any benefit of social support.

Discussion

Searching for an explanation

Participants were preoccupied with their pain, but despite frequent contact with the health services they remained confused. They were convinced that something biomedical was wrong with them, could not understand why their pain should persist and reported despair that no one appeared to be doing anything medical to help them, 'there must be something wrong but nobody seems to want to help' (Becky).

Uncertainty is an important experience in chronic health conditions and a key factor in its related distress (Härkäpää *et al.*, 1996; Radley, 1994) and the degree of information that is available to the chronically ill to assist them in their understanding is often sparse (Bury, 1991; Locker, 1991). Uncertainty has been shown to correlate with distress, helplessness and reported pain intensity (Idler, 1993; Jensen, Turner, Romano & Karoly, 1991; Williams & Thorn, 1989) particularly if it is believed to be due to chance, to endure with no relief or to be mysterious in origin.

The participants in this study actively sought to make sense of their experience but failed consistently to relieve their feelings of uncertainty and confusion. According to one form of attribution theory, seeking an explanation which establishes a cause is a typical response to such uncertainty (Brewin, 1988). No one particular attributional style has been linked to distress in pain and chronic illness (Radley, 1994) and for the participants their frustration and hopelessness appeared not to be consequent upon a discrete attributional category but to follow from their more fundamental inability to attribute any cause at all. Brewin (1988) concluded that 'explanation is almost certain to be an integral part of any reaction to adversity' (p. 108), and for those in benign chronic pain it appears especially difficult to establish any form of useful explanation.

In the absence of facts they can understand, patients with chronic illness often use whatever 'common-sense' concepts they have to hand and construct their own meaning and representations of their illness (Leventhal & Diefenbach, 1991). Holzman & Turk (1986) recognized this process in their chronic pain patients:

Patients will behave during illness in ways that are consistent with the conceptualizations they hold about their symptoms ... When information is ambiguous they rely on general attitudes and beliefs based on prior learning. These beliefs determine the meaning and significance of the problem (p.5).

The participants in this study were grossly dissatisfied with their understanding of their illness and exposed the inadequacy of their own, primarily medicalized, illness representations. There was a contrast between the reality of their chronic pain and their lack of any useful framework to explain its chronic nature.

The participants' frustrations highlighted the dominance and essential weakness of the application of a purely biomedical model in their attempts to conceptualize their situation. Such medicalization of our understanding of our bodies is referred to extensively in the medical sociology literature (Bendelow & Williams, 1995; Frank, 1990) and is shown in this study to be a major impediment to the participants' endeavours to understand and accommodate to their pain. To date their efforts to understand the ambiguity and uncertainties of their pain had had only punitive and disabling psychological and social consequences. Without an explanation they could understand, they could not establish any basis for taking therapeutic action, retain a sense

of control, or establish and defend the credibility and legitimacy of their illness or themselves.

Comparing this self with other selves

Participants evaluated their situation by using comparisons with themselves and others in the past, present and future. This revealed their sense of loss and threat, and the debilitating impact of their experience on their self-concept. Their pain had imposed change and denied them the opportunity to be who they once were and wished still to be. Any contemporary self-regard was poor and stood in contrast to a nostalgic recall of a past when they described themselves at their very best, in an idealized form.

As part of coming to terms with and accommodating to the demands of their chronic pain, it has been argued that an individual must interpret and repair the disruption such pain causes in such a way that it makes sense in the context of their life story (Bury, 1988; Williams, 1984). The participants showed, through their comparisons and descriptions, only partial fragments of such a reparation and despite lengthy pain careers remained preoccupied with a sense of confusion, loss and threat. Their accounts were similar to those related by Charmaz (1983) who described how the chronically sick suffered in a constant struggle to lead valued lives and maintain definitions of the self which were positive and worthwhile:

A fundamental form of suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones (p.168).

The need to reconstruct or reshape a self-concept in the face of the impact of a chronic illness has emerged as a theme in many recent studies on a wide range of chronic conditions. For example, Kelly (1992) and Yoshida (1993) worked with patients enduring radical surgery, and spinal cord injury and each emphasized the problematic nature of the contrasting impact of the condition on the individual's private self and public identity. For the participants in this study, any positive self-image had faded to become the stuff of nostalgia. They retreated into their past to maintain some self-regard in the face of their experience of chronic pain. However, the focus on an idealized past only appeared to amplify their sense of loss.

Comparison with others is considered to be instrumental in the formation of attitudes (Festinger, 1954) and utilized to cope with uncertainty and anxiety when information is limited, as in the case of chronic illness (Molleman, Pruyn & Van Knippenberg, 1986). Festinger's theory suggests that people need to have stable appraisals of themselves and that in the absence of more objective measures will resort to social comparison.

Studies have suggested that downward comparisons with those considered to be worse off or with an imagined 'worse world', can promote positive affect and well-being in individuals under stressful conditions by enabling them to resist the erosion of their self-regard (e.g. DeVellis *et al.*, 1990; Taylor & Lobel, 1989). However, other studies such as those by Buunck, Collins, Taylor, Van Yperen & Dakof (1990) and Hemphill & Lehman (1991) have suggested that the relationship is neither strong nor direct and that the comparison with those in a 'worse world' can also promote negative affect under certain conditions. The downward comparison with 'worse worlds' has been identified as problematic in a number of chronically ill populations (Affleck, Tennen, Pfeiffer & Fifield,

1988; Blalock, Afifi, DeVellis, Holt & DeVellis, 1990). Jensen & Karoly (1992) showed that comparative evaluation was really only effective in those with short pain careers and of little use in long-term chronic pain. The anxiety inherent in the physical condition itself has also been shown to play an important mediating role (Vanderzee, Buunk & Sanderman, 1995).

The participants' comparisons stood in contrast to the argument that views them solely as a beneficent coping strategy. They found no sanctuary in being better off than those who were in a wheel-chair or dying of cancer and were often more frightened as a result. Their uncertainty denied them any guarantee that their own condition would not deteriorate and that one day they might not inhabit the 'worse world' already inhabited by others they compared themselves with.

The participants employed a wide variety of comparisons with themselves in other situations and with other people around them in their attempts to describe and evaluate their situation. They compared themselves downwards with 'worse worlds' and upwards with better ones interchangeably and no one form appeared to serve a single discrete function. To be understood, each comparison needed to be seen in its personal context and it was in their complex network of comparisons that the individuals' sense of their situation was revealed. Overall, comparison was an equivocal coping strategy and served best as an index of the participants' attempts to manage their distress and uncertainty and helped to reveal the personal meaning of their chronic pain.

Not being believed

To the participants, the awareness and understanding other people had of their chronic pain was poor, and being believed and judged appropriately could not be guaranteed. Having pain regarded as 'real' is a major cause of concern for those taking time off work (Pinder, 1995; Tarasak & Eakin, 1995) and the need for 'legitimation' is considered by Bury (1991) as necessary to:

re-establish credibility in the face of the assault on self-hood, personal integrity and threat to social status (p.456).

Bury (1988) emphasized the lack of any social stability for the chronically ill as each of their relationships is put at risk; 'relationships do not guarantee particular responses' (p.92). Although stability could be re-established, to the sufferers it often felt precarious at best.

In common with the experiences of people with chronic illness related by Radley (1994), the participants endeavoured to continue to live in their social world of healthy people, often appearing and trying to appear healthy themselves, but failing habitually to live up to the expectations and responsibilities implicit in that world. As a consequence they were often both self-critical and defensive. Unable, in their uncertainty, to justify to others or themselves why they should remain in pain, they felt vulnerable to shame and disapprobation.

Pain behaviour has been described as a form of attention seeking maintained by secondary gain (Fordyce 1976; Heaton, Getto, Lehman, Fordyce, Brauer & Groban, 1984). The participants in this study seemed to feel obliged to appear ill as any appearance of good health was considered by others as evidence of unreal, invalid pain or malingering. Rather than seeking attention, participants appeared to be both deflecting any potential criticism and conforming to the expectations of others in relation to the identity of those who claim to have pain. No reward or understanding was felt by those who whilst remaining in pain, attempted to improve their health, appearance or

mobility. There was an ongoing tension between their private experience of their bodies, and their social identity. Kelly & Field (1996) maintained that this tension is at the core of the everyday and distressing experience of chronic illness. For the participants in this study the invisibility and day-to-day variability of their chronic pain left their apparent public–social identity, to some extent, unchanged whereas the restrictions and intense unpleasantness of their body had eroded radically their personal sense of self. As a consequence, overt and visible distress and disability was often the only currency available to them to establish the legitimacy and 'reality' of their pain to others, but this only compounded the erosion of their self-regard.

Withdrawing from others

To the participants, their chronic pain was problematic as it was an invisible and private experience but had profound social consequences, some of which have been outlined in the previous section. They were required to reconcile the restrictions of their pain with the demands of their social network, and more often than not this resulted in their withdrawal from social contact. Their accounts showed how the utility of social contact and comparison for self-affirmation and support was negated by their fear of misunderstanding and rejection.

The tendency to seek out others for support when under stress has been shown to decrease under certain conditions (Buunk & Hoorens, 1992). Charmaz (1983) also described how feeling discredited by others and unable to reciprocate social support or fulfil the obligations implicit in past role relationships are important factors in the suffering and consequent social withdrawal related to chronic illness.

In common with the experience of sufferers of rheumatoid arthritis (Bury, 1988) the participants in this study felt their pain affected their relationships with those around them. They had no 'role prescription' in their social network to guide their social interaction. They were unable both to perform ordinary activities in socially appropriate ways and to explain why they could not, and found it easier to be alone. In a study on a similar sample of patients with benign pain, Rose (1994) identified a four-stage process through which the participants in the study, proceeded as they accommodated to their pain. Similar to those in this study, participants had found it hard to make sense of their condition and in their failure to do so had developed a strong sense of emotional and social isolation, loneliness and alienation. They had found it hard to exist in their social world, and safer to retreat from it, returning only after having reestablished some form of self-regard. In each case once they had re-entered their world, it was in a different place to that occupied during their previous, pain-free life-style.

The accounts of the participants in this study highlighted how their experience of chronic pain was closely linked to a sense of stigma, shame and apologism. Chronic pain left them anticipating and fearing misunderstanding and rejection and while the lack of social contact was mourned, the personal costs associated with engagement with others meant that they preferred to withdraw from that social world.

Conclusions and general discussion

Mainstream empirical research highlights the 'puzzle of pain' and the lack of concordance

between pain sensation, disability and organic peripheral pathology but has been criticized for being too correlational, able only to speculate on the processes involved in a patient's pain career (Jensen *et al.*, 1991). Through adopting the phenomenological approach it was possible in this study to access the individual, 'insider's perspective' (Conrad, 1987) of living with chronic pain and focus on some of the underlying processes involved in a way which complements the extant research.

The accounts of the participants in this study revealed their multidimensional experience of chronic pain. They shared an inability to explain the persistent presence of their pain or reconstruct any contemporary self-regard. In their uncertainty, despite having a benign condition, they feared for their future. They could not establish the legitimacy of the chronic nature of their pain either to themselves or to others in their social world. As an appearance of good health or activity was generally considered to be incompatible with any claim to remain in pain, the participants felt obliged to appear ill to satisfy the requirements of others. By default, participants treated their own pain as a stigma and tended to withdraw from social contact.

The participants' accounts, as analysed in this study, highlighted how their pain frustrated both their need to attribute a cause for its chronic presence and to attain a stable appraisal of themselves from which they might establish a sense of control or positive self-regard. They felt a pervasive sense of loss and, as they failed consistently to understand or explain why their pain should persist, they felt threatened, unable to guarantee themselves a benign future, free of pain or shame and social rejection.

Some recent writings have aimed to develop a phenomenological approach to the body, illness and pain which conceptualizes it as a unitary, and embodied, yet multidimensional phenomenon which reflects the wide variety and subjectivity of chronic pain and illness, as evidenced by studies such as Borkan, Reis, Hermoni & Biderman's (1995) but goes beyond the traditional mind-body duality to encapsulate both its physical and psychosocial aspects in a theory of the embodiment of experience. In 'embodiment', the perception of reality is taken from the perspective of our having a 'lived body' (Bendelow & Williams, 1995; Frank, 1990) and not simply being a psyche attached to, or reacting to, flesh and blood. Kleinman (1988) highlighted how much our body is 'taken-for-granted' until it becomes restricted and painful, at which point it emerges as something distinct and alien, or 'disharmonious from the self' as Bendelow & Williams (1995) put it. Kelly & Field (1996) criticize the current literature for neglecting the body in the search for the meanings related to chronic illness and pain and maintain that an embodied view of experience needs to be established because of the body's 'primary salience' to our sense of self and identity.

While we would agree with the need to take the body's reality seriously and consider that we have, indeed, have presented our participants as suffering embodied beings, we would also argue the case for psychological studies which focus on how the body and physical states are conceptualized and given meaning by the patient. In our study, it is through the accounts of how they are confused by, and psychologically battle with, their bodies that the embodied personal suffering of the participants is made manifest. This is especially the case with pain, as mainstream researchers have themselves come to recognize that personal psychological constructs are essential to understanding patients' experiences.

What status should be accorded the accounts presented by the participants in our

study? We believe that when talking about their pain conditions, participants are struggling to articulate their beliefs and affective states. They may not entirely succeed in making correct inferences when we listen to them but nevertheless an articulation of personal beliefs is the aim of the project. In this regard we would clearly distinguish the epistemology and aims of IPA (Smith, 1996a) from those of an alternative qualitative approach—discourse analysis (DA) (Edwards & Potter, 1992; Potter & Wetherell, 1987, 1994). DA is sceptical of the claim of a connection between account, cognition and behaviour, preferring to concern itself with how accounts are constructed rhetorically and to serve social and discursive ends. Radley & Billig (1996) treat illness accounts in a similar way, e.g. 'people use health beliefs to make themselves accountable to others and to articulate for others their own position in the world' (p.222). We do not dispute that this is a part of what people do when giving accounts of health and illness. What we would argue is that this is neither the only nor necessarily the most important thing they do. We would contend, ultimately, however, that this is an epistemological rather than an empirical question. Whether verbal accounts are best viewed as attempts to express personal beliefs or as interactively constructed and impelled linguistic devices reflects an investigator's prior theoretical commitments and concerns. Therefore we would argue that there is a place for both forms of analysis.

Finally, just to clarify our position on the status of participants' accounts. We do not subscribe to the view that the cognitions underlying these verbal reports are the 'fixed inner attitudes' that Radley & Billig described as an alternative to their own position. Rather, we believe they are complex, dynamic and shifting entities formed and reformed, in this case, as patients struggle to make sense of their condition and to articulate that struggle to the listener.

The themes which emerged in this study highlight the need to attend to the psychological processes and constructs that the patients in chronic pain live through and bring to a pain clinic. Two of the goals of many chronic pain management programmes are to enable patients to understand the chronic nature of their pain, and acquire particular coping skills and strategies. The patients could achieve a more comprehensive understanding of their experience and strengthen their therapeutic alliance and rapport with the health service staff if the themes related in this study were also addressed appropriately. Through this alliance they, and those involved from their immediate social network, could learn to understand their condition in less self-persecutory ways and realize greater benefits in the longer term through better adjustment and accommodation. Where processes of grief, shame or denial were addressed, however, patients could be expected to feel considerably more distressed at first. Should their anxieties remain uncontained or unresolved it would jeopardize the successful outcome of any programme. Constructive change in those areas would not be achieved quickly or without considerable psychotherapeutic input. The commitment of both staff and patients, and adequate additional time and resources, would therefore be required.

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