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16 ‘Idle Devils’ and ‘Household Engineers’: Identity in Chronic Widespread Pain

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Abstract

Chronic widespread pain, in which pain is experienced in multiple bodily areas, is estimated to affect between 4.7% and 11.2% of the population but little is known about the experiences of this group of people. Previous research on chronic illness has offered insights into the ways in which sufferers attempt to construct new identities or maintain old ones, which may be relevant to the experience of people with chronic widespread pain. This paper is based on ongoing research which uses in-depth interviews, diaries and family member interviews to explore the experiences of this group of people. The paper uses the accounts of two men and their spouses to explore the ways in which key features of chronic widespread pain may influence identity. For Harry, the invisibility of pain raises possible accusations of ‘idleness’ or malingering, leading to attempts to maintain identity as a worker, despite the uncertainties of a chronic condition. Harry attempts to reduce the impact of his illness on his identity, through presenting himself as part of the wider group of the unemployed, leading to additional tensions. In contrast, Duncan creates a new identity as a ‘household engineer’, demonstrating his physical competence and control over aspects of his condition through performance of household chores. He, and his wife, present his pain onset as a positive opportunity to renegotiate their roles within the family. The accounts of Harry and Duncan provide insight into the experiences of living with chronic widespread pain and the different ways in which lost identities can be recreated.

Introduction

Chronic widespread pain, in which pain is experienced in multiple bodily areas, is estimated to affect between 4.7% and 11.2% of the population (Hunt et al., 1999; Croft et al., 1993). However, little is known about this group of people. Studies of chronic pain have tended to focus on specific body parts, or on the pain as part of a diagnosed fibromyalgia syndrome, or on specific patient groups, such as those attending pain clinics. Studies of chronic illness have provided important insights which may be applicable to the experience of

chronic pain, for example, the work of Charmaz (1987, 1991, 1997), Williams (1984, 1993) and Bury (1982, 2001), amongst others, tells us about the identity dilemmas faced by people with chronic illnesses and the ways in which they construct new, or maintain past, identities. While chronic pain is a key symptom of many chronic illnesses, it is also becoming increasingly used as a diagnosis in its own right, and, as such, has features that distinguish it from chronic illness, for example, the invisible, subjective and 'familiar' nature of pain influences aspects of individuals' experience and may also influence self and identity.

The research described in this paper is taken from an ongoing project exploring the experiences of people with chronic widespread pain in a community setting: how this group, and their families, experience and manage their everyday lives and how they make sense of their condition within the broader context of their lives.

Method

Procedure

A series of in-depth interviews were conducted with eight people experiencing chronic widespread pain (recruited via questionnaire from GP practices), and, where appropriate, their family members. Initial interviews used a life-grid approach (Parry et al., 1999), which facilitated participants' telling of the story of their lives with chronic widespread pain, rather than focusing solely on the condition. Follow-up interviews, unstructured participant diaries and follow-up interviews based on the diaries were also completed.

Participants

The data presented here is from two participants, who I have called Harry and Duncan, and their wives, Carol and Becky.

Harry is in his early fifties and lives with Carol and their son Robert, who is at college. He worked as a factory fitter and foreman, before being made redundant ten years ago. Harry has received a diagnosis of psoriatic arthropathy, which he describes as a 'condition', rather than an illness, in common with other participants. Harry and Carol chose to participate in all the interviews (and diary completion) jointly.

Duncan is also in his early fifties, married, with two daughters, both at university. He worked in the police before retiring due to ill-health ten years ago, following a 'silly' motorbike accident at work, in which a bike fell on him. His wife, Becky, works full time as an administrator. Becky and Duncan chose to be interviewed separately.

Findings

In this section I begin to explore some of the ways in which chronic widespread pain has influenced aspects of identity for Harry and Duncan, particularly in relation to work.

'Idle Devils'

Harry: Well I always used to think that people who didn't go to work were idle devils. I am saying that very politely because I really did think they were, you know, "Nothing up with them, get off [to] work". I think perhaps one of the things I was worried about - what people thought of me, because I perhaps thought it of other people because with mine, there is no physical sign. If you got a light on your head that said like 'PAIN', the redder it went, the more pain they knew you were in, but because you can't actually physically see it, I think that is one of the draw backs. [...]

Int: (to Carol) Is that what you meant when you said, you talked about the stigma of being ill?

Carol: Yes, I think it is more so, with me always working, then you sort of think of people say, "Oh she works nights and her husband stays at home". Because it has been said, oh yes it has been said - "Oh golly you are working all nights, you must be mad" [etc] I did nights before he was poorly anyway so, but it is a stigma that goes with it. [...] Well you think that they think he was idle, because I would have thought it myself, I must admit at one time, yes.

[Harry and Carol follow-up to lifegrid interview]

This extract raises a number of issues about identity as a worker, for both Harry and Carol. Their biggest fear was that other people would think Harry idle - they know that other people would think it because they themselves have thought it about others. Although Harry is part of what has been described as the 'separate world' of chronic pain (Good, 1994; Hilbert, 1984; Kotarba, 1983) he, and Carol, are also showing awareness of the 'ordinary world', through their reference to shared cultural understandings of the meaning of unemployment. Carol also suggests that Harry would be seen as not being a 'good husband', in that she had to work nights. Harry too, elsewhere, describes how he initially felt guilty because he could no longer fulfil the male role of provider, but then introduces the idea that the world has changed and this is not expected any longer.

The invisibility of pain referred to by Harry raises the possibility of accusations of malingering, which Harry counters by stressing their previous hard work, prior to having their son. Presenting an identity as hardworking then raises an additional threat to identity, that of being seen as greedy or

selfish. Harry counters this by constructing his account so that earning money was advantageous given later events - "*it was a good job because you don't get much money when you aren't working do you?*" Williams (1993) sees avoidance of debt as part of the maintenance of virtue in the face of illness or disability, in that it represents competence and control over one's self. Thus for Harry and Carol, having worked hard in the past provides them with an extra personal resource for control over Harry's condition.

Harry tells the story of the gradual unfolding of his 'condition' in relation to the extending time of his sick notes, from a week, to a fortnight, then a month, and finally six months, which he describes as "*the end of the world*" - in narrative terms an 'epiphany'. This also tells us about Harry's experience of the chronicity of his condition, or rather lack of experience of his condition as chronic. Acute pain, minor or severe, is considered a 'normal' experience which carries the expectation of removal by medical intervention or through time (Morris, 1991). The unique nature of chronic pain is the difficulty in defining it as chronic at any one point. The working definition used by health care professionals of 'over three months' does not indicate whether it will last three months and one week or thirty years, and how one's life might be affected. As Carol puts it: "*in the beginning we didn't think he wouldn't not work*" and, for Harry, this has not changed "*... I have never thought to myself, I will never work again. I don't even think that now really, really I don't. Probably won't do, but I don't think that anyway*". Harry maintains his identity as someone capable of work even though he is not currently working, a position based partly on his experience of the world of unemployment:

I had to go to [place] to the social services or something. And I am going to sound dead snobby and sound awful now, I just felt I was with the dregs of the world, the security guards were on and they were all rough. I thought "Oh god what I am doing here?" I think that is when the stigma come as well because I thought, "I hope to god nobody thinks I am like these". That is being awful I know, but I did think that, I really did...." *[Harry follow-up to lifegrid interview]*

Harry stresses the reason for his finishing work as the bankruptcy of his employer, not his illness, thus placing himself within the wider social structure, and locating himself as one of many to whom this has happened, rather than an individual who is unable to work because of illness, or implied moral weakness. However, at the same time, this places him in the group with which he fears being associated - the 'dregs of the world' - who do not have control over their lives or over their behaviour. The invisibility of Harry's condition increases the possibility of his being mistaken for part of this world.

Duncan and Becky make similar moral claims to Duncan's being a hard worker, being dedicated to, and enjoying, his job. Their construction of the story of Duncan's finishing work shows how they give sense and meaning to the onset of the pain within the wider context of their lives and how an

alternative identity is constructed for Duncan following this biographical disruption.

'Household Engineers'

I go to work, Duncan is the 'household engineer'. When he finished work in 91 just as I had got a full time job, so he finished about a month afterwards. So it worked out quite well. *[Becky (spouse) interview]*

Actually when she started work at [x] when all this happened to me, she was only part time. But just after this happened to me, she got offered a full time job and as I say we believe in fate so we had a complete role reversal so that worked out for the better, really ... *[Duncan life grid interview]*

Duncan and Becky use similar words and phrases when telling the story of Duncan's finishing work, suggesting a joint account, constructed prior to the interviews. Morris (2001) makes a similar observation and suggests that this may be due to cultural discourses around illness which "*may require a consensual and supportive approach as morally correct*" (p.556). Certainly the accounts produced by Duncan and Becky reflect this.

Duncan describes his working life prior to his finishing work as involving spending long periods away from home, missing children's birthdays, and so on. He and Becky invoke the concept of fate in presenting his condition as an opportunity to 'make up for' this. The men in Charmaz's (1997) study viewed their chronic illness partly as 'an opportunity'. For Duncan this means spending time with his children and developing strong relationships with them, an opportunity that might not otherwise have been open to him. This is not to suggest that Duncan was pleased to have had the accident, but that he and Becky have reconstructed their lives, and the story of their lives, in a way which enables them to present and experience their changed circumstances in this positive way.

Becky and Duncan's term 'household/domestic engineer', while used half-jokingly, is part of Duncan's presentation of himself as capable and confident in the house and an extension and continuation of a past identity. His account also details the changes in his attitude towards his condition, thus reflecting his wider success in coming to terms with it:

Yeah, things like, being a practical sort of bloke, I've always been able to cook. Any man who says he can't cook is an idiot, it's simple, it's easy, just follow a recipe book for goodness sake, so I developed that. Although of course I find it difficult, not the cooking, the physical side, I've got to, like I said about the potatoes at the sink, I've got to bring them down here on the board [...] Make some lovely, I'm not bragging or boasting, I'm not a bad cook, I'm OK. [...] Then I have to become the househusband, domestic engineer, chief cook and bottle washer. Iron shirts. Man who says he can't iron, liar, its easy. [...] Ironing,

cooking. I wouldn't do shirts at first. "They're easy these are, come on, it's simple". It took me a while. Sit down to do it. That's OK. And it takes me a lot longer. [...] Cleaning's easy, you've just got to do it right, keep the place clean, that's simple, with all these modern sprays and things it's easy. But other things like I couldn't take a Hoover upstairs to save my life, so we've got 2, keep one upstairs, that's one way of - It all sounds very simple, but I would say it took about 6 months for me to get into a - I'm a man of routine, that's how I am. [...] It takes me a long, long, very long time to do it, that's the frustrating part of it. I'm thinking, "Oh a few years I could have done this in half the time" and I can't so that's it. As I said I can't expect my wife to come home and do it after she's been working all day, it's not on. Not on at all. [Duncan follow-up to lifegrid interview]

Duncan here is not just presenting himself as capable and competent but is also demonstrating his control, over the physical environment, over his body, over himself, over time, and ultimately therefore, over his pain. He presents himself as a good husband, through consideration of what is 'right', in terms of the changed roles. Becky acknowledges both his expertise in carrying out the role of 'household engineer', and his 'fairness' as a person in consideration of what their changed roles entail, thus maintaining the consensual account. She also plays a collaborative role (see Charmaz, 1997) in maintaining Duncan's positive identity through manipulation of her time, for example, slowing down on household tasks in order to reduce the salience of his reduced physical capabilities.

When I asked Harry and Carol about their management of household tasks, they constructed a joint account, in which Harry emphasises that they had carried on 'as normal' (before Carol's redundancy) for them, with Harry doing what he could manage. Harry emphasises the lack of change in their way of managing, hence reducing the impact of his illness on routine and normality:

Carol: Sundays is usually a good working day, isn't it? What we try -

Harry: - with always working in the week, you have always done it on a Sunday, haven't you, full dusting?

Carol: I get up and do everything, everything moved, all that. All being well, you run me the hoover round which isn't too hard is it? You wouldn't properly, what I would call, wouldn't properly clean up.

Harry: I am here you know! Do blokes clean the same as women? I don't think they do, do they? That is not being male oriented or sexist or anything.

Carol: I don't think they do.

Int: My partner doesn't notice things like that.

Harry: That's it they don't! I mean Carol will say to me - I say "It's alright". "Don't let anybody come in and see that", she will go.

[Harry and Carol diary interview]

When Carol attempts to criticise Harry, he turns this from a being a personal criticism by placing himself in the broader context of 'blokes', which

is then supported by both Carol and me through our agreement with him. They construct a gender-based description of attitudes towards housework (confirmed by me as interviewer in an attempt to reduce potential conflict; Arksey, 1996, comments on this issue), to explain their different behaviours in this area, thus removing the suggestion that it is because of Harry's reduced physical capacity. This contrasts with Duncan's separation of himself from other men, through his emphasis on his ability to cook and iron.

Discussion

Harry and Duncan's accounts bring to mind Catherine Riessman's (1990, 2003) narrative analyses of Burt and Randy, two men with multiple sclerosis talking about their divorces. Burt presents himself as a good husband and as a responsible worker, thus maintaining aspects of his masculinity, as do Harry and Duncan. Burt attributes various events, including the divorce and not being able to work, to his illness, removing any suggestion of moral blame on him as an individual. In Riessman's re-analysis, economic circumstances and resultant downsizing of his factory become an additional possible explanation for Burt's being unable to return to work, which Riessman describes as curtailing his freedom "*to perform (or even revise) a self*" (2003, p.15). In comparison, Harry's deliberate attribution of his job loss to wider economic factors removes his condition from his account. Similarly his attribution of difficulty in performing housework to his gender continues the removal of personal blame. Harry is able to do this because of the invisibility of the condition, the same invisibility which would also lead to its very existence being doubted, in contrast to Burt's more physically obvious MS.

Duncan minimises the impact of having to finish work through retelling it as a fortuitous life event, one which enabled him to make up for his deficiencies as a husband and a father in the life before that. His retention of a positive masculinity, at least within his family, is achieved by telling of his successes in other practical areas. (Although a key aspect of Duncan's positive identity as a 'household engineer' is precisely that it is within the house and therefore much more open to his control and less open to scrutiny by others. When the concept of household chores is extended to look at identity as presented to the outside world, through, for example, shopping, the complexity of the invisibility of pain becomes more apparent.) Duncan could be described as displaying a similar 'role flexibility' to Riessman's (2003) Randy, who used his diagnosis of MS to explore various alternative positive identities.

What I hope to have shown through a brief presentation of these two accounts is the way in which the experience of invisible pain creates a tension between needing to demonstrate the reality of the pain, but of not wanting to present an identity of being ill or disabled. Not working represents a significant

form of loss of identity for Duncan and Harry. Their accounts of regaining or maintaining a positive identity have taken quite different routes, from Harry's positioning himself in the wider worlds of the unemployed and of 'blokes', to Duncan's presentation of himself as practical and competent within a traditionally female environment. Through their accounts we also gain insight into their experience of living with chronic widespread pain, including issues of control, over lives, bodies and environment. While some of these issues are shared with chronic illness sufferers, they also continue to suggest differences between these two groups which warrant further exploration.

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