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# Establishing the (extra)ordinary in chronic widespread pain

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**ABSTRACT** Sufferers of chronic illness face delegitimation of their condition and threats to their identities. One way of establishing the legitimacy of their position is for sufferers of chronic illness to emphasize the 'ordinary' in their accounts. Sufferers of conditions which are chronic, invisible and contested, such as chronic widespread pain, have the same, and possibly greater, need to legitimize their condition and refute allegations of 'malingering' or psychological instability. The article uses interviews with women with chronic widespread pain to illustrate the ways in which the invisible, subjective and everyday nature of chronic pain leads to sufferers experiencing delegitimation of their condition. It suggests that the accounts of women suffering from chronic widespread pain are constructed to portray a positive identity in the face of this experience, particularly through the emphasis on the 'extraordinary'.

**KEYWORDS** *chronic illness; chronic pain; in-depth interviews; legitimacy*

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## Introduction

The prevalence of chronic widespread pain, in which pain is experienced in multiple bodily areas<sup>1</sup>, has been estimated at between 4.7 percent and 11.2 percent by community-based surveys (for example, Croft, Rigby,

Boswell, Schollum and Silman, 1993; Hunt, Silman, Benjamin, McBeth and Macfarlane, 1999). The research on which this article is based is part of a broader, ongoing project exploring the experiences of this group of people: the meanings they attribute to their pain; how they manage their everyday lives; how they make sense of their condition within the broader context of their lives; and the impact of pain on them and their families. This article will focus on how the accounts of women suffering from chronic widespread pain are constructed to portray a positive identity in the face of delegitimation.

The chronicity of an illness or a painful condition can affect the sufferer's experience (Hilbert, 1984) to the extent that the assumption of a shared everyday world is 'deformed' (Good, 1994). In conditions where symptoms are largely invisible, feelings of isolation can be compounded. Sociological studies of chronic illness and chronic pain have shown how sufferers face delegitimation – the systematic disconfirmation of one's illness perceptions (Ware, 1992) – by friends and family, and by the medical profession. In studies of fibromyalgia and chronic fatigue syndrome, for example, the invisible nature of the condition, the lack of 'objective' evidence of disease and the 'familiarity' of the symptoms of pain and fatigue are contributors to the perceived lack of credibility of sufferers (Asbring and Närvänen, 2002; Henriksson, 1995; Soderberg, Lundman and Norberg, 1999; Ware, 1992). Sufferers of chronic back pain face similar threats to legitimacy, also linked to the invisible nature of their pain (see, for example, Osborn and Smith, 1998; Rhodes, Mc-Phillips-Tangum, Markham and Klenk, 1999), as do sufferers of RSI (Reid, Ewan and Lowy, 1991).

In addition to the invisibility of chronic pain in the body of an individual, cultural constraints on the expression of pain mean that chronic pain may also be socially invisible (Morris, 1991). People experiencing chronic, invisible and contested conditions are caught in a double-bind, in that to express their pain (or fatigue) is the only way to attempt to have the condition taken seriously but the lack of accepted cultural ways of so doing (Hilbert, 1984) may contribute to the experience of delegitimation, for example through accusations of 'whinging' or being perceived as psychologically unstable. Other identities may also be threatened by doubts about the existence of a chronic, invisible condition, for example, identity as a woman (Johansson, Hamberg, Westman and Lindgren, 1999), a worker or a 'competent homemaker' (Ewan, Lowy and Reid, 1991).

Sufferers of chronic illnesses attempt to counter the process of delegitimation through attempting to 'maintain a sense of personal integrity, and reduce the threat to social status, in the face of radically altered circumstances' (Bury, 1991: 456). This may be achieved by asserting the physical, as opposed to psychological, origins of the illness (see, for example, Kugelman, 1999); by employing particular narrative strategies, in the case of back pain, 'to reduce the risk of being classed as "psychological" cases' (May, Rose and Johnstone, 2000: 225); by constructing accounts in which

personal responsibility for the pain is removed and sufferers present themselves as experts in their own pain (May et al., 2000); and by attempting to 'manage expression of feeling' in medical encounters (Rhodes et al., 1999). In addition, patients may attempt to find ways to maintain their previous identities or to assert new, positive identities in the face of disconfirmation (see, for example, Charmaz, 1987, 1991).

This article explores the use of 'extraordinary' stories by women with chronic widespread pain as one aspect of the process of establishing a positive identity in the face of delegitimation and threats to identity as family members and workers, in a cultural climate which is antipathetic to malingers.

## **Methods**

### ***The sample***

The sample was taken from responders to a survey carried out in New South Wales (NSW), Australia, in 1998<sup>2</sup> (see Blyth et al., 2001, for full details) designed to assess the prevalence of chronic pain in the community. A sample was selected from those who reported experiencing *any* type of chronic pain (20% of females and 17.1% of males). To obtain a sample suffering from chronic *widespread* pain, on the basis of the available information, potential participants were selected if they reported pain in more than one body site and if they reported no clear reason or cause for their pain onset. The broader study, of which this research was part, uses the stricter Manchester criteria (see endnote 1) for definition of chronic widespread pain. The sample in the study being described here was selected pragmatically on the basis of available information. However, four out of the six participants did meet the stricter criteria.

Written invitations to participate in an interview were sent to five men and 24 women, of whom seven (one man and six women) agreed and were able to participate. This surprisingly low level of response may have been due to the hospital initially advising that participants preferred to be interviewed at the hospital, rather than in their homes. This factor, combined with the timing of the interviews during relatively cold weather, may account for the initial low level of response. I later found that people actually preferred to be interviewed in their homes, which increased the response rates. One participant was not suffering from chronic pain and was therefore excluded from analysis. Results reported here are therefore based on six interviews.

### ***The interview***

Interviews, lasting between one and two hours, were carried out (by JCR) with participants, in their homes or at Royal North Shore Hospital, Sydney, during July 2000. Written and verbal information about the study was given to all participants prior to obtaining written consent. Life-grids (Parry,

**Table 1** Characteristics of participants

<i>Name (pseudonym)</i>	<i>Age at time of interview</i>	<i>Work</i>	<i>Family status</i>
Kathleen	51	Catering, now retired	Married Children and grandchildren
Susannah	59	Nursing and office work, now has own counselling business	Now single Children and grandchildren
Anne	57	Office work, now works as bridal milliner	Married Children Grandchildren
Alice	74	Nursing (home and overseas) and occupational health, now retired	Single No children Lives in a self-care retirement village
Elizabeth	75	Various jobs including research and voluntary work, now retired	Single No children Lives in nursing home
Joan	88	Office work, now retired	Twice widowed Children and grandchildren Lives in 'granny flat' next to daughter's house

Thomson and Fowkes, 1999) were used to facilitate respondents' telling of the story of their pain and to encourage reflections on the areas of their life in which their condition is experienced. Participants' understanding of the condition and their beliefs about its cause were also explored, together with their ways of coping with the pain. The life-grids used were A3-sized printed grids, with rows showing the years of a respondent's life, and columns the different areas of their life, in this case 'family/personal', 'work/leisure', 'health/illness' and 'pain'. Details were filled in by the interviewer, in negotiation with the participant, as the participant talked. Life-grids offer participants some degree of control over the structure of the interview and the order in which they deal with potentially sensitive topics (Parry et al., 1999). This approach can provide a way to understand the social context in which illness is experienced and reported (Murray, 1999; Radley, 1999); to explore identity (for example, Bendelow and Williams, 1995; Bury, 1982); and to look at the meaning people give to events (Bendelow and Williams, 1995; Bury, 1982; Williams, 1984).

### ***Description of participants***

Table 1 gives an outline of the characteristics of participants. Brief details are also given below in the context of interview extracts. All names are pseudonyms.

## **Analysis**

Interviews were transcribed fully and N5 (QSR, 2000) was used to manage the data. The transcripts were read in conjunction with completed life-grids in order to build up a picture of the participants' lives, before and since the onset of their pain. Issues identified are illustrated here with extracts from interviews.

## **Results**

The women in the study described vividly the ways in which the chronicity of their pain had transformed their world into one in which pain had become a normal part of everyday life and previous 'normal' life could no longer be brought to mind. This transformation and the consequent social isolation is similar to that described by sufferers of chronic illness and chronic pain in other studies and will not therefore be dwelt on here. The first part of this section will therefore focus on the descriptions given by the participants in this study of their experiences of delegitimation, including the disbelief of friends and family, the perception of others that the condition is psychological or not real and the consequent threats to their identities. The second part will focus on the ways in which the women attempt to counter the processes of delegitimation.

### ***1. 'They're called bludgers'<sup>3</sup>: delegitimation of the pain***

The embodied nature of the pain described by the women in this study leads to doubts about its very existence and consequent suggestions of malingering, as described below by Anne. She contrasts her experience of 'invisible' chronic back pain with her experience after one operation which gave her a visible, and hence legitimate, reason for sympathy:

I must admit I don't talk about it to anyone else. Even my kids don't really know. I mean, they know I have trouble and they know I can't do a lot of things I used to do, but I tend – if someone says 'How are you?', I say, 'Fine, thanks. How are you?'. Because another thing is people would smile especially; everyone else has this thing that you're trying to get out of things. There is an expression in Australia – they're called bludgers. I don't know if you know that. You know they are bludging; saying they have a backache because noone can see it. I mean, I had more sympathy from people when I had this tumour because I had a scar and bandage; that was visible. I've got this scar down my back that no-one sees and, you know, people think I've got a 'backache': 'Oh yes, you're whinging again'. So I don't talk about it. (Anne)

This extract raises and illustrates a number of issues, including the doubting of the existence of pain because of its invisibility; the consequent threats to identity; and the dilemmas over communication of pain.

The perceived link between the visible and the real, both in clinical medicine and wider society, is acutely felt by sufferers of chronic pain

(Good, 1994). Anne herself doubts the legitimacy of people saying they have backache, as did the RSI sufferers in Reid et al.'s study (1991: 608), making a distinction between 'liars' and 'genuine cases', and a 'vehement minority' in Rhodes et al.'s study (1999: 1192) who suggested that 'other' patients faked back pain. As members of a society which shares a cultural understanding of pain, sufferers may be both the subjects of, and makers of, 'misguided inferences' about pain and its legitimacy (Hilbert, 1984). Anne's account also echoes the women in Hilbert's (1984) study who had considered having unnecessary surgery in order to have a scar to 'show'. The search for visible, bodily 'proof' of pain is also a search for a physical, and therefore not psychological, explanation of their condition. Having a physical 'marker' of pain opens up additional communication possibilities and allows sufferers access to a medical and hence more culturally acceptable discourse. Similarly, other chronic conditions are legitimated by the existence of a diagnostic label even though they may have the same invisibility as chronic pain. Friends and family would be unlikely to doubt the experience of someone diagnosed with multiple sclerosis or, as Anne points out, someone with a scar. The importance of being believed is emphasized by participants in other studies of chronic unexplained pain (for example Bendelow and Williams, 1996; Osborn and Smith, 1998; Reid et al., 1991). Honkasalo (2001) refers to the 'double delegitimation' which occurs in chronic pain, due to the ambiguity inherent in chronic illness and the invisibility of chronic pain. In chronic pain this may be further exacerbated due to its unpredictable nature. This unpredictability may manifest itself in the body, whereby sufferers do not know from day-to-day where the pain will appear. Pain is also unpredictable over time, in that there may be 'good days' and 'bad days', or variation of pain levels within one day, although outwardly there is very little difference in a sufferer's appearance.

Not only does the invisibility of pain threaten a sufferer's identity as a credible person, it also threatens their identity as a worker, through accusations of attempting to 'bludge', or avoid responsibilities and be lazy. Additional threats may arise from suspicion from employers or colleagues that individuals are seeking compensation, a double accusation of attempting to avoid responsibilities and receive payment for it. Kathleen, for example, describes her employers watching how she 'bent and lifted'. She felt that her previous identity as a good worker was under threat and reasserts this through emphasizing her adherence to good lifting techniques. The negative media coverage of 'RSI' in Australia in the 1980s and the development of 'the 'blame-the-worker' explanation, or 'malingering' thesis' (Willis, 1994: 137) may have influenced the women's perceptions of how their employers and colleagues viewed their chronic pain.

Pretending to have a backache in order to avoid work – bludging – is not socially acceptable, but neither is talking, or 'whinging', about 'real' pain. For example, in the previous extract Anne explains that she does not talk about her pain because it is invisible and to talk about it risks being seen



as trying to avoid her responsibilities and being perceived as a 'whinger'. Chronic pain is essentially a private and unnoticed experience unless the sufferer decides to disclose it. It is also a social experience because of this 'choice' over whether or not to bring it into a social context (Kotarba, 1983), although the pressures towards disclosure and concealment exist simultaneously and the decision is never final (Hilbert, 1984; Kugelman, 1999). This fear of being seen to be 'whinging', or complaining, occurs throughout the women's accounts, and in other studies of chronic unexplained pain, for example, Ewan et al.'s (1991) study of RSI. Despite their sense of isolation from the everyday world, the women in this study seem acutely aware of socially acceptable behaviour regarding talk about their chronic widespread pain, illustrated in the following extract:

We are friends now [at the pool], literally after all those years and we share health, but you don't make a thing about it: 'How's your knee today?' – 'Oh, a bit bad'. Or I say to Susie, 'How's your back?' – 'Oh not too bad. Are you alright for coffee next Friday?', or something, and she will say, 'Oh, lovely'. So some people – there is the other person who you can't get away from – you would swear they were the only ones who. . . . (Alice)

Alice suggests that there is a certain amount of pain that can be acceptably talked about, but this has strict limitations, even within the culture of the hydrotherapy pool, where everyone has some form of health problem. Alice feels, and possibly exerts, a strong social pressure not to talk about pain ('you don't make a thing about it') which she goes on to illustrate with examples of 'acceptable' pain conversations. Alice then contrasts this with the unacceptable behaviour of dominating conversations with pain talk. Contrasting oneself in this way with others who complain excessively about pain may be a way for women to distance themselves from what is seen as a predominantly female discourse of 'whining and complaining' (Werner, Isaksen and Malterud, 2004).

The pressure not to talk about pain is not just felt from friends and family. Indeed, one suggested chronic pain management technique is 'to avoid talking about your pain as much as possible' (Nicholas, Molloy, Tonkin and Beeston, 2000: 182). This pressure may be exacerbated for women in cultures which admire the 'restitution narrative' (Frank, 1995), in which people are ill, recover and 'return to normal', or in which certain illnesses are seen as discrediting and hence to be hidden (for example, breast cancer, see Broom, 2001) or stigmatizing (for example, CFS, see Asbring and Närvänen, 2002). Cultural perceptions that women have a greater resilience to pain on a 'day-to-day' basis lead to the idea that women's pain does not therefore need to be taken seriously (Bendelow, 2000). Women therefore face a dual dilemma that expression of their pain is necessary if they want it to be taken seriously but, at the same time, this remains socially undesirable.

One aspect of the decision about whether to disclose pain – to translate



private pain into public pain – is the interpretation of the significance of the pain, for example, whether it is considered ‘normal’ or ‘abnormal’ (Helman, 2001). Again chronic pain presents a dilemma – it is not ‘normal’ to have pain which persists for a long time and which has no obvious cause, but this pain has become ‘normal’ for the person with it. Although the women in this study tended towards concealment of their pain, there are contexts in which they *do* talk about it, although these too are limited by fears of not being believed, or of being seen as a ‘whinger’. Kathleen’s description of her pain, for example, is couched in particular terms which reinforce culturally acceptable expressions and de-emphasize more problematic elements of discourse:

Int: So, do you talk to people, your family and friends, about your pain on a day-to-day basis?

Kathleen: No, no. I might when my shoulder plays up. I might say to my husband, ‘My shoulder is aching again, my elbow is aching. I’ll have to turn over’. But no, I don’t.

Int: Can I ask why that is?

Kathleen: I’m sure they don’t want to hear me whinging. I just don’t, because I can’t see any point in it really.

Int: Mmmm. So do you think they know how you. . .?

Kathleen: Well my children are married now, so they’re not at home. But they are aware. When the grandchildren were small they said, no, Grandma couldn’t pick them up, because of my back.

Kathleen has had intermittent episodes of chronic pain for over 20 years and her extract exemplifies the continuing difficulties in the public expression of private feelings. While all the women described situations in which disclosure became necessary due to, for example, inability to continue in a job or a need to explain behaviour which was ‘out of character’ (such as being unable to have grandchildren sitting on a knee), they used strategies of controlled information release (as described in Asbring and Närvänen, 2002). In doing so they mitigated social stigma and maintained positive identities as far as possible within the cultural milieu in which they operated.

## ***2. Extraordinary stories: legitimating chronic pain***

The interview process brings something of a challenge to the sufferers of chronic widespread pain. It is a direct invitation to step outside of the boundaries of discourse they are familiar with. However, the interviewee may also want to maintain a cautious approach, and conditioned release of information, as in ‘everyday’ life. For example, an interview is a social situation in which the participant has to ‘defend’ themselves against the same potential accusations of malingering, whinging or psychological instability.

The interviewer is usually healthy, demonstrated by the fact of their carrying out their job and the participant may therefore feel the need to legitimate their position throughout the interview (Radley and Billig, 1996). In the case of chronic illness one way of doing so is by construction of an ordinary identity, by making the extraordinary – the condition – ordinary, demonstrated through mention of ‘things that healthy people do in the course of everyday life’ (Radley, 1999: 24) or through accounts of ordinary events (Dingwall, 1976; Radley and Billig, 1996). In the case of chronic widespread pain, I suggest that the participants in my study attempt to achieve this through emphasizing the *extraordinary*, the ‘beyond everyday’, in their accounts, in order to present the pain as physical, and not psychological, and to portray a positive identity. In the following section I present some examples of what I have termed ‘extraordinary stories’ and explore their function in the context of the interview.

In this extract Anne is giving an account of a visit to her general practitioner during which the GP gives her an injection in her heel. The words of Anne and her GP have been set out as a conversation to reflect the style in which Anne told the story, using direct reporting of the actual words used:

GP: This should be really hurting you, because these are really painful.

[Anne: I’ve had them all over the place in my hips. The one through your heel, because they have got to go up through the heel because it is very thick and hard to get through]

GP: It is very painful.

[I’m on the bed gritting my teeth and waiting].

GP: This should be hurting you.

Anne: It is.

GP: Well you’re not reacting.

Anne: Well what do you want me to do – scream? I know it’s only going to take a few seconds.

GP: Well it should hurt you.

Anne: It is hurting.

GP: But you aren’t reacting like it’s hurting.

Anne: I don’t know what you’re expected to do. If I walk around all day going, ‘Ooh!, Aaaahh!’, people are going to have me locked up.

GP: It should be hurting you.

Anne’s account can be interpreted as having a number of different functions. The account she gives is initially not about her chronic pain, but begins with a description of having an injection. Anne refers to the

temporary nature of the pain of the injection as a reason for not reacting in the way that her GP seems to expect, thus implying a distinction between this pain and her chronic pain and also between the pain and her pain behaviour. The GP, despite Anne's continued assertions that the injection is hurting, rejects her verbal reports and continues to look for physical evidence of pain. Through this continued resistance to exhibiting physical pain behaviour, Anne is presenting herself as having a high degree of self-control. Other aspects of respondents' accounts reinforce this idea of the 'strong' and 'in control' self, epitomized by phrases such as, 'I've learned to live with it' (Kathleen) and, 'It is something that people can't really help you with – you have to do it for yourself' (Anne), exemplifying the coping strategy of 'mind over matter', often referred to by sufferers of chronic pain. Respondents reject any suggestion of a psychological origin for their pain and this particular coping strategy further emphasizes their control over their minds, hence strengthening claims for a physical origin to the pain.

A second purpose of Anne's account seems to be to demonstrate her high pain tolerance. She uses 'footing' (Goffman, 1981) – the direct reporting of the doctor's words – to justify and lend weight to her claim. The conversation Anne reports in direct speech is quite long, providing an opportunity to display herself 'as possessing a rather acute and veridical recall of otherwise doubtful or questioned events' (Edwards and Potter, 1992: 37). In this case the doubtful event could be the attribution of her high pain tolerance, the pain itself, or even the sanity of the teller ('people are going to have me locked up'). In this last comment Anne seems to move towards a broader reflection on her chronic pain, the nature of acceptable pain behaviour and pain talk and the cultural limits placed on this behaviour. She describes to the GP (and to the interviewer) the difficulty of communicating chronic pain and of cultural expectations regarding this ('I don't know what you're expected to do . . .'), a dilemma encapsulated by Hilbert:

One cannot moan *all* the time; one cannot confide or expect deferential treatment *all* the time; one cannot quietly withdraw for the rest of one's life; one cannot conceal such an object of one's attention all the time. Thus, culture fails once again to tell sufferers how to handle pain. (1984: 370)

Alice's story also illustrates the cultural constraints on pain behaviour and pain talk in the context of work:

I loved my work [as a nurse] and I suppose I look back and I always had a bit of a backache, but there again we just got on with it, you see. We never complained. The only time I complained when I was training, I think, when I was just about to have a ruptured appendix on New Year's Eve in my second year of training, and it was just sort of got out in time, and it was New Year's Eve and you didn't complain unless you were going to be dying. It was gangrenous and what-have-you when they got to it, so I suppose I was lucky to

have made it in that regard. I was just explaining how things were; you didn't go round saying, 'Oh, my back aches', or, 'My knees are funny today, I don't think I can work', because that just wasn't on. (Alice)

The contextual and factual details of the story again serve to verify the story and suggest a 'sharp' mind, strengthening Alice's claim for a high degree of self-control and high pain tolerance. The stoicism expressed here, epitomized by her phrase 'you just got on with it', suggests a shared cultural belief of that time (the events she described occurred in 1945). Similarly the phrase 'that just wasn't on' is used to express what were culturally acceptable forms of pain talk. In expressing her stoicism and conformity to culturally acceptable pain behaviour Alice is also presenting herself as a good worker, albeit in the past, countering any potential accusations of malingering.

These two 'extraordinary' stories are not necessarily attempts to communicate the current experience of chronic widespread pain, but are participants' attempts to present themselves as being a particular type of person, and to establish a positive identity. An examination of the contexts in which other 'extraordinary' stories occurred can further illuminate the function of these claims.

Joan's account of her high pain tolerance/threshold (participants used the terms 'pain tolerance' and 'pain threshold' interchangeably) occurs as part of a description of her shoulder and spine pain. She uses similar devices to Anne to assert her high tolerance of pain, invoking the authority of health care professionals and, additionally, of medical technology to lend weight to her claims:

I can't stand for very long because of it. It just starts to grab. I know I have a high tolerance, pain tolerance, because I have been told that a number of times. I brought one of those TENS machines and the lass at physio showed me how to use it. She said, 'Can you feel that?'. She was turning it up and I said, 'Yes, that's alright'. She turned it up a bit more and I said, 'That's alright'. And she said, 'You can't be' and I said, 'Well I am'. She said, 'You must have a high tolerance of pain'. I said, 'I think I've had so much that it sort of grows on you' . . . There have been nights I have just sat on the side of the bed and cried it has been so bad. (Joan)

The extraordinary story in this extract, told to demonstrate her high pain tolerance, follows Joan's statement of the physical effects of the pain and precedes her description of the consequences. By ascertaining her high degree of pain tolerance in the context of the physiotherapist's TENS machine, Joan establishes herself as a particular type of person – an 'extraordinary' person who can cope with high levels of pain. The audience then know that in order to make her cry, the pain must have been really serious. Her emphasis on the extraordinary is an attempt to communicate her experience of everyday chronic pain, in addition to presenting a positive identity as a person with a high pain threshold.

Presentation of a positive identity may also be achieved by using an extraordinary story to compare oneself with other people, as illustrated in Anne's extract:

I have a very high tolerance of pain. I don't know how they judge it but the fellow that did my spine said, because they told me I would be like a zombie for a few days on [medication] and what-have-you. He told me I'm the only person that came out of having major spinal surgery with a smile on my face. And I said, 'My mother told me never to be rude to anyone'. And I always did what I was told, and I said, 'You know you can't inflict it on anyone else'. A friend had migraines and everyone suffers when she has migraines and that is why hopefully I never inflict it on anyone else. (Anne)

Medical technology and health professionals' comments are again used to provide further validation to the story and to suggest that the surgeon might also have considered it 'extraordinary' for someone to emerge smiling from major surgery. Anne's account can also be seen as an extreme (or extraordinary) example of conformation to cultural expectations on women to hide negative emotions. Anne demonstrates her awareness of social expectations regarding pain behaviour and pain talk, through comparison with her friend who does not conform to these expectations. The comparison of the teller with 'others' is, as already suggested, a way of distancing oneself from the discourse of 'whining and complaining' and thus presenting a positive identity.

The 'work' done by women with chronic medically unexplained muscular pain in order to be perceived as credible patients in encounters with health care professionals is described by Werner and Malterud (2003). The women in their study employed strategies which would make their illness credible, present themselves as mentally stable, while simultaneously maintaining their self-esteem and dignity as women in a potentially discrediting encounter. This involved negotiating a balance between, for example, not looking 'too strong or too weak, too healthy or too sick, or too smart or disarranged' (p. 1414). Anne's accounts of the GP visit (previously) and surgery (above) and Joan's account of the physiotherapist's visit could also be seen in this way. They present themselves as strong and in control of their pain, while not denying its existence, and conforming to cultural constraints around expression of pain.

Demonstrating this awareness of the cultural constraints of talking about pain provides a further context in which the presentation of oneself as having a high pain threshold occurred. Although the interview invited the women to talk about their pain, they still felt a need to defend themselves against potential accusations of talking too much about pain, and to demonstrate their awareness of 'correct' behaviour. Kathleen, for example, commented that '[it] sounds dreadful, doesn't it, when you talk about pain?'. Alice's reflection, following, that she hadn't been 'a bad talker', occurred towards the end of quite a long interview:

I'm a very good listener, haven't been a bad talker either, not bad. I'm usually not, I'm more of a listener. Maybe I needed to get something off my chest. There are those people who corner you somewhere: 'No idea what I'm suffering, no idea. My hip, my legs, are driving me mad' . . . They are the people whose threshold – whose pain isn't really any worse than Jo Blow's, but they can't help it I suppose [. . .]. I consider that I've got a reasonably high threshold of pain, I think, and I know I have friends who think I don't do too badly. (Alice)

After having spent almost two hours talking about herself and her pain, Alice attempts to lessen the risk of being seen to be whinging, through emphasizing her identity as a listener and asserting her high pain tolerance. She also compares herself with other people with 'low pain thresholds', who do not have awareness of acceptable pain talk. Her phrase 'they can't help it' again suggests that she is someone with a high degree of self-control and invokes the 'mind over matter' strategy of dealing with pain.

A further function of the extraordinary stories is to attempt to maintain a previous positive identity which is under threat due to the chronic pain:

But I mean, I can remember crawling round the bedroom to make the bed. I'm not one for sitting down, I can't stand the mess. I'm not fanatical about housework by any means, but my husband would go to work. He'd say, 'Leave the dishes, I'll do them when I come home', but I would have to do it. It is silly things, you make things more difficult for yourself. (Anne)

Anne is presenting herself here as a 'good housewife' ('I can't stand the mess') despite her pain, and as a previously active person ('I'm not one for sitting down'). The RSI sufferers in Reid et al.'s (1991) study similarly described themselves as conscientious and previously hardworking, and demonstrated 'proof' of this in their accounts, in order to lessen the inference that they did not 'deserve' to have time off work. They want to perform their social roles, whether through paid work or housework, but only the seriousness of the pain prevents them from doing so. Horton-Salway (2001) suggests that one function of the emphasis on active lifestyles which occurs throughout narratives of various illnesses is that of asserting the physical, as opposed to the psychological, origins of the condition. Anne emphasizes that she is 'not fanatical about housework', countering any potential accusation that she might have brought it on herself (see Horton-Salway, 2001) or any possible suggestions of psychological instability. In a further extract from Anne's account, below, the impression is conveyed that housework is not a choice but an ongoing responsibility, even if the pain means that paid work can no longer be performed (see Johansson et al., 1999):

Well, with everything that I had, my mother lived here, but the rest of my family lived overseas, so it was just a matter of you had no-one, so you just had to get on with it. My husband helped as much as he could, but he had to go to work and, even when I had the plaster cast and when I was on crutches, you devise ways of getting the washing out to the clothes line and down steps and out of

doors and things. I was expert at sort of managing things, I used to have a little – what do you call them? – a shoulder bag type thing, I used to put in my cleaning, anything I wanted and hobble around with that, so you find ways of managing things. You don't have a choice, you just have to do it. (Anne)

Despite her limitations, Anne is able to present a positive identity as an expert in 'managing' her condition and her responsibilities. She also presents an identity as alone but strong ('you had no-one'), despite some help from her husband and the presence of her mother. Stoicism in the face of hardship is a dominant theme throughout Anne's account, possibly reflecting broader popular ideas of the migrant experience. Anne's account also illustrates a particular dilemma for women with chronic widespread pain, in that in order to maintain a positive identity through continuation with traditional female tasks, women risk being seen as not really ill (Johansson et al., 1999).

## Discussion

The women in this study used 'extraordinary' stories as part of an attempt to portray positive identities in the face of delegitimation. They presented themselves as hard workers – and therefore not malingerers or compensation-seekers; as sane and in control – and therefore their condition could not be perceived as 'psychological'; as listeners – and therefore not whingers; as people who can cope with high levels of other kinds of pain – and therefore *this* pain must be real; and as people who know what the cultural expectations are regarding pain behaviour – and are therefore 'normal'. Their accounts also echo those of chronic *illness* sufferers who assert their normality through description of ordinary everyday activities. People with chronic pain are simultaneously presenting their 'ordinariness' and their 'extraordinariness'.

The stories told by the women could be interpreted simply as 'dramatizations' of symptoms, as suggested by Kleinman (1994: 181) in his description of Stella, who felt the validity of her experience challenged and hence, 'like most other chronic pain patients, feels pressed to dramatize her symptoms. Her pain is twelve out of ten.' Dramatizing pain in this way, to deal with potential invalidation, means that one might not be taken seriously. The alternative, to downplay the pain in an attempt to appear normal, means that the sufferer runs the risk of not being believed. However, the extraordinary stories that I have described were not told simply as descriptions of the experience of chronic pain itself, but as part of an attempt to overcome this dilemma, to present a particular identity, and through this, to legitimate the pain.

The stories were told to me as an interviewer and as a representative of a wider audience. My interpretation is that the stories were told in the knowledge that I would find them extraordinary, not that they were extraordinary to the chronic pain sufferer themselves, for whom such experiences had



become part of their 'ordinary' existence. The women conveyed the impression that the stories had been told previously, having been constructed for the purpose of countering accusations, for example, of malingering, in the workplace; to portray a positive identity, for example, at work or at home; or to present oneself as psychologically stable, in a medical setting. Different settings may evoke different presentations of self and the emphasis of the extraordinary stories could change according to the contexts, but with the aim of fulfilling the same purpose – of legitimating pain and person.

Bury (1991) suggests that legitimization is problematic in conditions where symptoms occur in milder forms in the normal population. The everyday nature of the symptoms may exacerbate the disconfirming responses when sufferers attempt to communicate the nature of their distress. In chronic fatigue syndrome, for example, symptoms such as headache, fatigue and sore throat may be perceived as trivial, leading to further delegitimation of the condition (Ware, 1999). In contested conditions which rely almost exclusively on patients' experience for communication, and in which symptoms are largely invisible, ordinary and everyday, extraordinary stories may therefore be told. People with other contested conditions, such as chronic fatigue syndrome, may have other 'extraordinary' stories to tell.

Chronic pain has, with a few notable exceptions, been subsumed under the study of chronic illness, yet there are key differences between the two. These differences may be related to the nature of chronic pain – it is invisible, subjective and everyday, and is not legitimated by a diagnostic label. Language and the ways that people have to express their experience may be influenced by the nature and characteristics of the condition. The way in which people present themselves, attempt to communicate their experience of pain and to legitimate their condition, for example, through the use of extraordinary stories, may also be different and therefore deserves attention. Exploring the function of such stories may also help health care professionals to understand the experiences of women with chronic widespread pain.

### **Notes**

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1. In the Manchester definition of chronic widespread pain (MacFarlane, Croft, Schollum and Silman, 1996: 1629) pain is considered to be present in a limb if at least two sections from four are indicated as painful. Pain is considered to be widespread if it occurs in the axial skeleton, above and below the waist and in contralateral limbs (e.g. lower back, plus left arm plus right leg).
2. Ethical approval for the study was given by the Human Research Ethics Committee, Northern Sydney Health (9606–093M).
3. A colloquial Australian/ New Zealand word meaning to evade responsibilities, to be idle or to 'cadge' (Macquarie Dictionary Online, 2002).

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