

Journeys with chronic pain: Acquiring stigma along the way

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Abstract

Chronic pain has been identified as a major and underestimated health care problem, with extensive individual, social and economic ramifications. Recognition of pain as a multidimensional experience has contributed to the biopsychosocial model of health gaining substantial recognition in the pain management domain.

There is evidence, however, that the 'promise' of the multidimensional approach has not been realised in the daily lives of people with chronic pain. A relationship between stigma and chronic pain has recently begun to emerge in the qualitative literature concerning the lived experience of chronic pain. Drawing on a narrative study with twenty people with chronic pain, this paper will use the conceptual framework outlined by Link and Phelan (2001) to illustrate the social processes involved in the stigma acquired by people in their journey with chronic pain. Stigmatisation has significant consequences for people living with chronic pain which cannot be addressed at an individual cognitive level. This adds salience to the author's contention that the social dimension of chronic pain needs to be further articulated and addressed at a policy and practice level, not only to ensure a more comprehensive response to chronic pain, but also to ameliorate the social suffering experienced by people living with chronic pain in our community.

Key Words: Chronic pain, stigma, social environment.

1. Introduction

Chronic pain has been identified as a major and underestimated health care problem, with extensive individual, social and economic ramifications. It is estimated that the annual economic cost of chronic pain in Australia exceeds AU\$34 billion (Access Economics 2007). Available epidemiological evidence suggests chronic pain is a relatively common health problem in Australia and is a significant public health issue (Blyth et al. 2001).

Recognition of pain as a multidimensional experience has contributed to the biopsychosocial model of health gaining substantial

recognition in the pain management field (Nielsen and Weir 2001).¹ This in turn has facilitated the development of new approaches to chronic pain treatment, ostensibly aimed at integrating the biological, psychological and social domains of individual experience. There is evidence, however, that the 'promise' of the multidimensional approach has not been realised in the daily lives of people with chronic pain (Nielsen 2009). In particular, it has been argued that the application of the biopsychosocial model continues to direct attention to the biological and psychological aspects of the pain experience, while minimising or ignoring factors located in the social domain which may also be significant.

It has been proposed by the author of this paper that in order to more comprehensively respond to the complex phenomenon of chronic pain, the social dimension of the experience needs to be further articulated and addressed at a policy and practice level (Nielsen, 2009). This contention is illustrated in this paper through an exploration of the relationship between stigma and chronic pain. Drawing on a narrative study with twenty people with chronic pain (Nielsen, 2009), stigmatisation is shown to be a social process that has significant consequences for the stigmatised which cannot be addressed at the individual cognitive level. The paper highlights the critical importance of focusing not only on the individual with pain, but also on the social environment within which the individual lives, and the ways in which these domains intersect and influence each other.

2. Defining chronic pain

Chronic pain is a complex phenomenon which is not easily or neatly defined. A variety of definitions and classification systems exist in the pain field. The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage" (Merskey and Bogduk 1994:210). Most simply, pain can be considered chronic when it persists longer than expected; a period of six months or longer was used for the study reported on in this paper.

3. Study participants

The narratives referred to in this paper were part of the author's doctoral study on the social dimension of living with chronic pain (Nielsen, 2009). In this study, narrative interviews were conducted with a convenience sample of 20 adults with chronic pain, predominantly residing in the state of Queensland, Australia. Participants were required to have ongoing pain which had persisted for at least six months, with little or no identifiable pathology. There is evidence that people with chronic pain without obvious physical pathology are a particular 'pain' sub-group that may be subject to social disadvantage (Chibnall and Tait 1999; Haugli et al. 2004; Kouyanou et

al. 1998; Marbach et al. 1990). Consequently, this sub-group of people with pain were the focus of this study. Participants were diverse in terms of age, background, and location and duration of pain.² Study participants were asked to ‘tell the story’ of their pain in whatever way made sense to them. Transcripts of these stories were analysed using a qualitative interpretive method³, resulting in three principal themes and seven sub-themes. This paper is concerned with the sub-theme ‘Acquiring stigma’.

4. Defining stigma

A relationship between stigma and chronic pain has recently begun to emerge in the qualitative literature concerning the experience of living with chronic pain (For example see: Asbring and Narvanen 2002; Holloway et al. 2007; Jackson 2005; Kenny 2004; Richardson 2005). Contemporary discussions of stigma continue to acknowledge Goffman’s (1968) classic explication of the concept (Holloway et al. 2007; Link and Phelan 2001; Scambler 2004), whereby an individual with a socially-discredited attribute experiences rejection or discrimination as a result of that attribute.

However, literature concerning stigma demonstrates variability in definition and application (Link and Phelan 2001). In this paper, the concept of stigma as developed by Link and Phelan (2001) will be applied; that is, that “stigma exists when the elements of labelling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold” (2001:382). The advantage of this definition in the current context is that it focuses attention on the social environmental factors that create and sustain stigma, rather than the predominantly individualistic or interpersonal focus of other literature on stigma (Link and Phelan 2001:366). The components of stigma, as conceptualised by Link and Phelan, are discussed with reference to the narratives which formed the basis of the author’s doctoral study.

3. The interrelated components of stigma and chronic pain

Labelling

The term ‘labelling’ in this context refers to the taken-for-granted culturally created categories that are used to identify differences that matter socially (Link and Phelan 2001). These categories are part of the cultural system of the social environment in which people live, and as such are incorporated into the individual’s ‘ways of seeing’ themselves and others. The process of being labelled is not necessarily problematic; the majority of differences between people, for example, eye colour, are minimally, if at all, socially relevant (Link and Phelan 2001). It is only when the attributed label identifies a difference that is *socially salient* that labelling may become significant.

For participants in the study reported on in this paper, the process of labelling was grounded in a problematic and unsuccessful search for diagnosis and cure of their pain. Hilbert (1984) appropriately described living with chronic pain as an atypical and acultural experience: atypical as chronic pain does not conform to the trajectory of 'normal' pain and acultural because:

The cultural resources usually summoned to render pain meaningful are inadequate when pain persists. Chronic pain sufferers are afflicted with a 'condition' which from their vantage point makes no sense and defies every attempt to stabilise it (Hilbert, 1984:368).

Lack of diagnosis and a clear treatment path, combined with the open-ended nature of chronic pain, also meant participants could not perform the roles of the socially acceptable sick person; that is, actively participate in the recommended treatment regime and then return to normal duties. Participants therefore could not comfortably occupy the sick role, as developed by Parsons (1958). Thus, the lack of a culturally condoned, straightforward label for their condition, as is available for many other health states, contributed to participants being alternatively, if not explicitly, labelled as somehow different or difficult.

Stereotyping

In the Link and Phelan schema, the process of labelling is not inherently stigmatising. A label only becomes problematic when it is linked to a set of undesirable characteristics that become a stereotype (Link and Phelan 2001:369). The stereotype of 'malingering' was one that the majority of participants in the study felt had been applied to them to varying degrees. This stereotyping was experienced both socially and psychologically. Socially, most participants felt health professionals, and society more generally, questioned the reality of their pain in the absence of an identifiable cause or an observable manifestation of disability. As one participant stated: "if it's not explained by a blood test or an x-ray or whatever, it doesn't exist". As a result, the possibility of being a malingeringer was, even if not overtly stated, a status participants felt was implied by some health professionals during the consultation process or by others more generally in society if their chronic pain condition became known. Stereotyping of the chronic pain patient may indeed result in more than stigmatisation; Chibnall and Tait's body of work (Chibnall et al. 1997; Chibnall and Tait 1999; Chibnall et al. 2000; Tait and Chibnall 1997; Tait and Chibnall 2005) suggests that biomedical evidence has an "inordinate amount of influence" on physician pain judgements, and may contribute to under-treatment of pain.

Psychologically, the majority of study participants wrestled with the same cultural stereotypes they felt others were applying to them, particularly in the absence of an acceptable or meaningful diagnosis. This was reflected in the search undertaken by all participants for some form of pathology or injury that would explain their pain. For many, not only did this search fail to find a diagnosis or cure for their pain, but they had in fact suffered unexpected side-effects of treatment or iatrogenic harm. Study participants generally resisted the malingerer stereotype, as they knew they were living with very real pain. Simultaneously, however, they found it difficult not to apply the culturally-acquired model of mind-body dualism to their own situation, thus revealing the threat that if a bodily reason could not be found, the pain must be “in their head” or in some way psychosomatic. The implicit implication of this was that they might be suffering from some form of mental illness, with all the additional cultural stereotypes that this implied.

Labelling and stereotyping had clearly affected the lives of the study participants, both in terms of their relationships and interactions with others, and in their view of themselves. They were confronted with what Archer (1995) termed a ‘constraining contradiction’; that is, the interaction between two irreconcilable but inter-related elements: ongoing pain in the absence of biomedical evidence. However, as individuals, they lacked the transformational power to change the circumstances in which they found themselves.

Separation

The third component of the Links and Phelan stigma schema is separation; that is, when social labelling and stereotyping implies a separation of “us” and “them” (Link and Phelan 2001:370). In other words, the reactions of others produce a sense of being devalued or disrespected, or in some way different in a negative way to others in society (Green et al. 2005:205). Stigma can therefore be seen to be a *cumulative* process mediated through socio-cultural interaction:

Thus, other components of the stigma process – the linking of labels to undesirable attributes – become the rationale for believing that negatively labelled persons are fundamentally different from those who don’t share the label – different types of people. At the same time, when labelled persons are believed to be distinctly different, stereotyping can be smoothly accomplished because there is little harm in attributing all manner of bad characteristics to “them” (Link and Phelan 2001:370).

The majority of study participants described a process of separation through the gradual recognition that their pain was atypical and acultural.

The ever-present nature of chronic pain meant that participants were constantly aware that they were different; they had what Hilbert described as “an extreme personal idiosyncrasy” which although invisible, was constant, preoccupying, and could not be left at home for a good night out (1984). The omnipresent nature of chronic pain created and continually reinforced a sense of isolation and estrangement from society (Hilbert 1984:370). For example, one participant talked about her non-existent social life, and the need to carefully weigh up the potential consequences of going out with friends – “whether I go and do that and then manage the pain that I know is going to happen afterwards”. Other participants described varying processes of gradually withdrawing from society.

Participants’ narratives also demonstrated what could be termed a more active process of separation in regard to the way they were treated by some health professionals. The invisibility and subsequent lack of legitimacy of their chronic pain would appear to be at the core of this phenomenon. For example, one participant deliberately structured his narrative to include a section on what he introduced as “how the medical profession has dealt with me”. He described being treated with cynicism and suspicion, particularly when requesting pain relieving medication. Another participant said she believed she was considered “a liar and a cheat”, while another woman said she felt that others were always judging the veracity of her pain story. Without a culturally assigned role or status in our society (Hilbert 1984; Jackson 2005), chronic pain sufferers are positioned in a negative stereotype which separates them not only from society as a whole, but also from more ‘deserving’ people with legitimate health problems (Jackson, 2005:333). This can be related to what Holloway and colleagues (2007:3) have termed “moral stigma”; that is, chronic pain sufferers are labelled as “morally weak” when there is a lack of congruity between pain behaviours and biomedical findings. In this way the plight of the person with chronic pain can be individualised, and therefore not a threat to those of ‘us’ who are not like ‘them’.

Status Loss and Discrimination

The process of labelling, stereotyping and separation constructs a rationale for devaluing and excluding people within society. Link and Phelan referred to this process as culminating in status loss and discrimination, the fourth component of their stigma schema. Further, they identified stigmatised groups as being disadvantaged generally in social determinants such as income, education, psychological well-being, housing status, medical treatment and health (2001).

The most obvious way in which the majority of study participants experienced status loss was through loss of employment and subsequent reliance on government benefits. Loss of employment led to a general

downward movement of participants in the status hierarchy, which over time led to what Link and Phelan described as “a cascade of negative effects on all manner of opportunities” (2001:373).

Link and Phelan further categorised discrimination into individual and structural discrimination. They suggested that, within the stigma literature, the most common way of conceptualising connections between labelling, stereotyping and discrimination falls within the individual category; that is, the labelling and stereotyping of an individual directly leads another individual to overtly discriminate against the labelled person, such as by rejecting a job application (Link & Phelan, 2001). While this form of discrimination could be identified in some of the participants’ narratives in the study, the concept of *structural* discrimination is more pertinent to the focus of this paper due to the focus on the social dimension of living with chronic pain.

The concept of structural discrimination “sensitises us to the fact that all manner of disadvantage can result outside of a model in which one person does something bad to another” (Link & Phelan, 2001:372). Link and Phelan used the example of institutional racism to illustrate how accumulated institutional practices can work to disadvantage racial minority groups, even in the absence of individual prejudice or discrimination. Similarly, in this study, participants’ stories of struggling to maintain employment illustrated the impact of disabling environments, rather than inherent limitations of the individual. One participant, for example, spoke of the requirement of being “100% fit” before she would be allowed to re-commence her nursing duties. From her perspective, lack of support and harassment from her employer eventually made her position untenable, and she resigned. Although her arm pain may have eventually meant she was unable to work in the nursing role, she felt she was never provided with a supportive work environment to explore her remaining abilities, or to develop an alternative role which would have retained her knowledge and experience within the workplace. Other participants said they believed they had little choice but to leave their employment when it became clear they could no longer physically fulfil duties the position required, and there appeared to be little in the way of alternative employment options available.

Of more relevance to participants in this study as a whole is the *discriminatory potential* of status loss. Link and Phelan point out that while labelling and stereotyping may initially have led to lower status, over time the lower status *itself* can become the basis of both individual and structural discrimination; they may become “the recipient of structural discrimination whether or not anyone happens to treat him or her in a discriminatory way because of some stereotype” (2001:373). For example, loss of status as a result of unemployment and subsequent financial dependence on government welfare benefits can have an impact on many aspects of an individual’s life,

such as being unable to participate in social and recreational activities, regardless of the reason for the person being unemployed.

Cultural stereotypes can also affect the labelled person in ways that do not involve obvious forms of discrimination (Link & Phelan, 2001). For example, as mentioned previously, the dominant mind-body dualism of biomedicine contributes to the expectation that if a cause for the pain cannot be found in the body, then it must be in the mind, and is in some way less 'real' than pain located in the body, or in some way indicative of mental weakness or illness. Participants themselves had internalised these cultural stereotypes, and therefore in some cases went to extreme lengths to locate a bodily cause for their pain so they would not become one of the 'them' implied through labelling and stereotyping. For example, one participant expressed her disdain of people who 'whinged' about their pain, identifying them as "totally negative" and "miserable", and emphasised through an anecdote of working through extreme pain to accomplish a physical task, that she was not that sort of person.

This concern about becoming a member of a devalued group in society was also evident in aspects of other participants' stories, such as expressed shame at receiving the disability support pension, inferring the strength of the welfare dependent or 'bludger' stereotype in our society. Similarly, the extent to which some participants went to retain their employment is indicative of the social value placed on being employed.

Thus the discrimination experienced by the stigmatised does not necessarily directly relate to the initial cause of the stigma, in this case biomedically unexplained pain, but can be widespread and have an impact on multiple life domains and life chances (Link and Phelan 2001). At the same time, not every individual in a stigmatised group will experience the same outcomes. The impact of stigma on study participants varied depending on their individual circumstances and resources. For example, those who could continue to work, had working partners, or other financial resources, such as income protection insurance, did not appear to experience the same level of status loss and financial difficulty as those who lost their livelihood and only means of income. However, there was sufficient commonality in participants' experiences to suggest a general pattern of disadvantage connected to having chronic pain.

Power

The discussion concerning stigma to this point has illustrated that the inter-related components of labelling, stereotyping, separation, status loss and discrimination were experienced by study participants. However, Link and Phelan have suggested that even with these components co-occurring, *power differences* need to be present for stigma to occur. Use of only the cognitive components of the concept; that is, labelling and stereotyping, to

define stigma could result in high social status groups such as lawyers and politicians being considered stigmatised groups. Stigma, according to Link and Phelan, is “entirely dependent on social, economic, and political power – it takes power to stigmatise” (2001:377).

In relation to chronic pain, the importance of power, and the associated status loss and discrimination components of the stigma concept, can be illustrated through consideration of differences between medical practitioners and the study participants. The majority of participants made negative comments about the attitudes and behaviour of medical practitioners. In response to this, doctors could be labelled and stereotyped as, for example, arrogant and lacking in compassion. However, doctors could not be said to be a *stigmatised* group as a result of this, as study participants did not possess the social, cultural, economic and/or political power that would result in serious discriminatory consequences for the doctors (Link and Phelan 2001). In the Link and Phelan schema of stigma, therefore, *power differences* are essential to the *social* production of stigma:

Groups both with and without power label and form stereotypes about the other groups...But what matters is whose cognitions prevail – whose cognitions carry sufficient clout in social, cultural, economic and political spheres to lead to important consequences for the group that has been labelled as different (2001:378).

Due to the importance of power in stigmatisation, Link and Phelan proposed a set of questions concerning the ability of potential stigmatisers to have an impact on a stigmatised group (2001). Central to these questions is whether those who might stigmatise have the power to significantly control access to major life domains like employment and health care (2001). Consideration of the study participants’ narratives illustrated that this is indeed the case for people with chronic pain. Limited or no flexibility in workplace expectations and demands; difficulty in obtaining timely and adequate pain relief; loss of income and subsequent financial difficulties; barriers to obtaining income support and therapeutic services - these are just some of the examples of the disadvantages experienced by study participants which could only occur where there is a power imbalance between the stigmatised and the stigmatisers (Nielsen, 2009). While the impact of stigma varied in degree amongst the participants, it can be concluded that stigma is a valid concept to apply to chronic pain. Stigmatisation is a *social* process that has significant consequences for the stigmatised which cannot be addressed at an individual cognitive level.

4. Responding to stigma

If the stigmatisation of people with chronic pain is a multi-level and flexible social process, as set out in this paper, changing stigma becomes more complex than adopting one specific intervention, such as changes to the work place or in the way health care practitioners communicate with their patients. Link and Phelan have suggested two principles which are worth considering when trying to institute changes to stigma for any particular group or condition. The first involves a multifaceted and multilevel approach. In response to the outcomes of the study reported on in this paper, the author has suggested a number of policy and practice directions, including a multi-focus educational strategy regarding chronic pain for health professionals, people with chronic pain and their families or friends, employers, and the general population; a consumer-based support and advocacy strategy; the clarification of care pathways; assessment of unmet need regarding pain management services; and strategies to address employment and income support issues (Nielsen 2009).⁴

Secondly, and perhaps most relevantly in the context of this paper, is that any approach to change:

...must ultimately address the fundamental cause of stigma – it must either change the deeply held attitudes and beliefs of powerful groups that lead to labeling, stereotyping setting apart, devaluing, and discriminating, or it must change circumstances so as to limit the power of such groups to make their cognitions the dominant ones (Link & Phelan, 2001:381).

Such changes in attitudes or beliefs and power relations will obviously not easily or quickly be achieved. Given that such a social revolution is unlikely to occur in the near future, what can be suggested? Based on the results of the author's study, and other research in the area (For example see: Hilbert 1984; Madden and Sim 2006; Ong et al. 2004; Paulson et al. 2002), the *meaning* attributed to chronic pain, both individually and more broadly in the social environment, is central to the stigmatisation process. Consequently, an important starting point in addressing the stigmatisation of people with chronic pain would involve a broad public education campaign about what chronic pain is, how it affects people, and what can be done about it. Evidence of such strategies in Australia is limited, and space does not allow discussion of the concept here. However Buchbinder (2008) has persuasively argued that the use of mass media to deliver health messages to the general community is a well-established preventative health strategy, and can be much more cost effective than

strategies that focus on individual patients or health care professionals. Indeed this is one of the high priority strategies proposed in the Australian Draft National Pain Strategy (www.painsummit.org.au), which will be the subject of a National Pain Summit in Canberra in March 2010.

5. Conclusion

Chronic pain is a significant health care problem for the individual involved, their family, and the wider society. Despite the common expectation that pain can be managed by medical intervention, this is not the experience of millions of people living with chronic pain.

The biopsychosocial model of health, incorporating the biological, psychological and social domains, has gained substantial credibility in the pain management field, being endorsed as the preferred model for chronic pain management and contributing to the development of new approaches to treatment and management. Yet despite these developments, people with chronic pain consistently report interpersonal, intrapersonal and social difficulties which have not been adequately addressed, or indeed appear to be exacerbated by, contact with the medical and allied health professions, and a lack of understanding and acknowledgement of their suffering in the public domain.

This paper has applied a multi-component conceptual framework to the narratives of people living with chronic pain to explicate the development of stigma as part of the social dimension of the chronic pain experience. Such investigations direct practitioners and policy makers to consider not only the person with chronic pain, but also other strata of society, such as the health care system, work places, and our cultural beliefs and folklore concerning what is 'normal' pain and how we make sense of other types of pain. Failure to adopt this extended view will not only deny individuals with chronic pain improved health services and social legitimacy for their condition, but will continue to entrench a social form of stigma which unnecessarily adds to the suffering of people living with chronic pain.

Notes

¹ Prior to the development and application of the biopsychosocial model of health to chronic pain, the biomedical model, underpinned by the Cartesian concept of mind-body dualism, was the dominant theoretical perspective used to understand pain. When applied to chronic pain, the biomedical model predominantly focuses on bodily malfunction, with the logical progression that treatment should also focus on the body. In the absence of an identifiable pathology to account for ongoing pain, the 'default' position of the biomedical model is that the problem must be psychological, rather than physical.

² Details of the participants have not been included in this paper; however these are available from the author on request.

³ Interpretive Phenomenological Analysis (IPA) J.A. Smith and M. Osborn, 'Interpretive Phenomenological Analysis', in J.A. Smith (ed.), *Qualitative Psychology a Practical Guide to Research Methods* (London: Sage Publications, 2003).

⁴ Space does not permit discussion of these strategies here. For more detail please refer to the author's thesis.

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