

# A Narrative Review of the Impact of Disbelief in Chronic Pain

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## ■ ABSTRACT:

Although the experience of being believed is frequently alluded to in chronic pain literature, few studies have specifically explored this phenomenon and even fewer reviews have been offered. This narrative review sought to explore the wider social context in which individuals with chronic pain may experience disbelief toward their pain. Articles were obtained through a search of eight databases and a hand search of the references of full-text papers. Key results within the articles were noted and integrated to form three main themes: stigma, the experience of isolation, and the experience of emotional distress. The experience of stigma can occur in a number of ways. It may be through actual or perceived encounters with others; it can be through the use of psychologic explanations of pain; it can come through a perceived challenge to one's integrity and subsequently affect an individual's identity; and such stigma may be influenced by negative female stereotypes. The loss of relationships associated with being disbelieved can lead to the experience of isolation. This may be self-initiated, particularly when an individual has been given a contested diagnosis. Finally, disbelief can lead to emotional distress. This can take the form of guilt, depression, and anger. Throughout the article, implications for health care professionals, working with individuals living with chronic pain, are discussed.

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Pain is famously defined by Margo McCaffery (1968) as "whatever the experiencing person says it is, existing whenever he says it does" (McCaffery & Pasero, 1999, p. 17). To act in accord with this definition of pain, one must take the words of the patient at face value. The practitioner must accept the patient's subjective report as being so. Therefore, the experience of having one's pain disbelieved may be described as the failure to accept an individual's account of his or her pain as true.

The reader should note that within the literature a similar concept is known as delegitimation. Norma Ware (1992), drawing on the work of the anthropologist Arthur Kleinman, defined delegitimation as "the experience of having one's

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perceptions of an illness systematically disconfirmed" (p. 347). Within her work in Chronic Fatigue Syndrome (CFS), Ware highlights examples of delegitimation, such as others rendering an individual's symptoms as trivial or psychologic. The concepts of being disbelieved and delegitimation are similar but not entirely synonymous. Perhaps a key difference is that an individual may have his or her experiences unintentionally discounted by others and thus experience delegitimation. This does not necessarily mean that the other person disbelieves the individual's pain account. The focus within this article will be on the disbelief of chronic pain, i.e., pain that has persisted for  $\geq 3$  months (Bond et al., 2006).

The initial starting point for this review followed contact with a review article by Clarke and Iphofen (2005). They offer an overview of the literature regarding the relationship between the health care professional and the patient in believing the patient's pain. A number of issues are highlighted. First, if patients are not taken seriously, this could compromise the accuracy of pain assessment. Second, regarding a study conducted by Werner and Malterud (2003), in which patients invest considerable amount of effort in maintaining a credible image, Clarke and Iphofen conclude that health care staff are "responsible for recognizing the suffering of the patient and should consequently aim to prevent further disempowerment" (p. 491). A third issue is that of labeling. Clarke and Iphofen suggest that labels are important in conveying the professional's belief in the patient's pain, although care is needed to ensure such labels do not disempower patients in their recovery.

Clarke and Iphofen offer an informative review with noteworthy recommendations for clinical practice. However, their review is restricted to the belief of chronic pain within the health care setting. The present authors sought to consider the wider social context (including the health care setting) in which individuals with chronic pain may experience disbelief toward their pain, for instance, within their workplace, neighborhood, and family. The focus of the present article, therefore, is on the consequences surrounding the disbelief of chronic pain and the ensuing implications this may have for health care professionals.

## METHOD

In preparation for a grounded theory study exploring the patient experience of chronic pain and being believed, a literature search was conducted. Although systematic search strategies offer a robust approach, the intention behind this review was not to undertake a systematic review of the literature but to consider the

context in which the future study would be situated. Therefore, this article comprises a descriptive summary and integration of some of the research surrounding being disbelieved. Some of the principles in undertaking this review can be found in Noblit and Hare's (1988) method of meta-ethnography, although that work was not explicitly drawn upon in this process. Such principles include the process of constant comparison, in which similarities and differences between studies are considered and integrated into a new framework.

As a starting point, a professional hospital librarian was asked to undertake a search of the literature. The librarian searched the nursing and medical databases Cinahl and Medline. This yielded 24 results. The first author then conducted a further search of a wider set of databases (Amed, BNI, Cinahl, Embase, Health Business Elite, HMIC, Medline, and Psycinfo) using the keywords "legitimise" or "legitimize" or "legitimacy," and "chronic pain." No restrictions were placed on the search date or the types of methodology used, allowing a broad scope for the review. This search yielded 50 results, of which 17 were relevant to the research topic. Both searches were conducted in July 2008 using the formerly named, and UK-based, National Library for Health search platform.

The references of relevant papers were searched to yield further papers which were obtained. Articles were read and the key points were noted. Similar issues were grouped together, yielding three main themes relating to the consequences of not being believed: stigma, the experience of isolation, and emotional distress. Table 1 provides a concise summary of these themes.

## RESULTS

The experience of being disbelieved was found to occur not only within chronic pain but also in other conditions, such as CFS. Although the experience of having one's pain being disbelieved appears to be frequently described in the literature, to the present authors' knowledge there are only a handful of papers that have explicitly investigated the experience of being disbelieved within chronic pain (Clark & Iphofen, 2008; Glenton, 2003; Kleinman, 1992; Reid, Ewan, & Lowy, 1991; Richardson, 2005; Werner & Malterud, 2003). Given the paucity of studies, the present review describes findings from studies considering other conditions, although such comparisons are speculative and require empirical validation. The purpose of including other conditions is to illuminate the experience of being disbelieved. It is not to claim that conditions such as fatigue and pain are experienced in

TABLE 1.

**Summary of Key Themes and Concepts Surrounding Disbelief in Chronic Pain**

## Theme 1—Stigma and Disbelief

- 1) Felt Versus Enacted Stigma: Discrimination can be experienced even in the absence of other people actually expressing disbelief.
- 2) The Stigma of Psychologic Explanations: With its origins in a mind-body dualism, explaining chronic pain in terms of psychologic factors can be experienced as disbelief.
- 3) Stigma and Identity: The lack of proof to demonstrate chronic pain can affect an individual's identity such that their personal integrity is challenged.
- 4) Stigma, Female Stereotypes, and the Reporting of Pain: The perception that women are more emotionally expressive and seek help more readily evokes a psychologic explanation for their pain, leading to the experience of disbelief.
- 5) Pain as the Fifth Vital Sign: Patients experience a tension between being understood and being accused of complaining about their pain. The regular assessment of pain could help here.

## Theme 2—Isolation, Disbelief, and Stigma

- 1) Isolation and Disbelief: The experience of disbelief can lead to the loss of relationships, and as a consequence individuals can become isolated.
- 2) Isolation, Stigma, and Avoidance: In the case of contested pain syndromes, patients may actively hide their diagnosis from others to avoid stigma. This can increase a sense of isolation.

## Theme 3—Emotional Distress and Disbelief

- 1) Distress and Depression Following Disbelief: Individuals can experience guilt, depression, and distress after being disbelieved. The lack of control individuals have over proving their pain might be a contributing factor.
- 2) Anger and Opposition in the Face of Disbelief: An alternative emotional response to feeling disbelieved is the experience of frustration and anger. This may be particularly pertinent where individuals encounter barriers in their pursuit of health-related goals, such as obtaining a diagnosis and pain relief. A consequence of this might be to seek help elsewhere.

similar ways, although in support of such comparisons one might consider the work by Ware (1992), who notes the similar nature of delegitimation experiences within CFS and chronic pain. Just as some individuals with chronic pain seek to have their pain recognized (Allcock, Elkan, & Williams, 2007; Clarke & Iphofen, 2008), others may need to fight to have their fatigue believed by those around them (Arroll & Senior, 2008; Cohn, 1999; Dickson, Knussen, & Flowers, 2007; Ware, 1992).

**Stigma and Disbelief**

One of the effects of not having one's pain believed is to feel stigmatized. A key father of sociology, Erving Goffman, describes stigma in a number of ways, but essentially as the possession of "an attribute that is deeply discrediting" (Goffman, 1963, p. 13). Within the chronic pain literature both felt and enacted stigma have been reported. In an exploratory study of epilepsy sufferers, Scambler and Hopkins (1986) define felt stigma as the fear of being stigmatized, whereas enacted stigma is the actual discrimination of individuals on the basis of their difference.

**Felt Versus Enacted Stigma.** Using an interpretative phenomenologic analysis (IPA) approach, Jordan, Eccleston, and Osborn (2007) reported on the distress and pressures of parenting children with chronic pain. The authors described the guilt of the parents in desiring something wrong to be found with their child, such as the parents' desperation for a diagnosis.

Conversely, the elation of parents in obtaining a medical label for their child's pain could be seen and understood in the face of feeling societal disbelief toward the reality of the pain. Intriguingly, the authors noted that their experience of disbelief was largely felt, because no particular individual expressed disbelief toward them.

The concept of felt stigma can be contrasted with enacted stigma, the actual experience of discrimination. Holloway, Sofaer-Bennett, and Walker (2007) offer detailed accounts of enacted stigma experienced by those with chronic back pain. Like Jordan et al., their study used IPA and a similar-size sample of 18 participants (17 participants in Jordan et al.). Unlike that study, however, which used a focus group approach, Holloway et al. conducted individual interviews to elicit narratives of living with chronic pain. Loss, experiences of being in various "systems" (i.e., health care and social security systems), and stigmatization were some of their main themes. Sources of such stigma were socially wide ranging and included medical professionals, employers, the general public, and even spouses. One participant reported having her medication thrown at her by a nurse and was told she was "costing the NHS far too much money" (p. 1,459). Another participant reported being told his pain was due to his lack of fitness. Still another reported receiving letters through his door accusing him of falsely claiming benefits, following the receipt of his Motability car. These experiences of enacted stigma stand in contrast with felt stigma, where there is no outright disbelief expressed toward the individual.

***The Stigma of Psychologic Explanations.*** For an individual to be legitimately ill in the eyes of others, the individual often needs to have a credible explanation for his or her illness. Moreover, there is the belief that real and legitimate diseases have organic causes (Chang et al., 2006). In chronic pain, however, it is not always possible to have a credible explanation, especially when there is a lack of evidence to demonstrate physical pathology. Bendelow (2009) describes medically contested diseases such as repetition strain injury (RSI), CFS, and chronic low back pain as those “in which the patient experiences distressing physical symptoms... but there is usually an absence of physical signs, clinical explanation, or medical diagnosis” (p. 58). Bendelow’s work highlights the problems of the Cartesian mind-body divide within medicine, describing the stigma attached to diseases of the mind. Subsequently in conditions where there is no physical evidence of tissue damage, a (stigmatizing) psychologic explanation is often drawn upon.

Lillrank (2003) supports this assertion in her analysis of 30 women’s autobiographies. She collected her data through stories entered into a writing competition which described men’s and women’s back pain experiences in Finland. In her paper she focused on the concept of diagnostic uncertainty. Because medical investigation failed to shed light on a physical cause of pain, the mind-body dichotomy was invoked: If the cause is not in the body it must be in the mind. The consequence of this for some women was for medical staff to claim the pain was in their head. Lillrank explained that this was a highly stigmatizing experience for the women, because of the moral discourse that a psychologic explanation draws on. Subsequently “the women were seen as crazy or lazy” (p. 1,051).

This point is iterated by the participants in a study by Claire Glenton (2003). She and a colleague undertook a content analysis of an online discussion board hosted by the Norwegian Back Pain Association. This consisted of ~200 contributors. Alongside this, she conducted interviews with 19 participants experiencing chronic back pain. Under the theme entitled “psychosocial and psychiatric diagnoses,” Glenton described how participants were concerned about the stigma attached to mental illness. They were also worried about their experiences being discredited if they received a psychologic diagnosis for their physical pain.

These studies highlight the stigma associated with adopting a psychologic framework for understanding pain and the impact this can have in stigmatizing—or discrediting—individuals. Health care professionals need to be aware of the potential stigma associated with a psychologic explanation of pain when interacting with patients.

***Stigma and Identity.*** A further impact of stigma arising from not being believed is its effect on identity. In an Australian sample of six women with widespread pain, Jane Richardson (2005) considered how individuals use narratives to maintain a positive identity. Richardson highlighted the Australian term “bludge” which means to “avoid responsibilities and be lazy” (p. 36). This term formed part of her main findings, with one of her themes entitled “They’re called bludgers’: delegitimation of the pain” (p. 35). Richardson described how the invisibility of pain (and the subsequent lack of evidence) threatened the identity of individuals as credible people. It also cast doubt on their identity as hard workers, because individuals were described by others as bludgers. Consequently, in an effort to maintain a credible identity, Richardson’s participants positioned themselves as hard workers.

Whereas Richardson’s work focused on the social identity constructed by individuals with chronic pain, other studies suggest that the disbelief of pain affects an individual’s self-identity. Rhodes, McPhillips-Tangum, Markham, and Klenk (1999) interviewed 70 patients, all experiencing chronic low back pain. They presented the results of a thematic analysis on a subset of 54 of these participants. A key issue they highlighted was that of the pain’s invisibility and the subsequent use of imaging techniques to make visible (or not) the underlying pathology. Sometimes imaging came into alignment with the patient’s report of pain. Sometimes it did not. In the absence of a positive test result, individuals struggled to discuss their pain with others. Indeed, the “patients may articulate a disconfirmation deep enough to threaten their sense of self-identity” (p. 1,197). Holloway et al. (2007) added that the multiple stigmatizing encounters faced by individuals are likely to challenge their self-identity. They went on to advocate the need for pain management programs to address issues of personal identity.

Further support for the impact on an individual’s self-identity can be found in the literature on CFS. Norma Ware (1992) conducted interviews with 50 Americans experiencing CFS. She wrote about the humiliation and shame experienced by this group after having their symptoms either minimized or dismissed by others: “Their shame is the shame of being wrong about the nature of reality” (p. 354). Similarly, Dickson et al. (2007) undertook 14 interviews in a UK sample of CFS sufferers. They described how the challenge toward the individual’s symptoms was interpreted as a challenge to his or her personal integrity. Participants described feelings of rejection and isolation following such challenges.

The shame, humiliation, self-doubt, and affront to the individual’s integrity experienced by those with

chronic pain and CFS suggest that being disbelieved can affect the way individuals see themselves. Given that the experience per se of having chronic pain can negatively affect an individual's sense of self (Smith & Osborn, 2007), the additional challenge of having one's pain disbelieved may act to further compound the negative effect on self-identity. Further research is warranted to specifically explore the impact of disbelief on the construction and the perception of an individual's self-identity within a chronic pain population. It may be of particular interest to observe those whose self-identity is not affected by experiencing disbelief, to identify and promote protective factors. This may then inform those who run pain management programs.

**Stigma, Female Stereotypes, and the Reporting of Pain.** The disbelief of pain experienced, particularly among women, may be compounded by negative stereotypes. These certainly abound within the research literature. For example, McGowan, Pitts, and Carter (1999) investigated how chronic pelvic pain (CPP) was viewed by general practitioners (GPs) in Britain. The authors used a telephone survey in which a total of 75 GPs were interviewed. Eighty percent of the respondents were male. At times, GPs drew on stereotypes of typical patients with CPP in their work. One GP suggested, "I'm talking anecdotally here, they're usually on the big side, quite overweight... they are anxious types, worriers" (p. 307). Another reported, "I think that if women are fat and tearful then there's likely to be a psychological component" (p. 312). For this GP, displaying emotional behavior equated to having psychological needs. Perhaps the emotions that individuals bring to the consulting room trigger a psychological discourse in the minds of others? This could potentially lead to a (stigmatizing) psychological explanation being used for the pain.

Work by Noone and Stephens (2008) revealed further negative female stereotypes around help-seeking behavior. The seven men in that study, drawn from a rural New Zealand community, constructed women as seeking medical help for trivial reasons. This enabled the men to present a positive image of themselves, potentially serving to minimize the illness experience in women. Frantsve and Kerns (2007) described the increased burdens faced by women in the medical consultation, highlighting work by Werner and Malterud (2003) which suggests physicians may be biased against women as they struggle with the tension of appearing either too healthy or too sick.

As previously described, Richardson (2005) presented individual accounts of women who sought to construct a positive identity of themselves. Those par-

ticipants avoided being identified as individuals who excessively talk about their pain. To complain too much is to risk undermining one's authenticity (Frantsve & Kerns, 2007) and subsequently one's credibility. However, to underplay one's illness experience may be to risk not being taken seriously (Richardson, 2005), effectively leaving individuals in a bind.

This brief consideration of the literature regarding female stereotypes appears to suggest that women may be more prone to stigma, a situation potentially fueled by the prominent "histrionic" stereotype (Smith-Rosenberg, 1984). This does not exclude the possibility, however, that men may also experience the tension between appearing healthy and sick.

**Pain as the Fifth Vital Sign.** Indeed, health care professionals need to be aware of the tension patients face between adequately describing their pain to be understood and not overplaying their story so as to risk the accusation of complaining about their pain. Perhaps one way of overcoming this tension is through a more structured assessment of the patient's pain. In recent years the notion of viewing pain as the fifth vital sign has come to the foreground, advocating the necessity to regularly assess pain severity in patients (Royal College of Nursing [RCN], 2008).

Within the UK, this is currently being championed by the Chronic Pain Policy Coalition (2009). Only 15% of patients report completing a simple pain assessment based on a scoring system, a statistic highlighted in the recent Chief Medical Officer's report in the UK (Donaldson, 2009). There is certainly scope for more widespread assessment of pain. Through the process of regularly assessing pain, patients may perceive that they have an invitation to openly express their pain severity to the health professional. According to some (RCN, 2008), the implementation of pain as a vital sign may not actually prove to be the substantial financial burden one might expect, thus increasing the attractiveness of its implementation.

In addition to regular pain assessment, nursing staff might make use of simple techniques to affirm the patient's pain. Clarke and Iphofen (2005) suggested strategies such as giving the patient permission to stand if necessary and offering physical support while the patient is walking. These and other simple human touches in the nurse-patient encounter may help to increase the confidence of patients that nursing staff appreciate the seriousness of their pain experience. Such confidence may subsequently ease the tension surrounding the adequate expression of pain to both nursing and medical staff.

**Summary of Stigma and Disbelief.** To summarize, stigma associated with the disbelief of pain may come from a wide variety of sources, including health

care professionals. Individuals may experience stigma both in the presence and in the absence of expressed disbelief of their pain. The experience of stigma may come through psychologic explanations of their pain being used or inferred. This is an issue that all health care professionals need to be aware of when dealing not only with chronic pain, but also with other conditions where there is no clear underlying pathology.

The impact of chronic pain and disbelief on identity is an issue that warrants further investigation. To avoid feeling discredited, individuals may seek to construct a positive identity. Conversely, the experience of disbelief may have the potential to adversely affect the way an individual sees him- or herself. Related to identity is the use and misuse of female stereotypes. Women who are more emotionally expressive may be perceived to have psychologic problems. This is entangled with the issue of how to effectively describe and express one's pain. The systematic use of a pain assessment tool may be one way to avoid the tension that patients face between the adequate expression of their pain and being taken seriously.

### Isolation, Disbelief, and Stigma

The experience of isolation is common in chronic illness. Isolation can be understood as the experience of physical distance of others from oneself. It may also be the experience of emotional distance, in that one may have close proximity with others while lacking a sense of emotional connection with them. Richardson (2005) highlighted how individuals with any form of invisible symptom (including chronic pain and CFS) can experience isolation. Within the field of chronic illness, Radley (1994) described how physical disability can lead to social isolation through restricted mobility. He also highlighted the impact of individual fears about how others will respond to them, suggesting that isolation can also be self-imposed to some extent as a strategy to avoid unfavorable responses from others.

Those suffering from chronic pain are by no means exempt from the experience of isolation, and in the present section a number of studies are presented that illustrate how individuals with chronic pain experience isolation. In particular the role of stigma, avoidance, and the experience of disbelief toward chronic pain will be implicated as contributing to the experience of isolation.

**Isolation and Disbelief.** Walker, Sofaer, and Holloway (2006) offered a detailed account of the losses experienced by those with chronic back pain. They undertook a narrative approach, interviewing 20 participants, and found that individuals experience loss in areas such as work, finance, relationships, identity, and hope. One participant recalled how "you're

stuck at home, you become a prisoner in your own home. Your life is the pain is your cell" (p. 204). Pain serves to restrict physical movement which subsequently serves to isolate individuals. Another participant described losing his relationship with his wife after her disbelief of his pain: "My wife even turned on me, thinking it was all put on... From that point on I've just lived on my own" (p. 203). Although Walker et al. did not explicitly describe the experience of isolation, the very experience of losing close friendships can serve to physically isolate the individual, with the ensuing (emotional) experience of loneliness made more likely.

Clarke and Iphofen (2008) identified isolation as a key part of life with chronic pain. Using a phenomenologic approach, they interviewed eight patients with chronic pain and analyzed the diaries that they kept. Their study highlighted the unseen nature of pain. Indeed the invisibility of pain led one of their patients to think that people in her church believed she was lying about the existence of her pain. As a result, she stopped attending her church, subsequently isolating herself from that community. Her account concurs with the disbelief expressed in the study by Walker et al. (2006) and adds support to the link between the experience of disbelief and subsequent isolation. Further research could provide empirical data to support this association.

Clarke and Iphofen then discussed how the lack of a medical label can prevent individuals from revealing their pain to others: "This lack of diagnosis or label for the chronic pain patient becomes the cloak of invisibility that hides chronic pain from the outside world" (Clarke and Iphofen, 2008, p. 662). With their pain out of sight from the world it is perhaps harder for others to emotionally connect with the daily experience of pain experienced by individuals. Individuals subsequently suffer not only the pain itself but also the isolation caused by the hidden nature of pain. This unseen pain hides from others, what is for many, a major part of their lives.

**Isolation, Stigma, and Avoidance.** In addition to the experience of disbelief, expressed or perceived, the experience of stigma can further serve to isolate individuals with chronic pain. With negative labels such as "social security sneaker" associated with chronic back pain (Glenton, 2003) and "compo bludger" associated with RSI (Reid, Ewan, & Lowy, 1991) it is understandable that individuals with stigmatizing illnesses may hide their symptoms from others (Brown, 1995; Reid et al., 1991).

Although pain may attract judgemental labels, medically sanctioned labels may also be experienced by patients as stigmatizing. Sim and Madden (2008)

undertook a meta-synthesis of qualitative studies considering fibromyalgia, a contested diagnosis in which individuals experience widespread pain. Whereas Clarke and Iphofen highlight the difficulty faced in the absence of a diagnostic label, the evidence presented in Sim and Madden's review (Mannerkorpi, Kroksmark, & Ekdahl, 1999; Schaefer, 2005) suggests that having an undesirable label, such as fibromyalgia, may lead to individuals hiding this from others. Studies in their review suggest those with fibromyalgia hide their diagnosis from others in an attempt to control the stigma and disbelief they can face from others. Although the process of hiding their diagnosis may be functional, it may inadvertently shut off part of their life from others, increasing a sense of isolation.

Holloway et al. (2007) presented two cases that lend further support to the link between isolation and stigma through the process of avoidance. In one case, an individual avoided seeking medical help for fear of being labeled a hypochondriac. In another case, a patient reported her distress at being treated by junior medical staff. The authors described how the consultants seemed to avoid treating patients with negative (and therefore uninteresting) test results. Stigma may therefore serve to increase social distance between the individual and those around them, in these cases health professionals. Further research is required to observe whether this is indeed so.

Of course, individuals do not always avoid others or hide their symptoms. For example, Werner and Malterud (2003) suggested that the consulting room provides an arena for individuals to stage a carefully scripted performance for their medical audience. This idea has received some support from Waddell, Bircher, Finlayson, and Main (1984), who concluded that it is essential for clinicians to distinguish between physical disease and illness behavior. The signs from one are not necessarily the same as those from the other. Perhaps there is room for professionals to embrace the message that patients are trying to communicate in the midst of their performance, even when a corresponding organic basis cannot be detected. The lack of physical signs and symptoms in the midst of the patient's pain experience did not prevent Waddell et al. from recognizing the vital role of the doctor as healer, a role that could be fulfilled only if the professional enters into the patient's presentation of his or her pain.

**Summary of Isolation, Disbelief, and Stigma.** The experience of chronic illness and, in particular, chronic pain can be an experience of social isolation. The invisible nature of pain and the experience of loss, disbelief, and stigma can all contribute to the isolation process. Although the physical disabilities that

individuals with chronic pain may have, potentially serve to restrict social interactions, some of the evidence presented in this section suggests that individuals themselves may initiate isolation. This can serve to offer protection from social stigma. The health care professional may be able to cut through some of the isolation experienced in patients with chronic pain through connecting and affirming the patient and his or her experience of pain. As the professional begins this process, the hidden nature of pain can be slowly uncovered, allowing a shared understanding of chronic pain to be gained.

### **Emotional Distress and Disbelief**

The presence of emotional distress is evident in those with chronic pain. For example, in an American sample of 511 chronic pain Veterans, Tan, Jensen, Thornby, and Sloan (2008) demonstrated an association between negative emotional experiences (for example, depression and anxiety) and an individual's pain and functioning. They also found a direct link between anxiety and disability, which they attributed to fear-avoidance behaviors. These associations were supported in an in-depth study of 18 individuals (Allcock et al., 2007): Following three focus groups of individuals recruited from a pain clinic, Allcock et al. found that those with chronic pain and poor mental health experienced insomnia, depression, anxiety, and irritability.

#### ***Distress and Depression Following Disbelief.***

More specifically, others have documented the presence of emotional distress in response to the disbelief of chronic pain. For example, Clarke and Iphofen (2008) noted that "the lack of explanation, the absence of physical signs to prove the pain narrative, and the feelings of being disbelieved by health care professionals caused great distress" (p. 661). This distress included depression. In support, they quoted one of their participants who reported suicidal ideation following others not believing the severity of her pain. Holloway et al. (2007) concurred with the association between depression and disbelief: Although they did not present any significant number of quotes in support, they did assert that their data backed up "the claim of Roy (2001) that there is a 'prima facie' case for accepting that depression of chronic pain patients is congruent with their life experiences and feelings of being seen as discredited" (Holloway et al., 2007, p. 1,462). In the absence of tangible evidence, perhaps individuals experience feelings of helplessness at being unable to prove their pain. They are powerless to demonstrate the reality of their chronic pain. The depression associated with such helplessness could then represent a form of the "learned helplessness"

proposed by Seligman (1975). Clearly, further research is needed to support an association between depression and the disbelief of pain.

A mixed-methods study ( $n = 52$ ) undertaken by Reid et al. (1991) revealed evidence of emotional distress in response to the disbelief of the painful condition, RSI. The authors described how “their [work colleagues’] skepticism was hurtful and humiliating, especially when a number were work friends whom the women had known for 20 or more years” (p. 605). Indeed the work atmosphere faced by the women in that study appeared to be one that was openly hostile to the experience of RSI. In addition to the skepticism the workers faced, any suggestion that questioned the legitimacy of taking sick leave associated with RSI compounded the feelings of guilt and depression experienced by the participants. In summary, the consequence of disbelief and outright hostility led to emotional distress presenting in different forms.

#### ***Anger and Opposition in the Face of Disbelief.***

Another aspect of emotional distress associated with being disbelieved is the frustration or anger that ensues. Several examples of this are presented in this section. For example, in highlighting the lack of objective signs associated with pain, Glenton (2003) described the anger expressed by one young girl: “The worst thing about not having a diagnosis is that a lot of people treat you like a drug addict. I hate those people! People like that do not know what it means to be in pain” (p. 2,247). The anger and hatred expressed here followed being misunderstood. If others knew what life with pain was like they might be slower to mislabel her. Glenton went on to describe the frustration experienced after the receipt of a psychologic diagnosis or explanation. As previously discussed, the use of psychologic labels can be experienced as stigmatizing. Glenton’s work subsequently demonstrated the anger and frustration associated with that experience.

Returning to the work by Reid et al. on RSI, there was evidence of great anger following the need to prove one’s pain. They describe the women adopting a “combative stance” (Reid et al., 1991, p. 608) to deal with assessments by insurance specialists. One woman expressed it this way: “I sit down there [in court] and put my arm on the Bible and said ‘If any God anywhere they can punish me if I tell lies, but I wish they punish them because they tell lies’” (p. 608). The women in that study constructed physicians as medical police who guard diagnostic boundaries. Failure to secure a diagnosis could be synonymous with a failed compensation claim. The authors described how patients left feeling angry because they were under the impression that the doctor had already made up his or her mind.

The notion of medical police betrays a perceived imbalance of power. A failed battle to convince the health professional of the legitimacy of one’s illness can have painful consequences for the individual. The doctor-patient relationship for some of these patients was far from collaborative.

Lillrank (2003) supported the experience of patient-led opposition in response to feeling disbelieved. She documented the persistence of women in believing that their pain was of a physical origin despite the adversity of medical uncertainty. Indeed, in response to experiencing disbelief of their pain from professionals who they had initially consulted, they pursued expert knowledge from other specialists. Moreover, Lillrank noted that the inability of some specialists to handle uncertainty led them to deny the patient’s pain. This undoubtedly conflicted with the patient’s goal of pain relief, helping to explain the necessity of the women’s fighting stance. Ultimately, however, the opposition put up by individuals, perhaps as part of their fight for recognition, can lead to fatigue. Jordan et al. (2007) documented how the parents in their research experienced exhaustion following the battle to secure resources for their child with chronic pain. Dickson et al. (2007) similarly describe the exhaustion following the pursuit of a CFS diagnosis, a painful irony given the inherent fatigue already suffered by those with CFS.

#### ***Summary of Emotional Distress and Disbelief.***

This section considered the emotional consequences of experiencing disbelief of one’s pain. There are already strong empirical data documenting the association of poor mental health with chronic pain. Qualitative research adds to the literature base by suggesting that the experience of disbelief can lead to depression, guilt, and anger.

The lack of control over the ability to prove one’s pain to others may contribute to experiences of depression. In the face of being disbelieved, individuals may also experience frustration or anger toward others; this may be especially so when individuals feel they are being blocked from accessing services or benefits. Health care professionals could help alleviate much of the emotional distress these patients experience. Were professionals to express their acceptance of the pain experience, patients may be less likely to adopt a “combative stance” toward them. Moreover, by empowering the patient with health care options, belief in the pain experience is communicated in a way that could counter experiences of learned helplessness. This could be as simple as providing information about different treatment options and therefore facilitating an informed choice.

Individuals whose pain is not recognized by professionals may actively seek recognition by pursuing



**TABLE 2.**  
**Summary of Recommendations for Health Care Professionals**

- 1) Professionals need to be aware that using psychologic explanations of pain can be experienced as a denial of the individual's pain. Caution must be exercised when using psychologic models with patients.
- 2) It is essential to be aware of the tension that patients can experience in the expression of their pain. Professionals might seek to openly invite patients to express their pain. This could form part of a regular assessment of the patient's vital signs.
- 3) As the professional understands and affirms the patient's story of their pain, both parties may develop a shared understanding, helping to address not only the patient's experience of isolation but also the anger and frustration that can stem from not being taken seriously.
- 4) Empowering the patient with health care options could be an essential step toward countering experiences of helplessness, particularly given the lack of control many patients experience in the persistence of their pain.

other medical opinions. Indeed, symptom legitimization has been described as one reason for seeking medical help (Main & Williams, 2002). The pursuit of multiple medical consultations to achieve recognition of one's pain may well have an economic impact on health services. Further research could investigate whether this is indeed the case.

Finally, it is of interest to note the variation in potential responses to being disbelieved: Some individuals are passive and may experience depression, whereas other individuals feel angry and are driven to seek further recognition. Further research could explore some of the factors that contribute to the behavioral and emotional responses to disbelief.

## CONCLUSIONS

This article set out to highlight the impact that being disbelieved has on individuals with chronic pain. Evidence has been presented to demonstrate this impact across three areas, namely, stigma, the experience of isolation, and the experience of emotional distress. Throughout this article, the authors have also sought to highlight how health care professionals might try to deal with disbelief in their clinical practice. Table 2 offers a summary of key recommendations for clinicians.

There is strong evidence to suggest that the experience of being disbelieved is stigmatizing. The concepts of felt and enacted stigma proposed by Scambler and Hopkins (1986) offer insight into the different ways that stigma can be experienced. Their concepts are supported within the present literature review: Even in the absence of expressed disbelief, individuals can feel stigmatized. Further research might seek to explore some of the factors underpinning the experience of felt stigma, given that the cause lacks clarity in contrast to that of enacted stigma.

A common stigmatizing discourse that is often drawn upon in the absence of physical pathology is to construct the source of pain as psychologic. This has been shown to discredit the illness experience of

individuals. Other work highlights how the emotional nature that is depicted in stereotypic views of women draws on a psychologic discourse to discredit the reality of pain. This may further affect the manner in which individuals are able to talk about their pain.

The invisibility of pain is possibly the central problem that sufferers face, and it is this aspect of pain that affects the identity of individuals. The lack of evidence to demonstrate the reality of the individual's experience may lead others to question the credibility of the patient. Such questioning can affect the sense of integrity that individuals wish to maintain.

The second major theme, isolation, receives some support from the literature, though not to the extent as stigma. The lack of credibility that individuals with chronic pain may have can lead to the loss of relationships, subsequently causing isolation. In some instances this isolation may be self-imposed as individuals seek to avoid the stigma attached to medically contested syndromes. Given the individual nature of living with pain, further research might seek to explore how individuals cope with experiences of isolation and how the health care professional might seek to enter into the world of the patient.

The final theme, emotional distress, again receives only moderate support from the literature and would benefit from empirical research to validate the association with disbelief. There is evidence to suggest that depression and disbelief are related, although it is likely there are mechanisms other than the learned helplessness proposed in the present article that precipitate the associated depression. There is clearly considerable anger and frustration following being disbelieved. This is understandable, given the strong desire individuals have for their pain to be recognized.

Most of the evidence presented in the present article stems from qualitative research, with a wide range of qualitative approaches used. These include a large-scale analysis of a discussion board (Glenton, 2003), narrative approaches (Walker et al., 2006), and the use of IPA within focus groups (Jordan et al., 2007). The high

utilization of qualitative methodology can be appreciated with the experiential nature of disbelief in chronic pain. However, the use of quantitative methods could be drawn on beneficially to both test and provide further evidence for the associations described in this article.

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## REFERENCES

- Allcock, N., Elkan, R., & Williams, J. (2007). Patients referred to a pain management clinic: Beliefs, expectations and priorities. *Journal of Advanced Nursing*, *60*(3), 248–256.
- Arroll, M. A., & Senior, V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology & Health*, *23*(4), 443–458.
- Bendelow, G. (2009). *Health, emotion and the body*. Cambridge, UK: Polity Press.
- Bond, M., Breivik, H., Jensen, T., Soyannwo, O., Treede, R., Scholten, W. (2006). Pain associated with neurological disorders. In *Neurological disorders: Public health challenges* (ch. 3.7, available online from <http://www.iasp-pain.org>), Geneva: WHO.
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior*, (Extra Issue), 34–52.
- Chang, L., Toner, B. B., Fukudo, S., Guthrie, E., Locke, G. R., Norton, N. J., & Sperber, A. D. (2006). Gender, age, society, culture, and the patient's perspective in the functional gastrointestinal disorders. *Gastroenterology*, *130*(5), 1435–1446.
- Chronic Pain Policy Coalition (2009). Retrieved May 27, 2009, from <http://www.paincoalition.org.uk/>.
- Clarke, K. A., & Iphofen, R. (2005). Believing the patient with chronic pain: A review of the literature. *British Journal of Nursing*, *14*(9), 490–493.
- Clarke, K. A., & Iphofen, R. (2008). A phenomenological hermeneutic study into unseen chronic pain. *British Journal of Nursing*, *17*(10), 658–663.
- Cohn, S. (1999). Taking time to smell the roses: Accounts of people with chronic fatigue syndrome and their struggle for legitimisation. *Anthropology & Medicine*, *6*(2), 195–215.
- Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health*, *22*(7), 851–867.
- Donaldson, L. (2009). *150 years of the annual report of the Chief Medical Officer: On the state of public health 2008*. London: Department of Health.
- Frantsve, L. M. E., & Kerns, R. D. (2007). Patient-provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. *Pain Medicine*, *8*(1), 25–35.
- Glenton, C. (2003). Chronic back pain sufferers—striving for the sick role. *Social Science & Medicine*, *57*(11), 2243–2252.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Penguin.
- Holloway, I., Sofaer-Bennett, B., & Walker, J. (2007). The stigmatisation of people with chronic back pain. *Disability and Rehabilitation*, *29*(18), 1456–1464.
- Jordan, A. L., Eccleston, C., & Osborn, M. (2007). Being a parent of the adolescent with complex chronic pain: An interpretative phenomenological analysis. *European Journal of Pain*, *11*(1), 49–56.
- Kleinman, A. (1992). Pain and resistance: The delegitimation and re-legitimation of local worlds. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience: An anthropological perspective*. California: University of California.
- Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science & Medicine*, *57*(6), 1045–1054.
- Main, C. J., & Williams, A. C. de C. (2002). ABC of psychological medicine: Musculoskeletal pain. *British Medical Journal*, *325*(7363), 534–537.
- Mannerkorpi, K., Kroksmark, T., & Ekdahl, C. (1999). How patients with fibromyalgia experience their symptoms in everyday life. *Physiotherapy Research International*, *4*(2), 110–122.
- McCaffery, M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles: UCLA Students Store.
- McCaffery, M., & Pasero, C. (1999). *Pain: Clinical manual*, (2nd ed). St. Louis: Mosby.
- McGowan, L., Pitts, M., & Carter, D. C. (1999). Chronic pelvic pain: The general practitioner's perspective. *Psychology, Health & Medicine*, *4*(3), 303–317.
- Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies*. California: Sage.
- Noone, J. H., & Stephens, C. (2008). Men, masculine identities, and health care utilisation. *Sociology of Health & Illness*, *30*(5), 711–725.
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.
- Reid, J., Ewan, C., & Lowy, E. (1991). Pilgrimage of pain: The illness experiences of women with repetition strain injury and the search for credibility. *Social Science & Medicine*, *32*(5), 601–612.
- Rhodes, L. A., McPhillips-Tangum, C. A., Markham, C., & Klenk, R. (1999). The power of the visible: The meaning of diagnostic tests in chronic back pain. *Social Science & Medicine*, *48*(9), 1189–1203.
- Richardson, J. C. (2005). Establishing the (extra)ordinary in chronic widespread pain. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *9*(1), 31–48.
- Roy, R. (2001). *Social relations and chronic pain*. New York: Kluwer/Plenum.
- Royal College of Nursing. Pain: The 5th Vital Sign. July 23, 2008. Retrieved June 2, 2009, from <http://www.rcn.org.uk/>.
- Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health & Illness*, *8*(1), 26–43.

- Schaefer, K. M. (2005). The lived experience of fibromyalgia in African American women. *Holistic Nursing Practice, 19*(1), 17-25.
- Seligman, M. E. P. (1975). *Helplessness: On depression, development, and death*. San Francisco: W.H. Freeman and Co.
- Sim, J., & Madden, S. (2008). Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. *Social Science & Medicine, 67*(1), 57-67.
- Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health, 22*(5), 517-534.
- Smith-Rosenberg, C. (1984). The hysterical woman: Sex roles and role conflict in 19th-century America. In N. Black, D. Boswell, A. Gray, S. Murphy, & J. Popay (Eds.), *Health and disease: A reader* (pp. 25-33). Milton Keynes: Open University.
- Tan, G., Jensen, M. P., Thornby, J., & Sloan, P. A. (2008). Negative emotions, pain, and functioning. *Psychological Services, 5*(1), 26-35.
- Waddell, G., Bircher, M., Finlayson, D., & Main, C. J. (1984). Symptoms and signs: Physical disease or illness behaviour? *British Medical Journal, 289*(6447), 739-741.
- Walker, J., Sofaer, B., & Holloway, I. (2006). The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. *European Journal of Pain, 10*(3), 199-207.
- Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly, 6*(4), 347-361.
- Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors. *Social Science & Medicine, 57*(8), 1409-1419.