Psychosocial Aspects of Persistent Pain

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Declaration

I, Olivia Charlotte Twigg, declare that the work presented in this thesis is original and my own work. This thesis contains original research undertaken during the Doctor of Philosophy (Clinical Psychology) at the Research School of Psychology of The Australian National University. This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is noted in the thesis itself.

Signed

Date 17/10/14
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Abstract

The biopsychosocial model posits that biological, psychological, and sociocultural variables interact in a dynamic manner to shape an individual’s response to persistent pain. Yet while this model is widely accepted in the formulation and management of pain, psychosocial factors are neglected in much of the persistent pain literature. As such, this program of research presents an examination of psychosocial factors, chiefly through considering internalised stigma from the perspective of people with pain, but also through examining pain judgments from the perspective of future healthcare providers.

Internalised stigma reflects a process where the anticipation or experience of negative sociocultural reactions based on pain are essentially turned inward, leading to negative feelings about self, identity transformation, or maladaptive behaviour. Study 1 presents a community based study that assessed the prevalence of internalised stigma and its interrelationships with self-concept and psychological well-being among people with pain (n = 92). Results demonstrated that a large percentage of participants (38%) endorsed the experience of internalised stigma. Internalised stigma had a negative relationship with self-esteem and pain self-efficacy, after controlling for depression. It was also associated with cognitive responses to pain, in terms of greater catastrophisation and a reduced sense of personal control over pain. Study 2 employed a longitudinal design to consider whether internalised stigma predicted the pain self-efficacy and self-esteem of people with pain (n = 57). Main findings suggested that an aspect of internalised stigma, social withdrawal, predicted reduced self-esteem six months later, when taking baseline self-esteem into account. While findings are tentative, they provide
evidence of the vicious cycle that can arise from experiencing internalised stigma in terms of isolation and decreased confidence in oneself.

Study 3 utilised a quasi-experimental design to consider the modifiable nature of internalised stigma and its capacity to be targeted in treatment. Participants in a cognitive-behavioural pain management program provided pre- and post-program measures (n = 45). Main results indicated that participation in the rehabilitation program was associated with decreased internalised stigma and increased stigma resistance in people with persisting pain. Disability and pain self-efficacy, but not depression, were identified as correlates of change. Finally, Study 4 examined the role of contextual variables in judgments of medical and nursing students (n = 116) by employing a within-subjects experimental vignette paradigm. Main findings suggested that psychosocial factors can have an important influence on perceptions of patients and their pain, including perceived malingering, but this often occurred in interaction with other patient variables.

Findings of the four studies are discussed within the context of a biopsychosocial pain formulation. Both socio-cognitive and socio-psychological theories are utilised in the interpretation of findings. Furthermore, discussion considers how this program of research augments qualitative work and builds upon research on internalised stigma in the mental health field. Promising implications for clinical practice, particularly the assessment and tailored targeting of internalised stigma as part of pain management, are discussed. This thesis presents novel findings in an area that has little existing evidence, and provides the empirical beginnings of a fruitful area of research.
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Chapter 1: Contextual Statement

1.1 Persistent Pain Background: Definition, Impact, and Prevalence

The International Association for the Study of Pain (2011) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". A key aspect of this definition is allowing for multiple contributing factors to the perception and experience of pain, rather than solely considering the presence of tissue damage. The definition reflects the fact that the relationship between tissue damage and pain is variable, with current knowledge reflecting the role of an individual’s interpretation of pain (Access Economics, 2007). The definition also notes that pain is an experience that encompasses sensory and emotional aspects. Finally, pain is subjective; there are no objective measures of it.

While there are a number of ways to categorise pain, chronic versus acute is one typically used in the field. The focus of this thesis is on persistent pain, also referred to as chronic pain, and the two terms will be used interchangeably throughout this thesis. Chronic pain is constant daily pain that has persisted for a period of at least three months in the previous six months (International Association for the Study of Pain, 2011). Chronic pain does not have a fixed time point at which it is distinguished from acute pain, but rather reflects that pain has persisted past the normal time of healing for the initial damage.

One in five Australians experience chronic pain at some point in their lives (Blyth et al., 2001). There are, however, disparities in the prevalence, and risk of inadequate treatment, across population groups, with higher risk being variously associated with age (older persons), gender (females), socioeconomic status (low), ethnicity (English as a second language) and geographic location (regional and
remote communities) (Blyth, van der Windt, & Croft, 2010; Institute of Medicine (US), 2011). Chronic pain is Australia’s third most costly health problem at $34 billion per annum (Access Economics, 2007). Van Leeuwen and colleagues (2006) have reported on the high cost of chronic pain to Australian employers from absenteeism but also reduced work effectiveness when present. People with persisting pain are also more likely to access healthcare services and have a higher frequency of visits (NSW Health Department, 1999). Similar financial burdens due to loss of productivity and health care utilisation have been reported internationally, for example, estimates suggest chronic pain’s annual cost in the United States is $560 to $635 billion (Gaskin & Richard, 2012). Thus, chronic pain presents both a financial and social challenge to society.

As the chronicity of pain increases, a number of other consequences can occur. While approximately 20% of Australians experience persistent pain, the impact this has on an individual varies. Estimates suggest that about 10% of people experience pain that interferes with their daily lives (11% males, 14% females; Blyth et al., 2001). Beyond the physical experience, pain affects an individual across multiple domains (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Sanders, Harden, & Vicente, 2005). It is important to note that chronic pain is not just uncomfortable; it can have a drastic effect on multiple areas of a person’s life including their relationships, employment status, mental health, and quality of life (Blyth et al., 2001; Gureje, Von Korff, Simon, & Gater, 1998; Hadjistavropoulos et al., 2011; Hogg, Gibson, Helou, DeGabriele, & Farrell, 2012; van Leeuwen et al., 2006).

1.2 Current Management of Persisting Pain

1.2.1 Pain management. Pain relief represents a fundamental human right, and an enormous human suffering stems from the inability to access effective pain
management (Brennan, Carr, & Cousins, 2007). There is an increasing acknowledgement in the field that the delivery of care to those living with chronic pain can be greatly improved. The Australian National Pain Strategy (2010) indicated that while less than 10% of people gain access to effective management for their pain, up to 80% could have their pain adequately managed. Unfortunately, there is often no cure for persisting pain hence the focus typically centres on effective palliation of the condition. Effective pain management essentially reflects minimising the impact of pain on a person’s quality of life and decreasing the use of health care services (Access Economics, 2007).

There is a growing recognition of the role of multidisciplinary programs in ensuring optimal pain management. Within a pain context, cognitive-behavioural programs have been established as effective and efficacious in improving long-term patient outcomes, including psychological well-being, physical functioning, pain experience, and decreasing pain interference (Morley, Williams, & Hussain, 2008; Williams, Eccleston, & Morley, 2012). Such programs are based on principles of a biopsychosocial model (reviewed below) and seek to achieve three broad aims: to improve the ability to self-manage pain and increase functioning; to treat comorbidities such as depression or anxiety; and to improve adherence to biomedical management while facilitating increased quality of life (Gatchel et al., 2003; National Pain Summit Initiative, 2010; Schultz et al., 2008; Williams, Nicholas, Richardson, Pither, & Fernandes, 1999). Multidisciplinary pain programs based on such principles are now being successfully delivered in Australia, Canada, the United Kingdom, the United States of America, and more recently South East Asia (Cardosa et al., 2012; Cousins, 2009; Molloy et al., 2006; Williams et al., 1999).
1.2.2 Australia’s National Pain Strategy. One effort that reflects a growing trend to improve pain management and effectiveness is the National Pain Strategy (National Pain Summit Initiative, 2010). Released in 2010, the National Pain Strategy reflected the first comprehensive initiative to systematically work towards improving the assessment and treatment of pain in Australia. The Strategy has six overarching goals: Goal 1: People in pain as a national health priority; Goal 2: Knowledgeable, empowered and supported consumers; Goal 3: Skilled professionals and best-practice evidence-based care; Goal 4: Access to interdisciplinary care at all levels; Goal 5: Quality improvement and evaluation; Goal 6: Research. Within Goal 1, a priority objective is to de-stigmatise the predicament of people with pain, especially chronic non-cancer pain. In order to work effectively towards such an objective, it is beneficial to first quantitatively measure the experience of stigma from the perspective of people with pain. This offers an opportunity to describe and understand the phenomenon across a larger sample of participants, to examine relationships between variables, and to assess for change that may be produced through the instigation of policy and guidelines. The absence of research on how stigma affects an individual with pain reflects an information gap underpinning the National Pain Strategy objective. The research program reported in this thesis seeks to contribute to addressing this gap. More broadly, the thesis aligns itself with the Strategy’s goals, particularly contributing towards Goals 1, 2, 3, and 6.

1.3 Conceptualisation of Pain: The Biopsychosocial Model

Traditional conceptualisations of pain came from a biomedical model of health, where the sole focus was on the role of etiological and pathophysiological explanations of chronic pain. Little, if any, focus was given to psychological or social factors which may exacerbate or maintain chronic pain conditions. However,
when Melzack and Wall's (1965) Gate Control Theory emerged in the mid twentieth century, the focus of research and conceptualisation of pain developed beyond a biophysical one. Importantly, Gate Theory emphasised the role of central nervous system mechanisms in the pain process, through positing that the brain is an active system involved in filtering, modulating, and selecting input (Melzack, 1993). This theory therefore conceptualised psychological factors as central to the processing of pain and thus new management targets were identified (Melzack, 1993). Melzack and Casey (1968) went on to argue that the experience of pain reflects a composite of sensory-discriminative, cognitive-evaluative, and motivational features. This represented a new way of conceptualising pain as more than a purely biomedical model. Engel (1977) was also among the first authors in the area to call for a new approach to the reductionist models which characterised the medical field. These new conceptualisations sparked a growth in research and progress that has led to the eventual development of the biopsychosocial perspective to chronic pain.

The biopsychosocial model is currently the most widely accepted model for the understanding and treatment of chronic pain (Gatchel et al., 2007). In contrast to traditional viewpoints, where the focus is on a single dimension, the biopsychosocial perspective is multidimensional and encompasses a number of perspectives. A biopsychosocial formulation of pain seeks to make sense of pain phenomena through the consideration of three main contributors and their interactions. As the name suggests, it is an integrated model which posits that biological, psychological, and sociocultural variables interact to shape an individual's experience of, and response to, chronic pain (Turk & Okifuji, 2002). As a starting point, it suggests that some physical pathology or change in the individual's muscles, joints, or nerves must occur, which generates nociceptive input to the brain (Turk & Okifuji, 2002). Such
input then produces psychological effects (i.e. pain appraisal and interpretation), as the individual perceives pain. This may involve attribution of the pain, as well as explanations and influences on future behaviour that can affect the body (e.g. activity withdrawal leading to muscle deconditioning). This appraisal process occurs within the context of the individual’s beliefs, which are shaped by factors such as previous experiences and personality traits. Responses to pain occur in a bidirectional manner in terms of cognitive and emotional associations. Such psychological interactions are grounded within the individual’s social context, such as their interpersonal relationships and dealings in the health care system. In summary, biopsychosocial models of chronic pain consider the way in which biological, psychological and social factors interact in a dynamic and multidirectional way to cause and maintain chronic pain (Turk & Okifuji, 2002).

The biopsychosocial model is important in broadening the focus of healthcare professionals to encompass psychological and social factors, and therefore offers new treatment targets for reducing pain-related distress and disability (Nicholson Perry, 2012). Through its conceptualisation of pain, this model argues that these contributing factors need to be addressed in interventions or else pain becomes a long term problem with increased disability, distress, and cost (Access Economics, 2007; Boersma & Linton, 2005; Turk, 2002).

**1.4 Psychosocial Factors in the Experience of Pain**

Although biopsychosocial models emphasise multiple areas, research is typically focussed on the intrapersonal aspects and leaves the social dimensions “relatively unexamined” (Hadjistavropoulos et al., 2011). And yet pain occurs in a social context, with interpersonal features being extremely important to shaping experience. Blyth, Macfarlane, and Nicholas (2007) have argued that although many
studies on people with pain argue for the importance of psychosocial factors they
typically look the ‘psycho’ aspect of this rather than examining social-environmental
influences. Thus, psychosocial factors are neglected in much research to date (Blyth
et al., 2007; Nielsen, 2007).

1.5 Psychosocial Experience: The Role of Stigma

Stigma, a Greek work for ‘mark’, has been stressed as an important way to frame the meaning and suffering of those in society. The roots of contemporary work in stigma come from Goffman’s (1964) *Notes on the Management of a Spoiled Identity*. Goffman (1964) considered stigma to refer to an attribute or ‘mark’ that is deeply discrediting and differentiates a person from the rest of society. He suggested that there are three broad types of stigma. Firstly, there are abominations of the body, which refers to a variety of physical deformities. Secondly, there is stigma related to individual character, such as mental disorder, imprisonment, addiction, or homosexuality, in which the individual is perceived as weak willed, domineering or having unnatural passions. Finally, “tribal” differences may also lead to stigma, as is the case with race, nationality or religion. Goffman (1964) argued that a wide range of imperfections tend to be imputed upon the stigmatised individual, purely on the basis of the original imperfection. In the case of chronic pain sufferers, which will be discussed in greater detail below, it is the second aspect of stigma which applies, whereby character blemishes rather than the chronic pain are the cause of stigma. That is, problems are not typically caused by the physical characteristics of pain but rather questions around weakness of will, addiction to drugs, perceived illegitimacy or mental illness (Glenton, 2003).

The work of Goffman (1964) was extended in the conceptual framework of Jones et al.’s (1984) *Social Stigma: The Psychology of Marked Relationships*. The
authors discuss stigma in terms of how a condition or attribute links a person to discrediting characteristics (stereotypes) via attributional processes. Jones et al. (1984) suggest that there are six dimensions of stigma involved in attributional processes that produce a negative emotional or behavioural response (discrimination) based on the initial label and stereotype. Firstly, concealability is related to how obvious or visible a condition is, and the idea that those who are able to conceal their condition from other people, particularly in initial interactions, often will do so. Course reflects whether the condition is reversible over time, with conditions that are irreversible and ongoing more likely to produce negative attitudes from others. Disruptiveness reflects the degree to which the condition hampers relationships and places a strain on interpersonal interactions. Aesthetics describes how affective reactions stem from conditions that are upsetting or repellent. Origin refers to the onset of the condition and the perceived responsibility for the problem. People who are seen as responsible for their condition are argued to attract unfavourable views or punishment from others. Peril considers the threat that a person’s condition induces in others. While this threat can be actual physical danger (such as in the case of communicable diseases) it also encompasses exposure to uncomfortable feelings of vulnerability.

Current conceptualisations of stigma are consistent with Jones et al.’s (1984) typology, in that the authors highlight the contextual nature of stigma; that is, a stigmatising condition can be perceived differently across settings. Presently, there are a variety of definitions in the literature, but stigma is typically conceptualised as an attribute or characteristic that conveys a social identity that is devalued in a particular social context (Crocker, Major, & Steele, 1998). Thus, stigma is specific to
1.6 Application of Stigma to a Persistent Pain Population

The application of stigma to the conceptualisation of illness has been well established in a “rich, cross-disciplinary literature” (Goldberg, 2010; Stuart, 2008). The literature pertaining to stigma in a range of psychological and physical illnesses suggests the power of stigma as a meaning-making construct within the context of chronic pain. Yet while expected, stigma is often left unaddressed in the field of pain (Goldberg, 2010).

A number of chronic pain’s features result in it being a condition that attracts negative social judgments via the attribution process outlined above. Consistent with features of course and disruptiveness, persistent pain is often irreversible and thus presents an ongoing rather than time-limited condition. Fitting with Jones et al.’s (1984) concept of disruptiveness is that the nature of persistent pain can bring about changes to relationship roles and responsibilities, complex interactions with the medical system, and disruptions to work role (Gatchel, McGeary, McGeary, & Lippe, 2014; Hadjistavropoulos et al., 2011; van Leeuwen et al., 2006). Of relevance to attributions relating to Onset and Peril, Goldberg (2010) discusses notions of suffering and its causes. He argues that pain’s arbitrary nature and the absence of a simple, easy to comprehend explanation for why some people will experience chronic pain is threatening for many people. Goldberg (2010) includes people with pain in this category, noting that they too join with health-care providers in a search for a single cause or identifiable pathology of their pain – even though such objective signs cannot be provided in many causes (Bhangle, Sapru, & Panush, 2009; Bogduk, 2004; Jones, McBeth, & Power, 2010). Moreover, the absence of
identifiable pain pathology suggests a reason for the stigmatisation in terms of queries about the legitimacy of the condition, with questions about malingering or perceptions that pain is in a ‘person’s head’ (Dumit, 2006; Frohm & Beehler, 2010). Although many academic circles have moved away from the concept of a body-mind dualism, this persists as an interpretative mechanism for some health care-providers, caregivers, community members, and people with pain. In summary, a number of chronic pain’s features within Western society lead it to be an attribute that is deeply discrediting.

**1.6.1 Internalised stigma.** The impact of stigma is often twofold, as not only can the individual experience stigma based on a discrediting attribute, but they may also come to turn these attitudes inward and experience internalised (self) stigma (Corrigan & Watson, 2002; Drapalski et al., 2013). Internalised stigma speaks to the inner psychological harm which can be caused by encountering stigma (Ritsher & Phelan, 2004). Internalised stigma is defined as:

A subjective process, embedded within a socio-cultural context, which may be characterised by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual’s experiences, perceptions, or anticipation of negative social reactions on the basis of their [condition] (Livingston & Boyd, 2010, p. 2151).

A social psychological model best conceptualises the process of internalised stigma. Firstly, stereotypes about people with pain are encountered through social interactions (Corrigan & Watson, 2002). This reflects an awareness element on the part of the individual. The next condition is that through being labelled the person has assumed ‘membership’ in the group people with pain (i.e. they are identified as a
‘chronic pain sufferer’). From here, there is the absorption or application of these negative views to themselves, reflecting a form of self-prejudice. Finally, through internalising the ideas or beliefs which they encounter about people with pain, an individual may feel less valued due to their condition. This devaluation produces a negative behavioural and emotional response (Corrigan & Watson, 2002).

As discussed in a social psychological application of stigma theory, a person who believes that they will be devalued and discriminated against due to their chronic pain will likely fear the possibility of personal rejection (Link & Phelan, 2001; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). Link and colleagues (2006; 2001) argue that this fear of rejection in turn leads to negative consequences, including avoiding social contact, strained social interactions, and loss of employment. As in fearing social rejection, a person may act in a more defensive manner, act less confidently, or avoid potentially threatening contact altogether (Link & Phelan, 2006). Similarly, Corrigan and Watson (2002) argue that a range of negative consequences stem from internalised stigma, particularly, self-esteem decrement and decreased self-efficacy. It is suggested that self-esteem will be challenged with those affected by internalised stigma feeling less able, valued, and worthy than others due to their condition (Corrigan & Watson, 2002; Link, et al., 2001).

Consistent with this, Modified Labelling Theory (Link, Struening, Dohrenwend, Cullen, & Shrout, 1989) suggests that the stigma of having been labelled with a given condition produces a series of behavioural reactions and coping strategies that can perpetuate a person’s problems. That is, the very act of being labelled as “chronic pain sufferer” can lead to a range of negative outcomes for the recipient of the label. This occurs due to the power of a negative label to shape a
person’s social identity and self-concept, with key concepts including processes of stereotyping and self-fulfilling prophecies. For instance, the more a person believes they will be stigmatised by others, the more they will socially withdraw (Gay, 2004). Further, from a “why try” perspective, Corrigan and colleagues (2009) argue a lack of confidence flows from a definition of the self that is based on perceived stigma. This leads a person to feel unworthy or unable to approach life goals. For example, through applying the stigma to themselves a person may feel unable to approach life goals and think there is little point in attempting them; such as, “why try applying for work when I’ll just encounter discrimination about my pain?” or “why bother socialising with friends - I’m a burden and they don’t want to hear about my problems?” Such behavioural responses perpetuate the negative emotional and behavioural reactions stemming from the initial experience of internalising stigma. In summary, social psychological framework outlines how a number of key consequences stem from internalised stigma: a loss of confidence in self and future, and an increased level of distress. This occurs whether the stigma is perceived or experienced.

An additional theory for elucidating the consequences that stem from experiencing internalised stigma is the Self Regulation Model (Foster et al., 2008; Foster, Thomas, Bishop, Dunn, & Main, 2010; Linton & Bergbom, 2011). This model posits that people with pain develop personal representations about their condition. These representations in turn influence behaviour and therefore patient outcomes (Foster et al., 2010; Leventhal, Meyer, & Nerenz, 1980). Research has showed that a person’s personal representations can affect their long-term disability and become a barrier to recovery; typically through the way these representations can lead to passivity, avoidance, or inactivity (Foster et al., 2010). Thus, internalised
stigma may influence behavioural outcomes when people with pain form unhelpful and demoralising personal representations about their condition, which pose a barrier to recovery.

1.6.2 Paradox of internalised stigma. It should be noted that not all people who encounter stigma internalise the stigma. Rather, some people may react with righteous anger to the attitudes of others (Corrigan & Watson, 2002; Link & Phelan, 2001). This may cause them to respond or take action due to the injustice of their social treatment. Thus, the experience of stigma may actually energise a person to act and empower them to change their situation. Others may respond with indifference to the experience of stigma (Corrigan & Watson, 2002; Link & Phelan, 2001). These three different responses are discussed as a paradox of internalised stigma, with a continuum of responses at one end internalised stigma and the other resistance or empowerment (Corrigan & Watson, 2002; Link & Phelan, 2001). Where people sit on the continuum is likely to be state related rather than trait related. It relates to factors such as: collective representations and cognitive primes (encompassing awareness of cultural stereotypes, perceived place of the group in the social hierarchy, and socio-political ideology); perceived legitimacy of the stigma; and level of group identification as a person with pain (Corrigan & Watson, 2002; Crocker, 1999). For example, a person with low group identification is likely to remain indifferent to stigma as they would feel that the prejudice or discrimination does not apply to them. In contrast, a person whose pain condition is salient to them, with high group identification but low perceived legitimacy would likely react with righteous anger and keep their self-esteem intact. Finally, a person with pain who identifies with the group, and considers the negative responses of others to be legitimate, will likely experience internalised stigma and self-esteem decrement.
1.6.3 Internalised stigma and persistent pain. Despite the clear importance and implications of internalised stigma for health and well-being, little if any quantitative work has examined internalised stigma and persistent pain. While the notion of stigma towards people with pain is expected, it is often left unaddressed in studies of persistent pain (Goldberg, 2010). A direct and detailed discussion of internalised stigma and persistent pain in the quantitative literature is essentially absent in the field.

One exception to this is considered here in detail (Lennon, Link, Marbach, & Dohrenwend, 1989; Marbach, Lennon, Link, & Dohrenwend, 1990). Lennon et al. indicated that participants with chronic face pain had a sense of estrangement from others, perceived that other people did not know what it is like to be in their situation, and felt that they were alone in their battle. A large percentage of respondents (71%) endorsed the statement “I wish that others could see my pain” which hinted towards a sense of isolation and perceived illegitimacy of their experience. Drawing on the same research sample, the research group also published work which considered potential sources of stigmatisation in relation to patient reports of feeling estranged or psychologically flawed due to pain (Marbach et al., 1990). Both these studies considered aspects of how the psychosocial context may affect a person with chronic face pain. However, in terms of measuring outcomes, Lennon et al. (1989) solely assessed social relationships while Marbach et al. (1990) focused on potential sources that contribute to such stigma (such as clinician labelling). Thus, work that examines outcomes beyond social relationships, such as psychological factors, would be beneficial in understanding the broader consequences of stigma. Additionally, these studies did not explicitly examine internalised stigma or interrelationships with self-concept. Finally, as these studies
were confined to facial pain, examination of a wider pain population is also of interest.

Given the dearth of quantitative work relating to internalised stigma and persistent pain, analogous work in the mental health field is briefly noted here. Research among people with serious mental illness has demonstrated the prevalence of internalised stigma across conditions, including bipolar disorder, schizophrenia spectrum disorders, and depression (Brohan, Gauci, Sartorius, & Thornicroft, 2011; Drapalski et al., 2013; Lysaker, Roe, Ringer, Gilmore, & Yanos, 2012). Work has moved to examine the relationships with self-concept, psychological well-being, and outcomes relating to the illness. While a range of outcomes have been explored, the most common findings highlight a negative correlation with self-esteem and positive correlations with depression and symptom severity (Boyd, Adler, Otilingam, & Peters, 2014; Munoz, Sanz, Perez-Santos, & Quiroga, 2011; Padurariu, Ciobica, Persson, & Stefanescu, 2011). It may also lead to decreased occupational engagement and treatment seeking or adherence (Munoz et al., 2011; Padurariu et al., 2011; Watson, Corrigan, Larson, & Sells, 2007). A recent multinational review highlighted the range of cultures that the construct has been examined across (Boyd et al., 2014). Given these outcomes, recent work in the mental health field has moved towards the development of interventions, which should be advanced to reduce internalised stigma. Initial findings suggest the promise of this approach (Lucksted et al., 2011; Yanos, Roe, West, Smith, & Lysaker, 2012).

1.6.4. Internalised Stigma among people with pain: Links to qualitative literature. Internalised stigma has received minimal examination in the quantitative pain literature. It does, however, emerge in qualitative literature that informs us
about the lived experience of those with persistent pain. Key aspects of the
discussion provided by qualitative work in this field are reviewed here.

An interpretative phenomenological approach indicated that stigmatisation is
a key theme in the lives of those with chronic pain (Holloway, Sofaer-Bennett, &
Walker, 2007). Participants spoke of stigma and a lack of empathy towards their
experience (Holloway et al., 2007). Similarly, other work suggests that negative
interactions with health care providers, family, friends, the community and
workplaces is internalised by people with pain and interferes with care-seeking and
participation in rehabilitation (Slade, Molloy, & Keating, 2009). Based on the pivotal
role of stigma in the lives of their participants, Holloway et al. (2007) recommended
that strategies to deal with stigma should be incorporated into pain management
programs.

Another aspect of stigmatisation that emerges strongly in the literature is the
psychological hurt of being disbelieved (Glenton, 2003; Thomas, 2000). Qualitative
research suggested that having pain perceived as being “real” is a key concern within
the context of questions about pain legitimacy. Glenton (2003) discusses the idea
that individuals who do not gain social acceptance of their suffering experience a
sense of de-legitimisation and believe that they need to “prove” themselves.
Consistent with this, other work has described how participants identified pain’s
subjective, invisible nature as challenging in a way that affected their social
interactions; it is difficult for others to believe something that they cannot see
(Thomas, 2000).

A struggle for credibility within the healthcare system is another key aspect
of stigma among people with pain (Dumit, 2006; Glenton, 2003). In-depth
qualitative interviews attest that the lack of “proof” of the person’s chronic back
pain, such as identifiable medical pathology, can lead a person to feel accusations that they are malingering (Glenton, 2003; Holloway et al., 2007; Slade et al., 2009). The experiences of those interviewed indicated that they consciously worked hard to ensure that their symptoms would appear as real, physical and socially visible to a doctor (Werner & Malterud, 2003). Further, Werner, Isaksen and Malterud (2004) suggest that the research interviews could be seen as performances, where the participants sought to convince others that their pain story and suffering was legitimate. Such experiences occur within a sociocultural context concerned about fraudulent compensation claims or inappropriate access to medications, which may prime a focus on malingering at the expense of rehabilitation or treatment efforts (Hadjistavropoulos, 2013).

Although many patients desire a physician rescuer who is able to cure their pain this is unlikely to occur. Such expectations are inconsistent with current treatment options for many chronic pain conditions. Thus, while doctors are initially trusted, this tends to swing to “untrusted” after the patient has multiple experiences of help-seeking without gaining a cure (Holloway et al., 2007; Thomas, 2000). Thomas (2000) describes the mistrust and alienation, which was reported by patients following medical encounters, and noted that this led to being unconvinced in the ability of others to help manage their pain. Thus, the nature of persistent pain itself coupled with perceived negative sociocultural interactions affected participants’ emotional experiences and openness to medical advice.

Social withdrawal also emerged as a key theme due to negative sociocultural reactions to pain. The lived experience of older people with pain suggests that loss of confidence and withdrawal from social engagements characterise the experience of those with neuropathic pain (Sofaer-Bennett et al., 2007). Other work has suggested
that a lack of understanding in our culture about persisting pain leads to a perceived need to hide chronic pain, even from one’s own family (Thomas, 2000). These findings led Thomas (2000) to suggest that internalised stigma, as had been explored in diseases such as AIDS, may be germane to people with pain as well.

In summary, qualitative research is valuable in highlighting the individual’s pain experience and issues that are central to their lives. The literature suggests that stigmatising encounters feature prominently in social interactions and can lead to a sense of invalidation, illegitimacy, and social withdrawal. Whether perceived or real, the consequences of encountering stigma are the same in terms of the effect on self-concept and psychological well-being. Yet such effects are still to be examined in quantitative literature, which would allow for internalised stigma to be operationalized among a pain population. This would in turn enable a more reliable and objective measurement of the construct, allow for relationships between measures of psychological well-being and self-concept to be established, and would present a way to utilise internalised stigma as a verifiable treatment goal among people with pain.

1.7 Two Perspectives on Stigma

Totic et al. (2012) have suggested that stigma may be considered from two perspectives: firstly, personal feelings related to being stigmatised (internalised or self-stigma) and secondly, a label or judgment imputed to another person. This thesis predominantly focuses on the first aspect, given there is a current gap in the literature that it seeks to address. However, in Chapter 5 attention is also given to labels imputed to another person and hence this perspective is outlined below.

Pain occurs within a sociocultural context and thus considering how others respond to a person in pain is critical to understanding pain experience
Research suggests that observing others in pain produces a range of emotional and behavioural responses in the observer (Decety, Echols, & Correll; Goubert et al., 2005). Such responses can subsequently affect the experience of the person with pain, signalling the bidirectional nature of context and pain experience (Coll, Gregoire, Latimer, Eugene, & Jackson, 2011; Hadjistavropoulos et al., 2011).

1.7.1. Judgments of pain within a healthcare context. An important element of understanding the perception of pain by others is the healthcare context. Chronic pain leads many patients to seek treatment at hospital emergency departments (McLeod & Nelson, 2013; Wilsey, Fishman, Crandall, Casamalhuapa, & Bertakis, 2008; Wilsey, Fishman, Ogden, Tsodikov, & Bertakis, 2008; Woodhouse, Peterson, Campbell, & Gathercoal, 2009). Healthcare providers are particularly critical in respect to pain judgments, given their role in diagnosis, delivery of treatment, and provision of information. However, professionals’ judgments about pain, particularly when chronic, are both uncertain and complicated (LaChapelle, Lavoie, Higgins, & Hadjistavropoulos; Tait, Chibnall, & Kalauokalani, 2009). Patients with persisting pain have been reported to suffer from underassessment, underestimation, and under-treatment of their pain symptoms (Perreault & Dionne, 2006; Tait et al., 2009).

1.8 Social-Cognitive Framework and Healthcare Provider Judgments

A social-cognitive framework provides insight into how provider judgments about a person with pain take place. Social cognition considers how people make sense of other people and themselves (Tait et al., 2009). It is usually applied to conditions of uncertainty, which is appropriate given persistent pain’s subjective and complex nature. From a social-cognitive framework, Tait and colleagues (2009)
have suggested that it is the subjective and uncertain nature of persisting pain which leads observers to the propensity to automatically access intuitive, bias-prone heuristics (Tait et al., 2009). From this model, three broad domains that relate to the patient, the medical provider (observer), and the social situation have been shown to influence assessments (Chibnall, Tait, & Ross, 1997; Clark, Potter, & McKinlay, 1991; Tait et al., 2009). That is, judgments of pain come to be informed by contextual information drawn from interpersonal and situational factors.

**1.8.1 Attribution Theory.** Attribution Theory is a particularly useful framework to apply in this field, as it incorporates the perceptions of both the individual patient as well as the observer (Weiner, Perry, & Magnusson, 1988). Attribution Theory fits within the social-cognitive model reviewed above. Attributional analyses suggest that in response to a situation or outcome, a search is undertaken in order to determine the cause of the outcome. It then moves beyond these to consider affective reactions, expectancies regarding (successful) outcomes, and behavioural responses (Weiner et al., 1988). Specific examples relate to the findings that perceptions of causality lead to a range of affects and expectancies for future behaviour, goals or outcomes (Weiner, 1995). For example, blame-based attributions have been demonstrated to decrease pity, increase anger and effect decisions to help or neglect a person with illness (Weiner, 1995; Weiner et al., 1988). Weiner, Perry and Magnusson (1988) demonstrated that changes in attribution result in changes in a person’s affective responses and behaviour judgments.

**1.9 Vignette Based Methodologies**

One methodological approach that is often used to explore the influence of contextual information in the perception of pain has been vignette research (Tait,
Vignette research typically involves presenting a participant with a patient scenario and then requiring a response with perceptions or decisions involved. This methodology therefore enables an examination of people’s judgments, the information that is used in making assessments (cues), exploring how such cues may be combined, and when observers stop searching for further information (Hughes & Huby, 2002; Kappesser & Williams, 2013; Tait, 2013).

Taken together, a growing body of vignette-based pain research has demonstrated that consistent with social-cognitive theory, factors related to the patient (e.g. ethnicity: Tait & Chibnall, 2014), the provider (e.g. level of experience: Tait et al., 2009; Tait, Chibnall, Miller, & Werner, 2011) and the situation (e.g. medical evidence: Chibnall & Tait, 1999; De Ruddere, Goubert, Vervoort, Prkachin, & Crombez, 2012; Kouyanou, Pither, Rabe-Hesketh, & Wessely, 1998) can systematically shape judgments such as level of pain intensity and emotional distress. The influence of non-functional factors in pain-related judgments is of concern (Marquie et al., 2004). While the information used may be intuitively appealing, much of it has little association with the pain severity or adjustment judgments that it shapes (Tait et al., 2009). As discussed by Marquie et al. (2004), the idea that one’s pain will be assessed differently depending on whether, for example, you are a female, is rather disturbing. Yet a growing body of work suggests that patients’ pain tends to be assessed within the context of variables relating to such characteristics; the ambiguous nature of pain leads providers to draw on (bias-prone) heuristics to simplify decision-making (Igier, Mullet, & Sorum, 2007; Tait et al., 2009).

Particular consideration has been given to the legitimising role of identifiable pain pathology in medical assessment (Kappesser & Williams, 2008). Work among
physicians, medical students, and community samples, has consistently demonstrated that patients described in vignettes as lacking identifiable pain pathology are ascribed less intense pain, less emotional distress, and lower levels of disability, compared to those described as having identifiable pathology (Chibnall & Tait, 1999; Chibnall et al., 1997; De Ruddere et al., 2012; Tait & Chibnall, 1997). This is despite current knowledge that persisting pain often occurs in the absence of identifiable pain pathology, that pain symptoms are poorly correlated with pathologic changes, and that obvious pathology is not usually found during conventional investigations (Bhangle et al., 2009; Bogduk, 2004; Jones et al., 2010).

As reviewed in Section 1.6.4, the implications of pain judgments are discussed at length in qualitative work. This work has highlighted the need for medical providers to be conscious of patients' experiences, particularly in order to avoid unintentional implications about their pain being illegitimate or feigned due to the absence of identifiable pathology (Frohm & Beehler, 2010; Gillmore & Hill, 1981; Glenton, 2003; Kool et al., 2010; Kouyanou, et al., 1998).

More recently, attention in the literature has turned to how psychosocial information may effect judgments about people with pain (De Ruddere et al., 2012). As discussed in Section 1.3, the biopsychosocial model posits that psychological and sociocultural variables interact to shape the pain experience (Turk & Okifuji, 2002). Yet how psychosocial information might differentially effect observer judgments of persistent pain has received insufficient examination in the literature to date (De Ruddere et al., 2014). Initial work has suggested the stigmatising nature of psychosocial information, in that a patient's pain intensity is downgraded when they are experiencing concurrent psychological distress, the patient attracts higher beliefs of deception, and there is less sympathy felt by an observer when reading about a
patient that has psychosocial stress (De Ruddere et al., 2014; De Ruddere et al., 2012; Tait et al., 2009). This area of research reflects an emerging literature and there is a need for other psychosocial information to be examined (De Ruddere et al., 2014; De Ruddere et al., 2012). Such an examination is presented in Chapter 5.

1.10 Thesis Rationale

Psychosocial influences are important to consider as chronic pain occurs in a social context and the relationship between a person and this context can play a pivotal role in affecting a person’s level of suffering and disability. The aim of this thesis is to examine internalised stigma in a heterogeneous pain population. The study program is imperative given that internalised stigma has been associated with a range of negative outcomes (Boyd et al., 2014). It is therefore highlighting the potential impact of pain previously unexamined in the literature. In this way, the thesis presents a new application of theoretical model relating to internalised stigma, and extends the current biopsychosocial consideration of pain.

This program of research incorporates several primary goals put forward in Australia’s National Pain Strategy (2010). Through aligning itself with these goals, it is hoped that this series of papers makes a contribution to efforts to foster empowered and supported health consumers (National Pain Summit Initiative, 2010).

Finally, the investigations presented in this series of papers have implications for treatment outcome. Clinically, work in the mental health field suggests that internalised stigma has implications for treatment and recovery (Boyd Ritsher, Otilingam, & Grajales, 2003; Lysaker et al., 2012). This therefore signals another important aspect of this research program. Through better understanding the process
of internalised stigma, and pain-related judgments of healthcare providers, a contribution is made to future avenues to improve patient outcomes.

1.11 Research Questions

Adopting a biopsychosocial model of pain, the focus of this thesis will be on psychosocial factors in persisting pain. This body of work will explore how psychosocial factors might influence the experience of pain. Stigmas present a rich area for study and comprise of multiple domains of interest (Weiner et al., 1988). As discussed by Weiner et al. (1988), stigma encompasses personal reactions and self-perception, including self-concept (Study 1 and 2), the ability to adjust and change with support (Study 3), and social perceptions such as pain judgments (Study 4).

1.11.1 Research question 1. The application of internalised stigma to a chronic pain population is novel. Therefore, the presence and prevalence of internalised stigma among people with pain presents the first research aim of this thesis and is examined quantitatively in the cross-sectional, quantitative research of Study 1. This body of research aims to answer the question: Is internalised stigma a feature of the experience of people living with pain? Specifically, it posits that negative attitudes about persistent pain are absorbed in a process that leads to internalised stigma among people with pain.

1.11.2 Research question 2. Beyond this consideration, Study 1 examines how internalising stigma in turn affects the experience and interpretation of pain and what this means about a person's self and their identity. Following the social-psychological framework of Link and Phelan (2001), and Corrigan and Watson (2002), coupled with self-regulation theory, it is predicted that internalised stigma will be negatively associated with measures of self-concept and psychological
wellbeing. Further, it is suggested that internalised stigma will be negatively associated with pain cognitions and illness representations.

1.11.3 Research question 3. To move beyond associations and interrelationships, Study 2 considers a prospective question through a longitudinal design. It tests whether internalised stigma among people with pain can predict aspects of self-concept, as measured through self-esteem and pain self-efficacy. This question flows from the framework of Link and Phelan (2001), and Corrigan and Watson (2002).

1.11.4 Research question 4. In considering internalised stigma in terms of pain management and treatment, Study 3 examines the question is internalised stigma static or changeable in its nature? Drawing on a quasi-experimental design, it considers whether internalised stigma decreases following cognitive-behavioural therapy in a pain clinic context.

1.11.5 Research question 5. This thesis (Study 4) additionally examines how factors identified as central to the pain experience in qualitative work influence pain judgments among future healthcare providers. Specifically, it uses an experimental within subjects design to examine how contextual variables related to psychosocial information can impact on perceptions of about a patient’s legitimacy as well as judgments about pain intensity and emotional distress.

In summary, this thesis explores psychosocial judgments about pain from two perspectives (Totic et al., 2012): firstly, personal feelings related to being stigmatised (internalised or self-stigma) are considered in Studies 1 through 3, and secondly, labels imputed to another person are examined in Study 4. Presented below are four studies intended for separate journal submissions (Chapter 2 – 5), followed by a discussion (Chapter 6) to draw the work together.
Chapter 2: Foreword

One of the primary directions of the present research program is to understand psychosocial factors in the experience of pain, specifically whether internalised stigma is a feature of people's experience. Chapter 2 and Chapter 3 assess internalised stigma among community members. In Study 1 (Chapter 2), the prevalence of internalised stigma and its interrelationships with self-concept and cognitive responses to pain are investigated. A cross-sectional quantitative design was utilised to examine this area. Rather than create a new measure of internalised stigma, this study instead uses an existing measure and applies it for a chronic pain population. The Internalised Stigma of Mental Illness scale was selected as it has been established as a valid and reliable measure of stigma with demonstrated applicability across cultures. The scale has been successfully adapted to enable research into a range of health conditions and a recent review concluded it is the only measure for an adult population to meet quality criteria (Stevelink, Wu, Voorend, & van Brakel, 2012).

The results of Study 1 indicate that a substantial proportion of people with pain endorse the experience of internalised stigma, where negative sociocultural attitudes have essentially been turned inward. Analysis allowed for relationships to be assessed between stigma and important outcome measures, namely pain self-efficacy, personal control over illness, and the tendency to catastrophise in response to pain. Study 1 documents a range of negative associations with internalised stigma. This suggests the potential role for targeting internalised stigma as part of management programs; this potential will be examined later in Chapter 4.
Chapter 2: Declaration

Title

Internalized Stigma in People Living with Chronic Pain

Authorship

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Candidate Contribution

The Candidate designed the study, with input provided by DB and MN. The Candidate conducted recruitment with assistance from MN. The Candidate conducted all data entry, analysis, and prepared the initial manuscript. DB and MN provided input on successive drafts of the manuscript.

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Internalized Stigma in People Living With Chronic Pain

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Abstract: Although persistent pain occurs in a sociocultural context, the influence of personal devaluation and invalidation is often neglected. As such, the present study sought to consider whether individuals' experience, perception, or anticipation of negative social reactions to their pain may become internalized and affect the self. To examine this issue, 92 adults with chronic pain responded to a questionnaire exploring the presence of internalized stigma and its association with a range of psychological consequences. As predicted, a large percentage of people with chronic pain (38%) endorsed the experience of internalized stigma. The results showed that internalized stigma has a negative relationship with self-esteem and pain self-efficacy, after controlling for depression. Internalized stigma was also associated with cognitive functioning in relation to pain, in terms of a greater tendency to catastrophize about pain and a reduced sense of personal control over pain. Overall, this study presents a new finding regarding the application of internalized stigma to a chronic pain population. It offers a means of extending our understanding of chronic pain's psychosocial domain. Implications are discussed in terms of the potential to inform clinical treatment and resiliency into the future.

Perspective: This article presents a novel finding regarding the presence of internalized stigma among people living with chronic pain. Internalized stigma is strongly associated with indicators of patient outcome. It presents an area for future work with the aim to improve our understanding and treatment of people living with pain.

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Key words: Pain, psychosocial factors, internalized, stigma.
perceptions, or anticipation of negative social reactions on the basis of their [condition].

Modified labeling theory\(^\text{19}\) suggests that behavioral reactions and coping strategies of those anticipating negative social perceptions based on their pain may lead to loss of self-esteem and self-efficacy. Further, self-regulation models\(^\text{12,13}\) suggest that internalized stigma may influence outcomes as patients form unhelpful and demoralizing representations about their pain, which shape behavior.

Although expected, internalized stigma and pain is often "[left] unaddressed.\(^\text{18}\) One exception is the work of Lennon et al\(^\text{23}\) and Marbach et al\(^\text{31}\) who indicated a sense of estrangement and isolation among their sample of chronic face pain patients. However, Marbach et al focused on potential sources that contribute to such stigma (eg, clinician labeling), whereas Lennon et al focused solely on social relationships. Thus, work examining outcomes beyond social relationships, such as psychological factors, would be beneficial. As these studies were confined to facial pain, examination of a wider pain population is also of interest.

In contrast to the scarcity of quantitative work in the area, extensive qualitative work considering the lived experience of those with pain identifies features of our sociocultural context that could lead to internalized stigma. Body-mind dualism is an interpretative mechanism for some health care providers, caregivers, and patients.\(^\text{18}\) Chronic pain's invisibility and lack of material pathology can lead to disbelief and allegations of malingering.\(^\text{14,18}\) As pain is a subjective experience, when it persists into chronicity patients typically have to justify and defend their experience, often leading to feelings of invalidation.\(^\text{11,22}\) Taken together, the psychological hurt of being disbelieved or alienated emerges strongly in the literature and should be attended to when working with patients.\(^\text{16}\) Holloway et al\(^\text{21}\) suggest that stigmatization is a central feature with a seemingly profound influence on patients' perceptions, self-esteem, and behavior, such as their interactions with those offering professional help. Similarly, Slade et al\(^\text{42}\) found that stigma interfered with care-seeking and rehabilitation participation, with participants endorsing the need for a greater focus on strategies to address this area.

Following such work, the present study is novel in aiming to quantitatively investigate internalized stigma among people with pain. Adopting Link and colleagues'\(^\text{24,25}\) framework, it hypothesizes that internalized stigma will be associated with self-esteem decrement and reduced self-efficacy. Given the importance of cognitive functioning in relation to pain for achieving clinical outcomes, this study also considers the role of 2 key variables: catastrophizing and illness perceptions (personal control). Following a self-regulation perspective, it hypothesizes that internalized stigma will be associated with higher levels of catastrophizing and lower personal control over pain.

**Methods**

**Participants**

Australian adults (\(M_{\text{age}} = 50.27\) years, \(\text{age range} = 18-86\) years) were recruited from the community through newspapers, online forums, and medical and allied health centers. All participants were required to be living with nonmalignant chronic pain, defined as current pain that has persisted for at least 3 months in the previous 6 months. No financial incentive was provided for participation. Approval from relevant institutional review boards was granted, and participants provided informed consent.

**Materials and Procedure**

Prior to recruitment, 10 Australian adults completed the survey. As this pilot was to ensure item understanding and ascertain completion time, those involved were not required to be living with chronic pain. The survey took all participants less than 30 minutes to complete. A survey booklet containing all measures was provided to participants who expressed an interest in the study. Participants were provided with a prepaid and addressed envelope to return the survey. All items were presented in the same order.

All measures are self-reported scales. Given that a number of instruments already exist to measure stigma for other chronic health conditions, it was not necessarily vital to develop a new instrument but rather to adapt a preexisting instrument to be suitable for a chronic pain population and validate this instrument accordingly.\(^\text{54}\)

**Demographics and Health-Related Variables**

The following demographic questions were included in the present study: gender, age (in years), employment status (as indicated through performing at least 1 hour of work for wages or salary in the past week or being temporarily absent from a job but maintaining attachment to it), highest level of education (measured categorically: year 10 certificate, year 12 certificate, university degree, technical college), time since initial onset of pain (measured categorically: less than 1 year, between 1 and 5 years, more than 5 years, no longer have pain), compensation case (measured categorically: yes, no), and questions about the onset (sudden onset, slow/gradual onset) and nature of pain (free text response, specifying condition and location of pain). Two items from the Brief Pain Inventory were included to assess the participant's current pain level and pain at its worst in the past 24 hours (Likert-type scale, anchored 0 = no pain, 10 = pain as bad as you can imagine).

**Roland and Morris Disability Questionnaire**

An adapted version of the Roland and Morris Disability Questionnaire, appropriate for a heterogeneous chronic pain group, was used in the study.\(^\text{37}\) Originally developed by Roland and Morris,\(^\text{45}\) the instrument assesses current level of physical disability due to pain. Consistent with the sound psychometric properties reported in previous pain research,\(^\text{37}\) Cronbach's \(\alpha = .86\) in the present study.
Internalized Stigma of Chronic Pain

The Internalized Stigma of Mental Illness Scale was developed by Boyd Ritsher, Ottingam, and Grajales to assess internalized stigma in relation to mental illness. Participants respond to a series of statements on a 4-point Likert-type scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). Five subscales are produced from the instrument: alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. The Internalized Stigma of Mental Illness Scale has good reliability and validity. The scale was modified with permission of the author for a chronic pain population; references to mental illness were removed and participants were asked to relate the items to their chronic pain (see Appendix Table 1). Items for the subscale stereotype endorsement were replaced to reflect chronic pain; however, reliability analysis indicated that this subscale did not fit with other items in the measure and was subsequently excluded from analysis. The adapted version utilized in the current study had Cronbach’s α = .90.

Pain Self-Efficacy Questionnaire

Developed by Nicholas, the Pain Self-Efficacy Questionnaire assesses the strength and generality of the participant’s beliefs about their ability to accomplish a range of activities despite their current pain. Scores range from 0 to 60, with higher scores indicative of greater self-efficacy. The scale has sound psychometric properties and in the current study Cronbach’s α = .91.

Self-Esteem

A single item self-esteem measure was utilized to assess self-esteem. The item asks participants, “Thinking about yourself generally, how true is the following statement of you: I have high self-esteem?” Participants respond on a 5-point Likert-type scale (anchored 1 = not very true of me, 5 = very true of me). This measure has been put forward as a quick, effective option for representing positive beliefs about the controllability of pain. It has high convergent validity with Rosenberg’s Self-Esteem Scale and nearly identical correlations with a range of criterion measures.

Revised Illness Perception Questionnaire

The Revised Illness Perception Questionnaire explores beliefs about illness and is adapted for chronic pain. Although the Revised Illness Perception Questionnaire is composed of 5 key components, only the personal control component was included in the present study. High scores on the personal control dimension represent positive beliefs about the controllability of the pain. In the current study, the Cronbach’s α (personal control subscale) = .76. Note that this scale has a small number of items (6), which affects the Cronbach’s α value. Inspection of the corrected item-total correlation values indicated no values less than .3.

Pain Catastrophizing Scale

The Pain Catastrophizing Scale assesses pain-related cognitions, particularly the tendency to think the worst about one’s pain. It has strong internal consistency, with a total reported Cronbach’s α = .95, and subscales ruminating .95, magnification .88, and helplessness .91. In the current study, the total Pain Catastrophizing Scale Cronbach’s α = .94 (helplessness = .91, magnification = .70, rumination = .91).

Short-Form Version of the Depression Anxiety and Stress Scale (DASS-21)

The DASS-21 was used as it is appropriate for research purposes and takes half the time as the full version. The DASS-21 has 3 subscales: depression, anxiety, and stress. The DASS-21 is advantageous for use in a chronic pain population given that it does not include somatic items and has sound psychometric properties. In the present study, the Cronbach’s α coefficient for the depression scale = .93, anxiety scale = .80, and stress scale = .88.

Analytical Plan

Prior to testing the study’s hypotheses, initial screening and cleaning was completed. Scale reliability was then assessed and the Internalized Stigma of Chronic Pain scale was constructed. The application of this scale was considered through descriptive statistical analysis. Subsequently, focus turned to testing the study’s hypotheses. Pearson product-moment correlation coefficients were generated to initially consider the strength and direction of the linear relationships between key independent and dependent variables. Multiple regression analyses were chosen because of the sample size, type of measures, study hypotheses, and desire to control for key covariates. Prior to running the regressions, analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Relevant square root transformations on the DASS depression scale were performed to improve distribution normality (skewness = .708, kurtosis = .255); however, as this did not affect the substantive interpretation, the untransformed scores are reported throughout. First, 3 hierarchical multiple regression analyses were performed to test the relationship between Internalized Stigma of Chronic Pain (a continuous independent variable) and the 3 continuous dependent variables (pain self-efficacy, illness perceptions, and catastrophizing). Second, the 1 categorical dependent variable (the self-esteem measure) necessitated the use of ordinal regression analysis in order to test its relationship with internalized stigma.

Results

Sample characteristics are provided in Table 1, with information regarding the nature of pain in Table 2, and a summary of the measures included in analysis provided in Table 3. Screening and cleaning processes identified 2 patients who did not report chronic pain. These were consequently deleted (n = 90 participants retained for analysis). No cases identified pain associated with cancer. Analysis of valid and missing cases indicated a small amount of data missing (<5%) and did not indicate any
Table 1. Summary of Sample Characteristics (N = 92)

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>MEASUREMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>70 (76)</td>
</tr>
<tr>
<td>Male</td>
<td>21 (23)</td>
</tr>
<tr>
<td>Age (y), mean (SD)</td>
<td>50.27 (14.75)</td>
</tr>
<tr>
<td>Education (completed)</td>
<td></td>
</tr>
<tr>
<td>Year 10 certificate</td>
<td>16 (17)</td>
</tr>
<tr>
<td>Year 12 certificate</td>
<td>6 (7)</td>
</tr>
<tr>
<td>University degree</td>
<td>37 (40)</td>
</tr>
<tr>
<td>Technical college (eg, diploma)</td>
<td>30 (33)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Currently employed</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>61 (66)</td>
</tr>
<tr>
<td>Yes</td>
<td>30 (33)</td>
</tr>
<tr>
<td>Compensation case</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>77 (84)</td>
</tr>
<tr>
<td>Yes</td>
<td>14 (15)</td>
</tr>
</tbody>
</table>

NOTE. Demographic variables reflect all participants who responded to the survey. Frequency values do not all sum to 92 because of missing data. Values are n (%) unless otherwise indicated.

errors; missing cases were treated via the exclude cases pairwise option in analysis.

Internalized Stigma Among People Living With Chronic Pain

Analysis established reliability and constructed the Internalized Stigma of Chronic Pain scale based on this. As examination of Table 4 indicates, the low, and at times

Table 2. Nature of the Participants’ Pain

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>MEASUREMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category/Syndrome</td>
<td></td>
</tr>
<tr>
<td>Relatively generalized syndromes</td>
<td>28 (23)</td>
</tr>
<tr>
<td>Syndromes of the head and neck</td>
<td>21 (17)</td>
</tr>
<tr>
<td>Spinal and radicular syndromes</td>
<td>41 (33)</td>
</tr>
<tr>
<td>Syndromes of the upper limbs</td>
<td>8 (7)</td>
</tr>
<tr>
<td>Syndromes of the lower limbs</td>
<td>17 (14)</td>
</tr>
<tr>
<td>Visceral and other syndromes of the trunk</td>
<td>5 (4)</td>
</tr>
<tr>
<td>More than 3 categories specified</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Total</td>
<td>123 (100)</td>
</tr>
<tr>
<td>Duration of pain</td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>5 (5)</td>
</tr>
<tr>
<td>Between 1 and 5 years</td>
<td>24 (26)</td>
</tr>
<tr>
<td>More than 5 years</td>
<td>59 (64)</td>
</tr>
<tr>
<td>No longer have pain</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Onset of pain</td>
<td></td>
</tr>
<tr>
<td>Slow/gradual</td>
<td>40 (44)</td>
</tr>
<tr>
<td>Sudden</td>
<td>49 (53)</td>
</tr>
<tr>
<td>Pain level, mean (SD)</td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>5 (2.18)</td>
</tr>
<tr>
<td>Worst in past 24 hours</td>
<td>7 (1.60)</td>
</tr>
</tbody>
</table>

NOTE. Category/Syndrome is based on the International Association for the Study of Pain’s Classification of Chronic Pain. Spinal and radicular syndromes include lumbar, sacral and coccygeal regions. Visceral and other syndromes of the trunk are those apart from spinal and radicular syndromes. Duration and onset of pain frequencies do not sum to 92 because of missing data. Category/Syndrome sums to greater than 92 because of a number of participants identifying multiple pain categories or syndromes. Values are n (%) unless otherwise indicated.

negative, corrected item-total correlations indicated that stereotype endorsement did not fit and was measuring something different from the scale as a whole. As such, the stereotype endorsement subscale was removed and Internalized Stigma of Chronic Pain scale used throughout analysis refers to the summed average of the other 4 subscales (mean [M] = 2.33, standard deviation [SD] = .48, range = 1.32–3.55; α = .90). The exclusion of the scores resulted in a slight increase in the scale’s total summed average (Mchange = .087).

A substantial proportion of the participants in the present study reported experiencing internalized stigma in relation to their chronic pain. Specifically, 38% (of n = 90) of people had a mean greater than 2.5. (This method of interpretation follows Ritsher and Phelan,43 who define high levels of internalized stigma as an average score above the midpoint of the possible range.) The mean and SDs for the subscales are included in Table 5. For reference, data reported in 2 studies, one of persons with schizophrenia spectrum disorders and the other depression or bipolar disorder, are included. The proportion of participants endorsing internalized stigma is comparable to the mental illness literature, which has typically explored the experience of internalized stigma in relation to severe mental illness. For example, Ritsher and Phelan43 report 28% (of n = 82) with internalized stigma, and Brohan et al report 22% (of n = 1,160) with moderate or high internalized stigma.

Table 3. Mean and Standard Deviations of Study Variables

<table>
<thead>
<tr>
<th>DESCRIPTIVE STATISTICS</th>
<th>n</th>
<th>MEAN</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>DASS-21</td>
<td>88</td>
<td>15</td>
<td>11.86</td>
</tr>
<tr>
<td>Anxiety</td>
<td>89</td>
<td>9</td>
<td>8.97</td>
</tr>
<tr>
<td>Stress</td>
<td>87</td>
<td>17</td>
<td>10.39</td>
</tr>
<tr>
<td>Illness Perception Questionnaire: Personal Control</td>
<td>88</td>
<td>21</td>
<td>4.08</td>
</tr>
<tr>
<td>Internalized Stigma of Chronic Pain</td>
<td>90</td>
<td>2.33</td>
<td>0.48</td>
</tr>
<tr>
<td>Alienation subscale</td>
<td>90</td>
<td>2.46</td>
<td>0.71</td>
</tr>
<tr>
<td>Discrimination experience subscale</td>
<td>90</td>
<td>2.27</td>
<td>0.61</td>
</tr>
<tr>
<td>Social withdrawal subscale</td>
<td>90</td>
<td>2.34</td>
<td>0.53</td>
</tr>
<tr>
<td>Stigma resistance subscale</td>
<td>90</td>
<td>2.22</td>
<td>0.53</td>
</tr>
<tr>
<td>Pain Catastrophizing Scale</td>
<td>84</td>
<td>21</td>
<td>12.85</td>
</tr>
<tr>
<td>Pain Self-Efficacy Questionnaire</td>
<td>90</td>
<td>28</td>
<td>13.32</td>
</tr>
<tr>
<td>Roland and Morris Disability Questionnaire</td>
<td>89</td>
<td>11</td>
<td>5.48</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>90</td>
<td>3.10</td>
<td>1.20</td>
</tr>
</tbody>
</table>

NOTE. Data reflect n = 90 cases, following the removal of participants no longer experiencing pain. The value of n differs between the variables because of missing data, which was treated via the exclude cases pairwise option as outlined above.

Internalized Stigma and Psychological Well-Being: Self-Esteem and Self-Efficacy

Initial results, displayed in Table 6, indicated a large, negative relationship such that the higher the level of internalized stigma a person endorsed, the lower their level of pain self-efficacy. Table 6 shows that depression and disability were significantly associated with self-efficacy. Depression was considered because of previous work in the area of
internalized stigma, which signals the importance of controlling for its influence on self-efficacy and self-esteem.\(^6\) Disability was also considered because pain self-efficacy is related to behavior and thus it is important to control for the influence of a person's physical disability due to pain. Hierarchical multiple regression analyses sought to establish independent associations between internalized stigma and pain self-efficacy. Consistent with previous research examining such demographic variables, \(^{35,42}\) age and pain level were considered; however, as these did not make a statistically unique contribution to the model (\(P < .05\)), they were not retained in analysis.

Depression and disability were entered at Step 1, explaining 42.9% (\(R^2\)) of the variance in pain self-efficacy. After entry of internalized stigma at Step 2, the total variance explained by the model as a whole was 59.2%, \(F(3, 83) = 40.185, P < .001\). The increase in explained variance is about 16%, \(R^2\) change = .162, \(F\) change (1, 83) = 33.178, \(P < .001\). In the final model, 2 variables made a statistically significant (\(P < .001\)) contribution: in order of importance, internalized stigma (beta = \(-.554\)) and disability (beta = \(-.264\)).

To consider whether internalized stigma is predictive of a person's self-esteem, ordinal regression was performed. Following crosstab analysis suggesting a potential problem with small cell size, categories were collapsed (low, middle, and high self-esteem, respectively). As above, analyses controlled for depression, following the model of Corrigan et al.\(^9\) Results showed that internalized stigma significantly improves our ability to predict self-esteem, holding depression constant (chi-squared = 43.870, df = 2, \(P < .001\)) and that the model fits the data well (\(P = .390\)). Nagelkerke's measure = .446 (\(n = 87\)). Analysis confirmed that the proportional odds assumption was not violated (\(P = .389\)).

The negative coefficient (\(-1.688\)) indicated that the log odds of self-esteem decreased as internalized stigma increased. The proportional odds ratio indicates that for a 1 unit change in internalized stigma, the odds of high self-esteem versus the combined middle or low self-esteem categories is 0.18 greater (95% confidence interval [CI] = .05--.65), given that depression is held constant.

**Table 4. Internalized Stigma of Chronic Pain: Corrected Item-Total Correlations**

<table>
<thead>
<tr>
<th>Stereotype Endorsement Subscale Items</th>
<th>Corrected Item-Total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often people use chronic pain to obtain narcotics</td>
<td>.027</td>
</tr>
<tr>
<td>People with chronic pain should be able to tolerate pain better as time goes on</td>
<td>(-.055)</td>
</tr>
<tr>
<td>People with chronic pain cannot live a good, rewarding life</td>
<td>.309</td>
</tr>
<tr>
<td>People can tell that I have chronic pain by the way I look</td>
<td>.074</td>
</tr>
<tr>
<td>People with chronic pain tend to exaggerate their pain for secondary gains (eg, to get sympathy or financial compensation)</td>
<td>(-.004)</td>
</tr>
<tr>
<td>Chronic pain is often all in a person's head</td>
<td>(-.077)</td>
</tr>
<tr>
<td>Stereotypes about people with chronic pain apply to me</td>
<td>.405</td>
</tr>
</tbody>
</table>

**Internalized Stigma and Cognitive Functioning in Relation to Pain**

Confirmatory in this sample was a significant bivariate correlation between catastrophizing and depression (\(r = .756, P < .001; n = 82\)). However, the role of internalized stigma has not been considered previously. Analysis indicated a large, positive relationship between the 2 variables, suggesting that higher levels of internalized stigma are significantly (\(P < .001\)) related to higher levels of catastrophizing about their pain (\(r = .678, n = 84\)). Hierarchical multiple regression analysis established the predictive ability of internalized stigma, while controlling for depression. Depression was entered at Step 1, explaining 57% (\(R^2\)) of the variance in pain catastrophizing. After entry of the adapted Internalized Stigma of Mental Illness Scale at Step 2, the total variance explained by the model as a whole was 64%, \(F(2, 79) = 69.453, P < .001\). The increase in explained variance is about 7%, \(R^2\) change = .066, \(F\) change (1, 79) = 14.477, \(P < .001\). In the final model, both depression and internalized stigma were significant (\(P < .001\)), with depression beta = .545 and internalized stigma beta = .333. Although unable to speak to causal direction, it does highlight a relationship not previously considered.

The relationship between internalized stigma and personal control was investigated using hierarchical multiple regression in order to control for the person's level of disability due to pain. Initial analysis had indicated a medium-strength bivariate correlation,\(^7\) with higher levels of internalized stigma significantly (\(P < .001\)) associated with a lower sense of control over pain (\(r = -.395\)) (\(n = 88\)). Disability was entered at Step 1, explaining 9% (\(R^2\)) of the variance in personal control. After entry of internalized stigma at Step 2, the total variance explained by the model as a whole was 18%, \(F(2, 84) = 9.245, P < .001\). The increase in explained variance is about 10%, \(R^2\) change = .102, \(F\) change (1, 84) = 10.413, \(P = .002\). In the final model, only internalized stigma was significant (\(P = .002\)), with beta value of \(-.339\).

**Discussion**

This study illustrates that a large percentage of people living with chronic pain endorse the experience of internalized stigma. This reflects feelings of alienation, social withdrawal, and discriminatory experiences based on pain, such as feeling out of place in the world or that their legitimacy is being questioned. This finding is of particular note as the internalized stigma construct previously has not been applied to a chronic pain population. Yet the proportion of those endorsing such experiences was comparable to levels observed in the mental illness literature. Thus, although previously unexamined in a chronic pain population, the current
application suggests the importance of attending to internalized stigma given the negative relationship with ways of thinking about the self and pain. It offers a means of broadening our understanding of the psychosocial correlates of chronic pain.

Assessing stigma in a quantitative manner allowed for relationships with measures of psychological well-being and cognitive functioning to be considered. Three key findings emerged. First, internalized stigma was endorsed by 38% of people living with chronic pain. This figure is comparable to levels seen in the mental health literature. Second, internalized stigma significantly predicted self-esteem and self-efficacy. This relationship was found even after controlling for depression; given the high comorbidities between pain and depression, controlling for how these conditions interact is critical. Third, internalized stigma significantly predicted the tendency to catastrophize about pain and perceptions regarding personal control, both of which speak to cognitive representations of pain. Such findings are noteworthy, given the potential for internalized stigma to adversely influence engagement in rehabilitation activities for pain management, workforce participation, and other patient outcomes.

**Internalized Stigma: Augmenting Qualitative Work**

A strength of this study is augmenting the body of qualitative literature in the field, by demonstrating that a large percentage of pain patients experience internalized stigma including alienation, social withdrawal, and discrimination experiences. This is consistent with Thomas's qualitative work, which speaks to the psychological hurt of isolation and withdrawal, and Glenton's work regarding perceived discrimination on the basis of pain. It supports Holloway et al's by demonstrating a significant association between internalized stigma and self-esteem. Additionally, significant relationships with perceptions of personal control and pain self-efficacy strengthen the findings of Slade et al by suggesting how internalized stigma may interfere with rehabilitation participation and patient outcomes.

**Theoretical Implications**

The results of this study may be situated within 2 broad theoretical models. First, results are consistent with the social psychological literature related to stigma processes. Following the self-stigma process proposed by Link and Phelan, this study's results support the model that internalized stigma leads to self-esteem decrement and psychological distress. Second, the findings may be conceptualized within biopsychosocial formulations of pain. Initially internalized stigma is a sociocultural construct that relates to the perceived attitudes, impressions, and judgments of other people about pain. This may occur through interactions with medical professionals, family, work colleagues, or others living with pain. This may occur through interactions with medical professionals, family, work colleagues, or others living with pain. However, in turn this affects an individual's psychological experience of pain, as demonstrated in this study through the link with self-esteem and pain self-efficacy. Thus, the findings of this study are consistent with a dynamic and reciprocal relationship between social and psychological variables in the experience of pain.

**Internalized Stigma and Self-Esteem**

Lowered self-esteem associated with self-stigma is consistent with modified labeling theory. This theory suggests that a person labeled as a "chronic pain sufferer" may anticipate devaluation or discrimination and engage in coping behaviors such as social withdrawal. The anticipation of both devaluation and discrimination, coupled with consequences such as withdrawal and alienation, are in turn associated with lowered self-esteem.

**Internalized Stigma and Self-Efficacy**

The relationship between internalized stigma and decreased self-efficacy also fits within modified labeling...
theory: the unwillingness to attempt behavioral tasks despite pain (low pain self-efficacy) would be suggested to stem from an internal state of demoralization and devaluation (internalized stigma). Corrigan et al.⁰ argue from a “why try” model that those who apply stigma to themselves consequently feel unworthy or unable to approach life goals. The authors⁰ suggest that a lack of confidence flows from a definition of the self that is based on negative stereotypes. Applying this to chronic pain, for example, people who feel that their pain legitimacy is doubted would question why they should even try to gain employment—believing it to be a futile pursuit.

Internalized Stigma and Cognitive Processes in Relation to Pain

Finally, internalized stigma was related to lower perceptions of personal control over pain and a greater tendency to catastrophize about pain. Such a finding is important given the role these variables play in influencing outcomes.¹³ Research across a diverse range of populations suggests that catastrophic thinking in relation to pain is a risk factor regarding the likelihood of the condition’s persisting, higher levels of reported pain, greater use of medication, and longer time in hospital.⁴¹,⁵⁰ This paper is consistent with previous findings regarding the relationship between depression and catastrophizing.⁵³ However, it extends this through demonstrating a contributory construct previously unconsidered. Although causal relationships were not assessed in this study, it is possible that through internalizing negative beliefs about the validity of his or her pain, an individual becomes increasingly catastrophic in his or her thinking about pain. Such a process would signal a circular relationship, with social factors playing a role in the development and maintenance of pain catastrophizing.⁵⁰ Another possibility is that people with internalized stigma are more likely to catastrophize in order to attract the attention of those in their social environment to receive support, via a more communal approach to coping.⁴⁶,⁵⁰ Finally, it is also possible that some shared cognitive mechanism, such as rumination, underlies both the tendency to catastrophize and the likelihood of perceiving or anticipating negative social reactions about pain.

From a self-regulation model, those living with persistent pain are thought to form representations about their illness that shape their behavior and therefore outcomes.¹²,¹³,²⁶ This study shows that illness representations about personal controllability are linked to an individual’s sociocultural context and the level of stigma internalized from this. Personal representations have been demonstrated to affect long-term disability and pose a psychological barrier to recovery, suggested to occur through responses such as passivity, inactivity, or avoidance of movement.¹⁵ In the context of these findings, addressing internalized stigma as part of treatment presents a potentially important way to modify patient outcome.¹ But this needs to be tested.

Clinical Implications

The paper has important implications regarding the capacity of internalized stigma to be used as an outcome measure and verifiable treatment goal. To date, this construct has not been reported in the pain literature and does not seem prominent in clinical practice, suggesting the need for greater consideration of the sociocultural context. Of particular interest would be to explore whether addressing internalized stigma elicits improvements in psychological well-being and behavioral outcomes important in the rehabilitation process. Recent work within the mental health field by Lucksted et al.⁵⁹ and Yanos et al.,⁶⁰,⁵⁹ for example, provides some support for this hypothesis. On an individual level, strategies such as personal empowerment and cognitive restructuring may prove beneficial. At a social level, Goldberg⁶⁰ refers to the notion of “repatriating” people who are living with chronic pain, arguing for the need to bring the pain sufferer back to a sense of community.

Limitations and Directions for Future Research

Although this study has made some important contributions to theory and practice, some caveats need to be considered when evaluating the results. First, given the study’s correlational nature, the causal direction of the relationships established remains unknown. As such, prospective research is necessary to elucidate the causal direction of the relationship between internalized stigma and psychosocial consequences. A second consideration relates to the nature of the sample. As the questionnaire was completed by participants who expressed an interest in the study, a self-selection bias is likely present. The sample also reflected a group of people with the shared experience of chronic pain, rather than considering different conditions or treatment settings. Because of the small cell size of pain locations, and the tendency for participants to report multiple locations, analysis considering how stigma varied depending on the nature of pain was not feasible. This is an area for future research. Additionally, future research should seek to validate the adaptation of the Internalized Stigma of Mental Illness scale for a chronic pain population with a larger sample that would allow confirmatory factor analysis to be performed.

Significantly, not all participants endorsed feelings of internalized stigma. In the present study, outcome variables were negative processes hypothesized to arise from internalized stigma. However, positive outcomes such as empowerment or righteous anger present the other end of the continuum worth exploring.⁵⁹ Thus, further research that considers factors that differentiate these groups, and the features of those who do not report internalized stigma, would be of interest. In particular, exploring factors that contribute to positive processes such as empowerment in the face of stigma would help to inform the use of training to facilitate resiliency or other protective factors into the future.
References


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Appendix Table 1. Internalized Stigma of Chronic Pain

Alienation
I feel out of place in the world because I have chronic pain
I am embarrassed or ashamed that I have chronic pain
I feel inferior to others who don’t have chronic pain
I am disappointed in myself for having chronic pain
Having chronic pain has spoiled my life
People without chronic pain could not possibly understand me

Stereotype Endorsement
Other people often use chronic pain to obtain narcotics.
People with chronic pain should be able to tolerate pain better as time goes on.
People with chronic pain cannot live a good, rewarding life
People can tell that I have pain by the way I look
People with chronic pain tend to be exaggerating their pain for secondary gains (e.g., to get sympathy or compensation)
Chronic pain is often all in a person’s head
Stereotypes about people with pain apply to me

Discrimination Experience
People discriminate against me because I have pain
People often patronize me, or treat me like a child, because I have chronic pain
People ignore me or take me less seriously just because I have chronic pain
Nobody would be interested in getting close to me because I have chronic pain
Others think that I can’t achieve much in life because I have pain

Social Withdrawal
I avoid getting close to people who don’t have chronic pain to avoid rejection
I don’t socialize as much as I used to because of my pain
I don’t talk about myself much because I don’t want to burden others with my pain
Negative stereotypes about chronic pain keep me isolated from the “normal” world
Being around people who don’t have chronic pain makes me feel inadequate
I stay away from social situations in order to protect my family or friends from embarrassment

Stigma Resistance (Reverse code before including in total score)
People with chronic pain make important contributions to society
I feel comfortable being seen in public with a person who obviously has chronic pain
Living with pain has made me a tough survivor
In general, I am able to live my life the way I want to
Chapter 3: Foreword

Chapter 2 has suggested the power of internalised stigma as a meaning-making construct within the context of persistent pain. This finding provides the rationale for the second study in this program of research. Chapter 2 suggested that anticipating or experiencing negative sociocultural responses on the basis of pain is associated with a person holding negative feelings about themselves and the transformation of their identity or behaviour. However Chapter 2's correlational nature meant that it was unable to identify the direction of these relationships. As such, Chapter 3 now builds on the findings by presenting a longitudinal design that sought to move beyond interrelationships and consider the predictive ability of internalised stigma.

As will be discussed in Chapter 3, a community sample was assessed at baseline and then six-months later. Outcome variables were selected based on the predictions of social psychological theory and the findings of Study 1, which indicated that decrements in self-esteem and self-efficacy might result from internalising stigma. The results of Study 2 are mixed. Findings did suggest the potential for internalised stigma to predict self-esteem at six-month follow-up, while holding baseline levels constant. However, an anticipated relationship was not found for pain self-efficacy. This study demonstrates the potential utility of examining internalised stigma among people with pain and offers multiple directions for future work to explore. Taken together, the results of Study 1 and Study 2 offer noteworthy support for the role of internalised stigma among people living with pain. It suggests the relevance of this construct in considering how living with a condition that attracts
negative sociocultural perceptions can be personally disheartening and may also affect the way a person feels about the self more broadly.
Chapter 3: Declaration

Title

Internalised stigma of chronic pain: Implications for self-esteem and self-efficacy.

Authorship

Olivia Twigg and Donald Byrne

Publication Outlet

Australian Psychologist

Current Status

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Candidate Contribution

The Candidate designed the study, with input provided by DB. The Candidate recruited study participants, conducted data entry and statistical analyses, and developed the initial manuscript. DB provided input on successive drafts of the manuscript.

Co-Author Signature

Ol. By

Professor Donald Byrne
Abstract

To de-stigmatise the experience of people living with pain, it is necessary to be able to assess stigma in a method that enables an examination of its prevalence and interrelationships with self-concept. This study is the first to consider whether internalised stigma predicts the pain self-efficacy and self-esteem of people living with persisting pain. To explore this issue, pain self-efficacy, self-esteem, and internalised stigma were assessed among 57 people with pain at baseline and then at follow-up six months later. While results indicated significant correlations between baseline internalised stigma and pain self-efficacy six months later, internalised stigma did not significantly predict pain self-efficacy when controlling for baseline pain levels. Social withdrawal predicted reduced self-esteem six months later, when taking baseline self-esteem into account. While the findings of this study are tentative, they suggest the vicious cycle that can arise from experiencing internalised stigma in terms of isolation and decreased confidence in oneself. Directions for future research, particularly in relation to self-efficacy research, and the targeting of internalised stigma as part of multidisciplinary pain management approaches are discussed.

Key words: confidence, psychosocial, management, self-concept, stereotyping, stigma
Internalised Stigma of Chronic Pain: Implications for Self-Esteem and Self-Efficacy

Persistent pain can have a devastating effect on a person’s psychosocial functioning and wellbeing, well beyond the physical suffering (Gatchel, McGeary, McGeary, & Lippe, 2014). As such, living with persistent pain presents a multidimensional experience. It has been associated with a range of adverse intrapersonal outcomes such as decreased work performance (van Leeuwen, Blyth, March, Nicholas, & Cousins, 2006), greater utilisation of health care services (Blyth, March, Brnabic, & Cousins, 2004; Von Korff, Lin, Fenton, & Saunders, 2007), and higher levels of emotional distress, including increased risk of suicide (Tang & Crane, 2006). These consequences are not uni-directional, but rather, interact in dynamic and reciprocal ways that pose a challenge for effective pain management.

A desire to ensure an integrated approach to pain management and treatment gave rise to the development of Australia’s National Pain Strategy (National Pain Summit Initiative, 2010). One of the Strategy’s primary goals is for people in pain to be a national health priority. Within this, a priority objective is to de-stigmatise the predicament of people with pain, especially chronic non-cancer pain (National Pain Summit Initiative, 2010). Stigma occurs when an individual is distinguished from other members of society based on their condition and encounters negative social or cultural responses (Goffman, 1964). To work effectively towards such an objective it is imperative to be able to quantitatively measure and thus understand the experience of stigma from the perspective of those living with pain. Such measurement enables an examination of prevalence, interrelationships with self-concept and psychological wellbeing, which in turn can inform clinical treatment and management targets.
Examination of chronic pain stigma has emerged in the qualitative literature over the past decade (Goldberg, 2010; Holloway, Sofaer-Bennett, & Walker, 2007; Nielsen, 2010; Slade, Molloy, & Keating, 2009). This work attests to the psychological influence that labelling and stereotyping has on participants’ views of themselves (Nielsen, 2010). Such findings are consistent with the proposition that internalised stigma, typically studied in the mental health literature (Corrigan & Watson, 2002; Corrigan, Watson, & Barr, 2006; Link & Phelan, 2001), may feature among those experiencing persistent pain. Internalised stigma represents a process where an individual absorbs negative societal views about pain, and comes to believe and apply these to themselves (Corrigan & Watson, 2002; Drapalski et al., 2013). The anticipation, or experience of, negative sociocultural reactions based on their pain is essentially turned inward, or internalised, leading to negative feelings about self, identity transformation, or maladaptive behaviour (Livingston & Boyd, 2010).

Internalised stigma has received minimal coverage in the quantitative pain literature, the exception being the work of Marbach and Lennon (Lennon, Link, Marbach, & Dohrenwend, 1989; Marbach, Lennon, Link, & Dohrenwend, 1990) in chronic facial pain, and recent movements (Young, Park, Tian, & Kempner, 2013) in the area of migraine pain. The absence of quantitative research in this area reflects an information gap underpinning the National Pain Strategy objective. This gap has recently begun to be addressed by authors considering a heterogeneous chronic pain population (Waugh, Byrne, & Nicholas, 2014). Results showed that a substantial proportion of people with pain endorsed the experience of internalised stigma, and that this was associated with low self-esteem, low pain self-efficacy, and mood disturbance (Waugh et al., 2014). Additionally, associations with psychological mechanisms related to pain were highlighted, specifically the tendency to
catastrophise about pain and perceptions of personal control over pain. However, this study was limited by its correlational nature, and prospective research is required.

As such, the present study is novel in considering if higher levels of internalised stigma are predictive of adverse outcomes, namely reduced self-esteem and pain self-efficacy. The selection of these two outcome variables is based on social psychological work which theorises that decrements in self-esteem and self-efficacy result from internalising stigma (Corrigan & Watson, 2002; Corrigan et al., 2006; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). From a social psychological framework, it is suggested that people with pain encounter negative beliefs about their condition throughout their interactions in society. Through internalising these beliefs, an individual is suggested to in turn feel that they are less valued due to their condition, and feel somewhat removed or isolated from society. A person's confidence in their future, and themselves, suffers due to concurrence with stigma (Corrigan & Watson, 2002).

Method

Participants

The research was conducted between 2011 and 2013 among people living with non-malignant chronic pain, defined as current pain that has persisted for at least three months in the previous six months. Participants ($M_{age} = 51.58$ years, $Range = 18-86$ years) reflected a heterogeneous pain population, who were recruited through community newspapers, online forums, and medical and allied health centres. No financial incentive was provided for participation. Approval from relevant Institutional Ethical Review Boards was granted and participants gave informed consent.
Materials and Procedure

Participants ($n = 92$) were provided with a survey booklet at baseline and were asked whether they would be willing to participate in a follow-up study. Of those surveyed, 87% gave consent to be mailed a questionnaire six months later ($n = 80$). Following a similar format to Schnell et al. (2010) these participants completed a self-generated six-element identification code, enabling their data to be linked across the two time points in an anonymous manner. At follow-up, 56 participants (70%) returned the questionnaire. This reflected 24 non-completers (30%), including one incorrect address and one deceased participant (2.5%).

All measures are self-report. The demographic questions and sample characteristics completed by participants at baseline have been described elsewhere (Waugh et al., 2014). Explained below are the measures used to assess the key variables used in analysis.

**Internalised Stigma.** The Internalised Stigma of Mental Illness Scale was developed by Boyd and colleagues (2003) to assess internalised stigma in relation to mental illness. It has recently been modified for a chronic pain population (Waugh et al., 2014). This modification has four subscales: Alienation; Discrimination Experience; Social Withdrawal; and Stigma Resistance (Waugh et al., 2014). Participants respond to a series of statements related to their chronic pain on a four-point Likert scale, (anchored: $1 = $Strongly disagree$, 2 = $Disagree$, $3 = $Agree$, 4 = $Strongly agree$). Scores are averaged, with higher values indicative of greater internalised stigma. In the present study, the scale has a high level of internal consistency, as determined by a Cronbach’s $\alpha = .89$. Subscale reliability in the present study was acceptable (Alienation = .83, Discrimination Experience = .76,
Social Withdrawal = .76, Stigma Resistance = .58), particularly given the small number of subscale items is known to reduce α level.

**Pain Self-Efficacy.** The Pain Self-Efficacy Questionnaire (1989) was used at baseline and follow-up to assess participants’ beliefs regarding their ability to accomplish a range of activities despite their pain. Possible scores range from 0 – 60, with high scores indicating greater pain self-efficacy. Consistent with the sound psychometric properties reported in the literature, Cronbach’s α = .92 (baseline) and Cronbach’s α = .93 (follow-up).

**Self-Esteem.** A single item measure (Robins, Hendin, & Trzesniewski, 2001) was selected, given its utility as a quick and effective measure of self-esteem. Previous work has demonstrated that the item has high convergent validity with Rosenberg’s scale (1989) and equivalent correlations with criterion measures (Robins et al., 2001; van Dirk & Haslam, 2012). Participants are asked, *Thinking about yourself generally, how true is the following statement of you: I have high self-esteem?*, with responses recorded on a five-point Likert scale (anchored: 1 = Not very true of me, 5 = Very true of me).

**Analytical Plan.** There were three phases of analysis. Firstly, participants’ baseline and follow-up data was matched based on self-generated codes. The assumptions of each statistical test were considered, to ensure appropriateness for analysis. Square root transformations for the internalised stigma scale were performed due to some departure from normality, however as substantive results did not differ, the untransformed results are reported. Independent samples t-tests and chi-squared analyses were used to compare the characteristics of participants who completed the study with non-completers.
In the second phase of analysis, hierarchical multiple regression was used to predict pain self-efficacy at follow-up based on internalised stigma. This technique controlled for baseline level of pain self-efficacy.

In the third analytic phase, the SPSS (IBM Corp, Armonk, NY) ordinal regression procedure (PLUM) was performed to consider whether internalised stigma predicts a person’s self-esteem, while taking baseline levels of self-esteem into account. This technique was selected as self-esteem represented an ordinal rather than continuous dependent variable. Following crosstab analysis suggesting a potential problem with small cell size for self-esteem, categories were collapsed (coded 0, 1, 2 for low, moderate and high self-esteem respectively).

Results

Sample characteristics are provided in Table 1 and Table 2. The follow-up participation rate met the minimum number of desired cases for regression analysis, based on Green’s (1991) rule. However as six participants supplied different codes at Time 1 and Time 2, their data was not able to be used, leaving 50 cases for analysis. No significant differences in internalised stigma, pain self-efficacy, self-esteem, disability, or depression, or any demographic characteristics were found between participants who participated in follow-up and those who did not (p > .05). The one exception to this was gender, with a chi-square test of independence (Yates’ continuity correction) indicating a significant association between gender and survey completion, $\chi^2 (1, n = 79) = 3.901, p = .048$. A greater percentage of females completed the follow-up study, compared to male participants which is typical of the literature (Smith, 2008).
Internalised Stigma and Self-Esteem

Results showed that internalised stigma did not significantly improve the ability to predict self-esteem (Wald $\chi^2(1) = 2.985$, $p = .084$), holding baseline self-esteem constant, although this was approaching statistical significance. Analysis also considered the role of each subscale in predicting self-esteem, while taking baseline self-esteem into account. As shown in Table 3, social withdrawal was a significant predictor of self-esteem, while other subscales were not.

For social withdrawal, analysis suggested good model fit, ($p = .992$), Nagelkerke's measure = .621 ($n = 47$), but most cells were sparse with zero frequencies. However, the final model significantly predicted self-esteem over and above the intercept only model ($\chi^2 = 37.144$, df = 3, $p < .001$), with results showing that social withdrawal significantly improved the ability to predict self-esteem, taking baseline self-esteem into account. A change in one unit of social withdrawal was associated with an odds ratio of .11; that is for each unit increase in social withdrawal, the odds of high self-esteem decreased by .11 times (95% CI, .02 to .58, Wald $\chi^2(1) = 6.804$, $p = .009$).

Internalised Stigma and Pain Self-Efficacy

Initial analysis using bivariate correlations revealed a significant, strong negative correlation between internalised stigma and pain self-efficacy six months later ($r = -.573$, $p < .001$, $n = 50$). However, hierarchical multiple regression indicated that the addition of internalised stigma did not improve the prediction of pain self-efficacy at follow-up over and above baseline pain self-efficacy alone, $F_{\text{change}} (1, 47) = .032$, $p = .858$. Similarly, none of the subscales significantly added to the model once baseline pain self-efficacy was taken into account ($p > .05$).
Post-hoc power analyses based on data utilised in analysis suggested the power to detect a moderate effect was reasonable ($\beta = 0.76$), however the study was underpowered ($\beta=.16$) in seeking a small effect size.

Discussion

The current study considered whether internalised stigma could significantly predict pain self-efficacy and self-esteem over time. A facet of internalised stigma, social withdrawal, was able to significantly predict self-esteem over time, when controlling for baseline levels. Results also suggested that internalised stigma overall might also have predictive ability as it trended in the anticipated direction, although statistical significance was not reached. In contrast to the findings relating to self-esteem, after controlling for baseline levels of pain self-efficacy, internalised stigma was not able to significantly improve our predictive ability of pain self-efficacy.

Self-esteem: Theoretical Links and Clinical Implications

Self-esteem was predicted by social withdrawal. Our findings are consistent with a social psychological framework (Link & Phelan, 2001), that social withdrawal is a mechanism through which stigma has a negative influence on the lives of people with pain. In response to the perception that individuals are devalued and judged by society based on their pain, a person may fear the possibility of personal rejection and avoid social interactions. As demonstrated by the current findings, this in turn decreases the individual’s self-esteem six months later. Self-esteem has long been considered to make an important contribution to psychological functioning and mental health (Sharma & Sharma, 2010). Consistent with Link et al. (2001) reducing internalised stigma is likely to lead to improvements in the self-esteem of people with pain.
The predictive relationship between social withdrawal and self-esteem also suggests that a vicious cycle can arise from experiencing internalised stigma. This finding is consistent with a protective coping mechanism (Ritsher & Phelan, 2004) of retreating from society due to the psychological hurt of pain-related judgements. But this withdrawal comes at a cost; feeling less worthwhile no doubt perpetuates a cycle of isolation and lack of connection due to pain. Nielsen (2010) has suggested that the “promise of the multidimensional approach” has not come to fruition and argues that an adequate response to persisting pain requires the consideration of the sociocultural context and its intersection with an individual’s life. The present study represents an attempt to consider such issues, and supports this work, through beginning to explore how the influence of social dimensions (stigma) may predict outcomes for people with pain.

At first glance, it may seem that social withdrawal and self-esteem are analogous, however this is not the case. Firstly, the internalised stigma of chronic pain’s scale items link directly to living with persisting pain and the experiences that stem from this. In contrast, self-esteem is a global measure. Secondly, the analysis took baseline self-esteem into account and thus the constructs were sufficiently different for social withdrawal to make a unique additive contribution.

The finding that stigma resistance does not predict self-esteem is consistent with previous work in the field (Ritsher & Phelan, 2004). This result is worth noting as the stigma resistance subscale reflects a positive attribute, speaking to empowerment in the face of stigma. As such, it is interesting that resistance to stigma was not sufficient for a person to experience increased confidence in themselves. Future work could consider targeted efforts to empower people with
pain and provide support that may help to positively increase how they feel about themselves.

Self-efficacy: Theoretical Links and Clinical Implications

A number of possible interpretations for the finding that internalised stigma did not predict pain self-efficacy, are provided. Firstly, similar to explanations proposed by Ritsher and Phelan (2004), the baseline correlation between pain self-efficacy and internalised stigma was substantial. Therefore, perhaps participants were already demoralised at the first point of measurement to the extent that further reductions were not observed. Duration of pain experience may have some influence too, although such analysis was not possible in the present study. It is worth bearing in mind that the ‘baseline’ measures of participants were not captured at the time of onset of internalised stigma, or at the onset of their chronic pain experience. Alternatively however, it may be that internalised stigma is not a strong predictor of pain self-efficacy although this would be at odds with established literature in the field. Given the theoretical frameworks linking internalised stigma to self-esteem and self-efficacy, exploration of the difference between general self-efficacy and pain self-efficacy is warranted. This would reflect a consideration of a person’s identity as a ‘chronic pain sufferer’ and compare general beliefs about one’s perceived ability to achieve future success to confidence in their future despite pain.

Limitations

A number of limitations should be noted. Firstly, as our follow-up sample size is small, and was predominantly female, it is advisable that the results be considered tentatively, pending replication in a larger, more representative sample. Despite the issue of statistical power, this is a new area in which there is little
existing evidence, and the present study provides the empirical beginnings of a fruitful area of work.

Additionally, this study considered the relationship between internalised stigma and two measures essentially tapping into self-concept. While critical for patient outcomes, these outcome variables nevertheless represent one outcome area. Future research could consider other life domains, such as behavioural outcomes like employment status.

A final limitation is that this study relied on self-report measures, which is a limitation shared with the vast majority of research in the area. However, recent work has considered implicit self-esteem techniques in addition to traditional methods (Greenwald & Farnham, 2000). Utilising such methodology may yield stronger effect sizes and a more nuanced understanding in the future of the research domain.

Conclusion

To de-stigmatise the experience of people living with pain (National Pain Summit Initiative, March 2010), it is necessary to assess stigma utilising an objective method that enables the measurement of stigma, increase understanding of stigma’s relationship to an individual’s psychological functioning, and advocate for stigma to be targeted as a verifiable treatment goal. Previous research has established associations between a range of outcome measures and internalised stigma (Waugh et al., 2014), however to the authors’ knowledge work has not yet considered the predictive ability of internalised stigma in a pain population. This study was the first to do so, with mixed findings. A key result was that social withdrawal from internalised stigma predicted self-esteem six months later, taking baseline levels into account. This suggests that one important outcome of clinical work aiming to reduce
internalised stigma, such as social withdrawal, would be improving the self-esteem of people with pain. The present study did not find however that individuals would necessarily experience changes in pain self-efficacy, although whether internalised stigma affects a broader sense of confidence in one’s ability remains to be investigated.

Key Points

What is already known about this topic:

- Internalised stigma can lead a person to experience a sense of demoralisation and devaluation due to their condition.
- Traditionally considered in the mental health literature, internalised stigma has recently been applied to a persistent pain population.
- Previous research has established associations between a range of outcome measures and internalised stigma, such as lower levels of self-esteem and pain self-efficacy, and unhelpful cognitive responses to pain.

What this topic adds:

- An examination of how internalised stigma may affect people over time;
- Support for the notion that internalising stigma leads to a vicious cycle of social withdrawal;
- A novel means of considering how the sociocultural context can impact on people with pain, which could be used by clinicians as a measurement tool and verifiable treatment goal.
Acknowledgements

The researchers would like to acknowledge the generous contribution and support that the participants made to this project.
References


Young, W. B., Park, J. E., Tian, I. X., & Kempner, J. (2013). The stigma of migraine. *PloS one, 8*(1), e54074. doi:10.1371/journal.pone.0054074
Table 1

*Summary of Sample Characteristics (n = 50)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>43 (86)</td>
</tr>
<tr>
<td>Male</td>
<td>6 (12)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>51.18 (15.48)</td>
</tr>
<tr>
<td>Duration of pain</td>
<td></td>
</tr>
<tr>
<td>Greater than nine months</td>
<td>50 (100)</td>
</tr>
<tr>
<td>Onset of pain</td>
<td></td>
</tr>
<tr>
<td>Slow/gradual</td>
<td>22 (44)</td>
</tr>
<tr>
<td>Sudden</td>
<td>25 (50)</td>
</tr>
<tr>
<td>Education (Completed)</td>
<td></td>
</tr>
<tr>
<td>Year 10 Certificate</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Year 12 Certificate</td>
<td>3 (6)</td>
</tr>
<tr>
<td>University Degree</td>
<td>19 (38)</td>
</tr>
<tr>
<td>Technical college (e.g. diploma)</td>
<td>21 (42)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Currently Employed</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>38 (76)</td>
</tr>
<tr>
<td>Yes</td>
<td>11 (22)</td>
</tr>
<tr>
<td>Compensation Case</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>43 (86)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (10)</td>
</tr>
</tbody>
</table>
Note. Values are Frequency, n (%) unless otherwise indicated. Not all percentages sum to 100 due to missing data.
Table 2

Mean and Standard Deviations of Study Variables

<table>
<thead>
<tr>
<th>Descriptive Statistics</th>
<th>N</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DASS-21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>49</td>
<td>14.73 (10.87)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>49</td>
<td>10.61 (8.90)</td>
</tr>
<tr>
<td>Stress</td>
<td>46</td>
<td>15.65 (8.48)</td>
</tr>
<tr>
<td>Internalised Stigma of Chronic Pain (Baseline)</td>
<td>50</td>
<td>2.37 (.47)</td>
</tr>
<tr>
<td>Alienation (Baseline)</td>
<td>50</td>
<td>2.52 (.71)</td>
</tr>
<tr>
<td>Discrimination Experience (Baseline)</td>
<td>50</td>
<td>2.37 (.58)</td>
</tr>
<tr>
<td>Social Withdrawal (Baseline)</td>
<td>50</td>
<td>2.41 (.52)</td>
</tr>
<tr>
<td>Stigma Resistance (Baseline)</td>
<td>50</td>
<td>2.14 (.54)</td>
</tr>
<tr>
<td>Pain Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>50</td>
<td>6.77 (1.72)</td>
</tr>
<tr>
<td>Worst in past 24 hours</td>
<td>50</td>
<td>4.50 (2.09)</td>
</tr>
<tr>
<td>Pain Self-Efficacy Questionnaire</td>
<td>50</td>
<td>30.52 (14.88)</td>
</tr>
<tr>
<td>Roland and Morris Disability Questionnaire</td>
<td>50</td>
<td>11.30 (5.37)</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>47</td>
<td>3.19 (1.14)</td>
</tr>
</tbody>
</table>

Note: All measures are at six month follow-up unless otherwise indicated.
Table 3

*Predicting Self-Esteem with Internalised Stigma of Chronic Pain*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Est.</th>
<th>SE</th>
<th>Wald $\chi^2$</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alienation</td>
<td>-0.842</td>
<td>0.536</td>
<td>2.473</td>
<td>-1.892</td>
<td>0.207</td>
<td>0.116</td>
</tr>
<tr>
<td>Discrimination Experience</td>
<td>-1.054</td>
<td>0.666</td>
<td>2.504</td>
<td>-2.358</td>
<td>0.251</td>
<td>0.114</td>
</tr>
<tr>
<td>Social Withdrawal</td>
<td>-2.200</td>
<td>0.843</td>
<td>6.804</td>
<td>-3.853</td>
<td>-0.547</td>
<td>0.009*</td>
</tr>
<tr>
<td>Stigma Resistance</td>
<td>0.886</td>
<td>0.709</td>
<td>1.561</td>
<td>-0.504</td>
<td>2.275</td>
<td>0.211</td>
</tr>
</tbody>
</table>

Note: Each analysis controlled for baseline self-esteem, with n=47 cases in all analyses due to missing data for 3 participants on follow-up self-esteem; df = 1 for all analyses; est. = parameter estimate, SE = standard error, * = significant, $p < .05$. 
Chapter 4: Foreword

The findings presented in Chapter 3 suggest a vicious cycle that can arise from experiencing internalised stigma by highlighting a predictive relationship between social withdrawal and self-esteem. This finding is consistent with a protective coping mechanism of retreating from society due to the psychological hurt of pain-related judgments. But this withdrawal comes at a cost; feeling less worthwhile no doubt perpetuates a cycle of isolation and lack of connection due to pain. Given the relationships with self-concept and psychological functioning that are indicated in Chapters 2 and 3, Chapter 4 moves to consider whether internalised stigma is a static construct or if it is changeable following participation in a multidisciplinary, cognitive behavioural based pain program. As pain is a complex condition, involving biological, psychological, behavioural, and sociocultural processes, effective treatment involves multidisciplinary interventions that target these different components of pain experience (Gatchel et al., 2007; Molloy et al., 2006; Sanders et al., 2005).

To consider the utility of internalised stigma as a verifiable treatment target, Chapter 4 (Study 3) employs a quasi-experimental design to test the treatment effect of an evidence-based program for internalised stigma. This reflects an effort to consider if, and how, current treatment approaches may be effective in targeting stigma. Findings suggest internalised stigma is a modifiable construct that group-based cognitive behavioural therapy is able to reduce. Therefore, Chapter 4 presents a novel step in attending to the psychosocial context of stigma highlighted in Chapters 2 and 3 through the assessment and treatment process. Findings reveal promising new clinical and research directions.
Chapter 4: Declaration

Title

Decreasing Internalised Stigma through a Chronic Pain Program: An Exploratory Study

Authorship

Olivia Twigg, Michael Nicholas, Donald Byrne, and Sarah Overton

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Candidate Contribution

The Candidate designed the study, with input provided by DB and MN. The Candidate collaborated with MN and SO to arrange recruitment and data collection. MN and SO led the delivery of the chronic pain program. The Candidate conducted all data entry, statistical analysis, and prepared the initial manuscript. DB, MN and SO provided input on successive drafts of the manuscript.

Co-Author Signatures

Professor Michael Nicholas

Professor Donald Byrne

Dr Sarah Overton
Abstract

Purpose: The study considered whether participation in a cognitive-behavioural group program was linked to declines in internalised stigma of chronic pain.

Method: Utilising a quasi-experimental design, the internalised stigma of patients with severe and debilitating chronic pain was assessed before and after an intensive cognitive behavioural group intervention at a large metropolitan hospital.

Results: Significant mean decreases were found between the pre- and post-program internalised stigma scores. Significant decreases in alienation and social withdrawal, but not discrimination experience, were found. Stigma resistance significantly increased post-program.

Conclusions: This study found that participation in a rehabilitation program was associated with decreased internalised stigma and increased stigma resistance in people with persisting pain. Disability and pain self-efficacy, but not depression, were identified as correlates of change. Future research can build on these findings by conducting a randomised control trial and also exploring the characteristics of patients who did not experience any change, to inform more targeted interventions.
Decreasing Internalised Stigma through a Chronic Pain Program:
An Exploratory Study

The biopsychosocial model is currently the most widely accepted model for the understanding and treatment of chronic pain.[1] As the name suggests, it is an integrated model which posits that biological, psychological, and social factors interact in a dynamic and multi-directional way to cause and maintain chronic pain.[2] This is in contrast to previous formulations that focused on biomedical explanations of pain. However, while the concept of a body-mind dualism has well and truly been put away in academic circles, it endures as an interpretative mechanism for some health care-providers, caregivers, and people with chronic pain.[3] Yet the persistence of body-mind dualism in everyday understanding is incompatible with chronic pain sufferers' experiences and contributes to stigmatisation of people with pain.[3,4]

Research suggests that chronic pain is a stigmatised condition, in that negative social judgements are made by other people that lead to prejudiced attitudes or discrimination against people on the basis of their pain.[3-6] More recently, work has begun to explore how this influences people with pain, through the concept of internalised stigma.[7-10] Internalised stigma occurs when the anticipation or experience of negative stereotypes or discrimination are turned inward and applied to the self, which can lead to withdrawal, shame, alienation, and personal devaluation.[11] Research has shown that internalised stigma is associated with lower levels of self-esteem and pain self-efficacy, and higher emotional distress.[8] Analogous work in the mental health field has demonstrated that internalised stigma can lead to a range of negative outcomes, such as treatment resistance, increased risk of suicide, reduced access to healthcare and subsequently decreased quality of
life.[12-16] As such, internalised stigma presents an additional burden for those who already suffer from the debilitating effects of chronic pain.

Clearly, this has clinical implications in terms of the assessment, treatment and rehabilitation of people living with chronic pain. Investigating how internalised stigma can be reduced or resisted is imperative.[17] However, prior to considering specific, targeted interventions to address internalised stigma, it is necessary to understand whether internalised stigma can be changed within current rehabilitative treatment settings.[12] This is because the core elements of cognitive-behavioural pain programs are similar to those suggested as central to the reduction of stigmatising beliefs about the self, and subsequent empowerment.[12,17,18] For example, group based interventions typically used to treat chronic pain incorporate opportunities for: the normalisation of illness, an increase in personal autonomy over pain, developing personal strengths, vocational rehabilitation, and challenging beliefs about the inability to connect with others due to pain.[19-22] We suggest these elements are also likely to target aspects of internalised stigma.[17,18]

Consequently, an improved understanding of whether participation in a cognitive-behavioural intervention may reduce self-stigma, and what factors correlate with change, is critical. Such information could be used to develop tailored modules to enhance outcomes for those with high internalised stigma. It will also give insight into how current models of care are able to assist those with internalised stigma.

The present study thus tested the hypothesis that internalised stigma would decrease after participation in a multidisciplinary intervention, compared to the hypothesis that internalised stigma would not change and thus be static. Two key research questions flowed from this hypothesis. Firstly, what level of reduction is
observed among participants, and are reductions seen across all facets of internalised stigma? Secondly, if significant changes are found, then correlates of change are also of interest. To consider this, the outcome measures of pain, disability, and depression were measured. These variables were chosen in line with previous research, given the importance of reducing disability and improving psychological well-being for people with chronic pain.[22]

Method

Participants

Data reflects a heterogeneous sample of people living with chronic, non-malignant pain, who were consecutive patients in the ADAPT program between May and October in 2013 (M_age = 43.82, age range =18 – 65 years). The program’s referral process as well as inclusion and exclusion criteria have been reported elsewhere.[22] Briefly, all patients were assessed individually at a large metropolitan hospital by a multidisciplinary team including a pain specialist, physiotherapist, and clinical psychologist. Each patient’s case was then reviewed at a multidisciplinary team meeting. Patients entered the program when the team agreed that further medical/surgical options were not appropriate, and the patient was significantly distressed and/or disabled by pain. The patients were at least six months post-injury but typically their pain has persisted for much longer. Data was collected as part of a larger assessment booklet, with no financial incentive provided. Participants provided informed consent, and relevant Institutional Review Boards granted permission.

Procedure and Measures

Prior to commencing the ADAPT pain program, participants responded to a survey booklet containing all measures. Patients then completed a three-week, intensive cognitive behavioural therapy program at a large metropolitan hospital.
The multidisciplinary program involves a full-time phase designed to assist people with pain that has resulted in high levels of distress, pain-related disability, or medication-reliance. The program’s strategies have previously been described in the literature,[22] with information also available in a detailed patient manual.[19] The program is broadly based on the work of clinicians at St Thomas’ Hospital in London [21] and has more recently been adapted in South East Asia.[20] Previous research and evaluation of the pain program has indicated its benefit compared to standard medical care.[21,23]

Following completion of the program, the participants again completed the survey booklet. All measures are self-reported scales.

Demographics, pain severity and pain distress. Participants were asked to indicate their gender, age (in years), and time since the initial onset of their pain (months). Four items akin to the Brief Pain Inventory were included to assess the participant’s current pain level, lowest and highest pain intensity in the last week, and usual pain level in the last week (likert scale, anchored 0 = No pain, 10 = Pain as bad as you can imagine). These four variables are summed to provide an average pain severity score. Participants were also asked to indicate how distressed they had felt by their pain on average in the previous week (likert scale, anchored 0 = Not at all distressing, 10 = As distressing as it could be).

Internalised Stigma. Following previous research,[8] the Internalised Stigma of Mental Illness scale [24] was modified for a chronic pain population. The modified version of the instrument, Internalised Stigma of Chronic Pain (ISCP), has four subscales: Alienation, Discrimination Experience, Social Withdrawal, and Stigma Resistance. Participants respond to a series of statements designed to assess the presence of internalised stigma in relation to their persisting pain (likert scale,
anchored 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). Scores are averaged to give a total score (Range 1 – 4), with higher scores thus signalling greater internalised stigma. Consistent with previous research,[8] the modified version had acceptable reliability, Cronbach’s α = .86 (Time 1) and Cronbach’s α = .90 (Time 2).

**Pain Response Self-Statements.** The Pain Response Self-Statements (PRSS)[25] catastrophising subscale was used to assess situation-specific aspects of participants’ cognitive response to pain, which may hinder their coping ability. Participants indicate their agreement with a series of statements on a six-point scale (anchored 0 = almost never to 5 = almost always). Higher scores are indicative of a greater tendency to catastrophise in response to pain. Previous work in the field has indicated good psychometric properties [26], and in the present study Cronbach’s α = .85 (Time 1) and .92 (Time 2).

**Pain Self-Efficacy.** The Pain Self-Efficacy Questionnaire (PSEQ)[27] was used to consider a participant’s confidence in their own ability to perform a range of activities despite pain. Scores range from 0 to 60, with higher scores suggesting greater pain self-efficacy. Consistent with the sound psychometric properties that have previously been reported,[28] Cronbach’s α = .91 (Time 1) and .94 (Time 2) in the present study.

**Physical Disability.** An adapted version of the Roland and Morris Disability Questionnaire (RMDQ),[26,29] appropriate for a heterogeneous chronic pain population, was used to consider the current level of physical disability due pain. Scores range from 0 to 24, with higher scores indicative of increased physical disability. Previous research has reported acceptable validity and reliability,[26] and in the present study Cronbach’s α = .87 (Time 1) and .89 (Time 2).
Depressive Symptomology. The Depression Anxiety and Stress Scale (DASS) was utilised in the present study, with the depression subscale having possible scores ranging from 0 to 42. A higher score is indicative of more severe depressive symptomology in the previous week. Importantly, the subscale does not include somatic items and thus is less likely to be (artificially) increased by chronic pain.[30] Previous research has established the scale’s validity and reliability for a pain population.[30,31] In the present study, Cronbach’s α = .96 (Time 1) and .96 (Time 2).

Analytical Plan. Screening and cleaning was conducted to ensure data met assumptions of analysis. Reliability analyses were performed to confirm each scale’s acceptability. There were three phases of analysis. Firstly, descriptive statistical analysis considered the frequency of participants who could be classified as experiencing minimal, mild, or high internalised stigma,[11,32] pre- and post-program. Analysis also considered the extent of improvement by calculating percentage change scores. Patients experiencing minimal to no internalised stigma at baseline (i.e. ISCP total <2.00) were excluded from analysis as they were already experiencing a targeted level of stigma pre-program. In considering percentage change scores, improvement greater than 25% was examined, with this cut-off score determined a priori, following the approach of Lysaker et al.[12]

In the second phase of analysis, paired sample t-tests were conducted to consider whether significant mean differences in outcome were associated with the intervention, adjusting for multiple tests using the Bonferroni method.

In the third phase of analysis, visual binning on scanned cases generated cut points at the mean and ±1 standard deviation, yielding four groups based on stigma change: no/negative, small, moderate, or large, percentage change scores. Three
mixed between-within subjects ANOVAs were conducted to consider the interaction between change in stigma and participants’ depression, disability, and self-efficacy respectively, across two time periods (pre-intervention, post-intervention). There was no violation in the assumption of homogeneity of variances or homogeneity of covariances. Data was normally distributed for disability; violations in normality were found for pain self-efficacy pre-intervention, and depression post-intervention, however as mixed ANOVA is somewhat robust to deviations of normality a decision was made to proceed with analysis. Follow-up tests adjusted for multiple comparisons using the Bonferroni correction.

Results

Sample characteristics are provided in table 1. Analysis indicated a small amount of missing data at Time 2 (<5%), which was treated via the exclude cases pairwise option. Following the removal of three outliers on the internalised stigma scale, distributions were considered acceptable and assumptions met for analysis. As seen in table 2, initial calculations indicated that the mean scores on the major target variables all improved significantly.

To consider internalised stigma, frequency calculations were performed, with the results in table 3 indicating around 18% of patients had high internalised stigma following the program. The level of percentage change in pre to post ISCP scores are displayed in table 4. Results revealed that when excluding participants who were already experiencing low levels of internalised stigma, 19% of participants reported a decrease of more than 25% (relative to their baseline stigma index).

A paired sample t-test revealed a large,[33] significant decrease in ISCP scores from Pre ($M = 2.53, SD = .40$) to Post ($2.19, SD = .45$), $t(39) = 6.517, p<.001$
(two-tailed), $\eta^2=.52$ The mean decrease in ISCP scores was .34 (99% confidence interval = .20-.48). Table 5 shows large,[33] significant improvements for the Alienation, Social Withdrawal, and Stigma Resistance subscales, but not Discrimination Experience.

**Correlates of change.** Depression: There was no significant interaction between stigma change and time on depressive symptoms, $F(3,35) = 1.806, p = .16$, partial $\eta^2=.13$. There was a main effect for time, $F(1, 35) = 23.907, p < .001$, partial $\eta^2=.41$, with an overall reduction in depression scores observed following the intervention ($M_{\text{difference}} = 8.58 \pm 1.76$). No main effect for stigma change was found, $F(3, 35) = .248, p = .862$, partial $\eta^2 = .02$.

Disability: There was a significant interaction between stigma change and time on disability, $F(3,36) = 3.002, p < .05$, partial $\eta^2=.20$. There was a significant effect of time on disability for the small stigma change: $F(1, 14) = 8.072, p = .013$, partial $\eta^2=.37$, $M_{\text{decrease}} = 3.20 \pm 1.13$; moderate stigma change: $F(1, 11) = 20.706, p = .001$, partial $\eta^2=.65$, $M_{\text{decrease}} = 4.00 \pm .88$; and large stigma change groups: $F(1, 6) = 14.785, p = .009$, partial $\eta^2=.71$, $M_{\text{decrease}} = 5.43 \pm 1.41$; but not the no/negative group: $F(1,5) = .217, p = .661$, partial $\eta^2 = .04$.

Pain Self-Efficacy: Analysis revealed a significant interaction between stigma change and time on pain self-efficacy, $F(3,35) = 3.413, p < .05$, partial $\eta^2 = .23$. There was a significant improvement in pain self-efficacy at post-intervention compared to pre-intervention, for the small stigma change: $F(1, 13) = 17.765, p = .001$, partial $\eta^2 = .577$, $M_{\text{increase}} = 14.00 \pm 3.32$; moderate stigma change: $F(1, 11) = 27.034, p < .001$, partial $\eta^2 = .711$, $M_{\text{increase}} = 12.83 \pm 2.32$; and large stigma change group: $F(1, 6) = 22.241, p = .003$, partial $\eta^2 = .788$, $M_{\text{increase}} = 18.29 \pm 3.88$; but not for the no/negative stigma group ($p = .749$). Follow-up tests revealed a significant
difference in pain self-efficacy between stigma change groups post-intervention, $F(3, 35) = 3.449, p < .05$, partial $\eta^2 = .23$. Pain self-efficacy was significantly greater in the high stigma change group compared to the no/negative group, $M_{\text{difference}} = 19.21 \pm 6.19, p = .019$. No other comparisons were significant ($p > .05$).

Discussion

The present study’s consideration of whether internalised stigma among people with chronic pain can change is novel. Consistent with previous studies on multidisciplinary cognitive-behavioural pain programs,[21,23] the mean scores on all the major target variables improved significantly. But the questions addressed here are whether internalised stigma changed as well, and how these changes might be related to changes in the other variables measured. Promisingly, and as predicted, results indicated a significant decrease in internalised stigma after the program. Post-intervention, 82% of patients did not report high levels of internalised stigma. Moreover, approximately one fifth of those with persisting pain that had caused ongoing distress or disability experienced clinically significant reductions in stigma scores. In essence, the findings demonstrate that internalised stigma is not a static construct and can be reduced among people with persisting pain.

Large reductions in patients’ Alienation and Social Withdrawal were observed. Such findings are important given these subscales reflect the subjective sense that one has a ‘spoiled identity’,[34] has behaviourally withdrawn from social interactions, and feels like an outsider, due to persisting pain.[24] Large, significant post-program increases were also seen in Stigma Resistance. This reflects empowerment and is a positively oriented subscale signifying patients were less affected by stigma. Finding effective ways to support people with chronic pain to
become empowered and resilient is important,[35] and this study is the first to explore how internalised stigma may be part of this process.

However, significant decreases were not seen in the Discrimination Experience subscale. While the scale is oriented to the present and does not include items regarding specific episodes of past discrimination,[24] it nevertheless references perceived discrimination (e.g. “people discriminate against me because I have pain” and “People ignore me or take me less seriously just because I have chronic pain”). Therefore, it is perhaps unsurprising that the program was unable to produce changes in this area given the short time period, as perceived discrimination may take longer to shift. Despite this, it had been hoped that the multidisciplinary program would offer positive, corrective opportunities for interactions with health care professionals, families, and workplaces, to reduce a sense of discriminatory experiences. But it is worth remembering that the treatment changes the patient – not those they interact with. The lack of progress in this area suggests the need for targeted psychosocial interventions, at multiple levels, tailored to support change.

The next finding related to correlates of change in internalised stigma, specifically pain self-efficacy and disability. Analysis revealed that the degree of stigma change had a differential effect on post-intervention improvements in disability and pain self-efficacy. The group who experienced greatest improvement in internalised stigma reported significant increases in pain self-efficacy and decreases in disability post-intervention. Whereas the pain self-efficacy and disability of the nil (or worsened) stigma group was unchanged from baseline to follow-up.

In contrast, levels of depression were reduced for all patients but did not interact with improvement in internalised stigma. This unexpectedly suggests no
relationship between stigma and depressive symptoms at either time point. Although depression may be associated with internalised stigma, it is a complex mental illness influenced by a range of precipitating and maintaining mechanisms.[36] That depressive symptoms failed to figure significantly in the process suggests that improvements in internalised stigma may not lead to changes in depression. This finding requires further exploration and validation.

Stigmatising encounters on the basis of chronic pain are well documented in the qualitative literature.[3,6,10] Our study lends support to such papers arguing for increased focus in this area. Further, our findings support work advocating for patient centred approaches that seek to reduce pain stigma by targeting the intrapersonal level,[6,18] and suggests that this can be achieved. The findings are also consistent with analogous work in the mental health field that signals promising results in terms of assisting people to manage the effects of internalised stigma.[17,37-40]

A number of limitations must be noted. Perhaps most significantly, the study lacks a control group. The quasi-experimental design means the findings are weakened in terms of internal validity. It is possible that the outcome may have occurred regardless of the treatment, due to factors such as maturation or history. However, the short time lapse between pre- and post-measurements does increase our confidence in the treatment as an explanation for change. An additional limitation reflects the small number of cases in some subgroups during analysis, and thus large confidence intervals around mean decreases. These limitations can be addressed in the future through utilising a randomised control trial design, with a larger sample size ensuring greater statistical power. Treatment as usual could also be compared to an enhanced intervention with modules designed to more directly
target internalised stigma, particularly dealing with perceived discrimination experiences.

A number of interesting future directions flow from the research. One avenue to explore is how these changes are maintained over time, as our study is limited by the lack of extended follow-up period. Another question is to consider in greater detail the participants for whom reductions were not realised, given findings showed some participants experienced no improvement or in fact increased stigma post-program. Considering this subset in greater detail would enable the development of more tailored interventions. Work could also explore which aspects of the group program were most effective in reducing internalised stigma. Finally, work could also consider whether brief, early interventions are effective in protecting people with persistent pain from internalised stigma and providing them with strategies that increase stigma resistance.

**Conclusion.** Preliminary evidence presented here suggests that it is possible to achieve reductions in the level of internalised stigma experienced by people with chronic pain, and to assist people to be empowered in the face of stigma. Future work is needed to verify these results in randomised control trials, and to explore the characteristics of those who continued to experience internalised stigma despite the intervention, and tailor interventions for this subpopulation accordingly.

**Declaration of Interest statement:** The authors report no declarations of interest. The Research School of Psychology at the Australian National University provided funding for project materials.
References


Table 1.

**Summary of Sample Characteristics, pre-program (N = 45)**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Measurement</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>43.82 (13.19)</td>
<td>45</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>25 (56%)</td>
<td>44</td>
</tr>
<tr>
<td>Male</td>
<td>19 (42%)</td>
<td></td>
</tr>
<tr>
<td>Pain Duration (months)</td>
<td>58.82 (73.94)</td>
<td>44</td>
</tr>
<tr>
<td>Pain Level (average severity)</td>
<td>5.70 (1.32)</td>
<td>42</td>
</tr>
<tr>
<td>Current</td>
<td>5.64 (1.80)</td>
<td></td>
</tr>
<tr>
<td>Distress level (past week)</td>
<td>5.69 (2.11)</td>
<td></td>
</tr>
<tr>
<td>Highest (past week)</td>
<td>7.71 (1.52)</td>
<td></td>
</tr>
<tr>
<td>Lowest (past week)</td>
<td>3.60 (1.64)</td>
<td></td>
</tr>
<tr>
<td>Usual (past week)</td>
<td>5.64 (1.45)</td>
<td></td>
</tr>
<tr>
<td>DASS-Depression</td>
<td>20.98 (11.15)</td>
<td>41</td>
</tr>
<tr>
<td>Pain Self-Efficacy Questionnaire</td>
<td>27.40 (11.45)</td>
<td>42</td>
</tr>
<tr>
<td>PRSS Catastrophising</td>
<td>3.02 (1.04)</td>
<td>42</td>
</tr>
<tr>
<td>Roland Morris Disability Questionnaire</td>
<td>11.88 (5.54)</td>
<td>42</td>
</tr>
</tbody>
</table>

Note: Values are Mean (SD) unless otherwise indicated. Variables reflect all participants who completed the initial questionnaires. Missing data reflects participants who did not provide information for that measure. Pain duration reflects n=44 as one participant did not report their pain duration numerically, instead indicating pain had persisted for as long as they could remember.
Table 2.

*Change in Target Variable Scores, Pre and Post Intervention*

<table>
<thead>
<tr>
<th>Scale</th>
<th>M (SD)</th>
<th>M Difference</th>
<th>t</th>
<th>p</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>99% CI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS</td>
<td>21.10 (11.42)</td>
<td>12.72 (10.39)</td>
<td>8.38 [3.86-12.91]</td>
<td>5.027</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>PRSS</td>
<td>2.97 (1.04)</td>
<td>2.16 (1.27)</td>
<td>.81 [.45-1.18]</td>
<td>6.038</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>PSEQ</td>
<td>27.51 (11.88)</td>
<td>39.69 (12.15)</td>
<td>12.18 [7.37-17.00]</td>
<td>6.860</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>RMDQ</td>
<td>11.88 (5.67)</td>
<td>8.58 (5.77)</td>
<td>3.30 [1.64-4.96]</td>
<td>5.392</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

Note. DASS = Depression subscale, PRSS = Catastrophising subscale, 99% CI = 99% confidence interval. *Significant at the $p = .01$ level. $df = 39$ for all analyses.
Table 3.

*Internalised Stigma of Chronic Pain, Pre and Post Intervention*

<table>
<thead>
<tr>
<th>ISCP</th>
<th>Pre</th>
<th></th>
<th></th>
<th>Post</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq.</td>
<td>%</td>
<td>Cum. %</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>1.00 - 2.00</td>
<td>6</td>
<td>14.3</td>
<td>14.3</td>
<td>14</td>
<td>35.0</td>
</tr>
<tr>
<td>2.01 - 2.50</td>
<td>16</td>
<td>38.1</td>
<td>52.4</td>
<td>19</td>
<td>47.5</td>
</tr>
<tr>
<td>&gt; 2.51</td>
<td>20</td>
<td>47.6</td>
<td>100.0</td>
<td>7</td>
<td>17.5</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>100.0</td>
<td>100.0</td>
<td>40</td>
<td>100</td>
</tr>
</tbody>
</table>

Note. *Cum.%* = Cumulative Percentage, *Freq* = Frequency (n), *ISCP* = Internalised Stigma of Chronic Pain. 1.00-2.00 reflects minimal to no internalised stigma, 2.01-2.50 reflects mild internalised stigma, greater than 2.51 reports high internalised stigma.
<table>
<thead>
<tr>
<th>Scale</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimum</td>
</tr>
<tr>
<td>Internalised Stigma of Chronic Pain</td>
<td>-14.90</td>
</tr>
<tr>
<td>Alienation</td>
<td>-29.41</td>
</tr>
<tr>
<td>Discrimination</td>
<td>-33.33</td>
</tr>
<tr>
<td>Social Withdrawal</td>
<td>-20.00</td>
</tr>
<tr>
<td>Stigma Resistance</td>
<td>-21.43</td>
</tr>
</tbody>
</table>

Note. This table excludes patients who were experiencing minimal to no internalised stigma prior to completing the program. *Stigma Resistance* has not been reverse scored in this table, in order to allow for intuitive interpretation whereby greater scores reflect a positive outcome of increased empowerment.
Table 5.

Internalised Stigma of Chronic Pain Subscales, Pre and Post Intervention

<table>
<thead>
<tr>
<th>ISCP</th>
<th>Mean (SD)</th>
<th>Mean Difference</th>
<th>t</th>
<th>P</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>2.73 (0.52)</td>
<td>2.30 (0.55)</td>
<td>.44 [.24-.64]</td>
<td>5.865</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>D</td>
<td>2.36 (0.53)</td>
<td>2.16 (0.67)</td>
<td>.20 [-.01-.41]</td>
<td>2.604</td>
<td>.013</td>
</tr>
<tr>
<td>SW</td>
<td>2.65 (0.56)</td>
<td>2.34 (0.58)</td>
<td>.31 [.12-.50]</td>
<td>4.425</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>SR</td>
<td>2.69 (0.43)</td>
<td>3.09 (0.43)</td>
<td>.39 [.19-.60]</td>
<td>5.154</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

Note. ISCP = Internalised Stigma of Chronic Pain; A = Alienation; D = Discrimination Experience; SW = Social Withdrawal; SR = Stigma Resistance; 99% CI = 99% confidence interval. *Significant at the $p = .01$ level. $df = 39$ for all analyses. Stigma Resistance has not been reverse scored in this table, in order to allow for intuitive interpretation whereby greater scores reflect a positive outcome of increased empowerment.
Chapter 5: Foreword

While the first three studies have explored how stigma may affect people with pain, consideration has yet to be given to how others may interpret and form pain judgments. A consideration of psychosocial factors in the experience of pain, and the way in which sociocultural judgments about pain can influence a person’s perception of self (Chapters 2 – 4), would not be complete without considering the role of healthcare providers. Healthcare providers, particularly doctors, are gatekeepers to the healthcare system, and through this, access to opportunities to legitimise one’s suffering or conversely encounter experiences that could lead to internalised stigma. Therefore, Chapter 5 (Study 4) concludes the program of research by examining the perceptions of medical and nursing students towards hypothetical pain patients. Medical and nursing students were selected as they will be making pain-related decisions in the near future and their perspectives are important to capture.

Chapter 5 describes the findings of vignette-based research. This methodology presents participants with a patient scenario and requires a response that taps into their beliefs and perceptions. This enables an understanding of the context and examination of pain judgments. Chapter 5’s experimental investigation manipulates four contextual variables that the literature suggests may be central to impressions of a patient during pain assessment: medical pathology, pain behaviours, onset-controllability (blameworthy attributions), and psychological referral. Results demonstrate the role of contextual variables in influencing perceived pain intensity, emotional distress, and patient legitimacy. Support was provided for the role of ‘blaming the victim’ for their pain experience, in terms of the tendency to approach such patients with a greater level of scepticism and lower ratings of pain and distress.
But on the other hand, psychological referral did not increase perceptions of malingering, a finding that is discussed in terms of clinical implications. Chapter 5 provides future directions from the perspective of both the healthcare provider, and patient, during pain consultations.
Chapter 5: Declaration

Title

The influence of contextual variables on judgements about patients and their pain.

Authorship

Olivia Twigg and Donald Byrne

Publication Outlet

Pain Medicine

Current Status

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Candidate Contribution

The Candidate proposed the research question and design, which was refined with feedback from DB. The study vignettes were developed by the Candidate and were modified with assistance from DB. The Candidate recruited study participants, conducted the statistical analyses, and developed the initial manuscript. DB provided input on successive drafts of the manuscript.

Co-Author Signature

[Signature]

Professor Donald Byrne
The Influence of Contextual Variables on Judgments about Patients and Their Pain

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Abstract
Objective. Professional judgments about persistent pain are influenced by contextual variables, which are features relating to the patient, the assessor, or the broader situation. Such judgments directly inform assessment and treatment and therefore represent an important area of research. While current formulations of persistent pain adopt a biopsychosocial framework, contextual variables relating to psychosocial information have not been well examined in the literature.

Design. We employed a within-subjects experimental vignette paradigm to investigate the influence of four contextual variables, 2 (medical evidence: present vs absent) × 2 (pain behavior: present vs absent) × 2 (referral to a psychologist: yes vs no) × 2 (responsibility: onset controllable vs onset uncontrollable), on perceptions of pain. Judgments about patients with chronic low back pain were made across several dimensions.

Subjects. One hundred sixteen medical and nursing students.

Results. Main findings revealed that identifiable pain pathology led to increased ratings of pain intensity and emotional distress, and decreased perceived likelihood of malingering. Pain behavior and referral to a psychologist were also found to increase ratings of pain intensity and emotional distress. Encouragingly, psychological referral was not found to increase the perceived likelihood of malingering. Responsibility for the initial injury was found to influence judgments, but this occurred in interaction with medical evidence as well as pain behavior.

Conclusions. These findings suggest that contextual variables have an important influence on medical and nursing students’ perceptions of patients and their pain. Theoretical and practical implications for provider training and community education are discussed.

Key Words. Pain; Rating; Assessment; Psychosocial information

Introduction
Persistent pain leads many patients to seek treatment at hospital emergency departments [1–4]. Rating of pain is now considered the “fifth vital sign”; the routine assessment and recording of patient pain intensity ratings are mandatory for many health care organizations [5]. Health care providers are particularly critical with respect to pain judgments as their judgments inform diagnosis, assessment, treatment, and referral options [5]. However, judgments about pain, particularly when persistent, are uncertain and complicated [5,6]. This has implications for the quality of clinical decisions, with contextual variables in assessment contributing to the underestimation of pain and interfering with treatment [5,7–9]. Therefore, considering factors that influence pain judgments represents a vital area for research.

Social Cognitive Framework
A social cognitive framework provides insight into how provider judgments are shaped. Social cognition
considers the way in which people make sense of other people and themselves, and is typically applied to conditions of uncertainty [5]. From a social cognitive framework, Tait and colleagues [5] have argued that judgments are influenced by the subjective and uncertain nature of persistent pain, which leads to the propensity to access intuitive, bias-prone heuristics [5]. Overall, pain judgments are influenced by information that is derived from the interaction between a patient and the medical provider, within a given situation [5,10,11].

Contextual Variables: Medical Evidence

Contextual variables reflect factors associated with the patient, observer, or the broader situation that influence the assessment of pain. To date, the literature has focused heavily on the role of medical evidence (i.e., whether there is identifiable pathology for the pain) in persistent pain judgments [7]. Research among physicians, medical students, and community samples consistently indicates that patients without identifiable pathology are ascribed lower levels of pain, less distress, and less pain-related disability than patients with supporting evidence [11-14]. Medical pathology was also given greater weight than information related to the patient’s history, physical examination, and functional disability [15].

It has been argued that the legitimizing role given to identifiable pathology reflects the persistence of biomedical models in the assessment of persistent pain [16]. The biomedical model focuses on biochemical, physical processes in the understanding and treatment of a condition and does not take psychological, environmental, and social factors into account. The model has dominated Western health care for the past century and focuses on biomedical model is therefore incompatible with the management and treatment of chronic pain, yet literature regarding pain judgments suggests that it persists as influential for care and treatment [16].

Perceptions of Malingering: Medical Evidence and Pain Behaviors

The implications of pain judgments are discussed at length in qualitative work, which considers the “lived” experience of the patient. Research has emphasized the need for medical providers to be cognizant of patients’ beliefs and sensitivities, particularly in order to avoid unintentional implications about their pain being illegitimate or feigned due to the absence of identifiable pathology [21–25]. Recent work has argued that the sociocultural context may prime medical providers to focus on malingering and argues that beliefs around patient malingering are likely to impede rehabilitation and treatment efforts [26]. However, little experimental work has examined how contextual variables such as identifiable pathology influence perceptions of malingering. As such, the present study seeks to explore this issue.

Coupled with an absence of pathology to account for pain, another feature of persistent pain that may increase perceptions of malingering is its “invisibility.” Qualitative literature argues that negative social reactions such as disbelief can stem from the fact that pain cannot be seen [19,22,27,28]. Consistent with this, experimental work has shown that nonverbal pain behaviors increase ratings of pain severity [29] and also pain genuineness in a task where observers were explicitly told that certain patients were faking and were then asked to rate genuineness [29]. However, whether the absence of pain behaviors increases perceptions of malingering when not explicitly primed has not been well examined in the experimental literature to date. The present study seeks to address this gap.

Contextual Variables: Psychosocial Information

More recently, attention in the literature has turned to the role of contextual variables that relate to psychosocial features. The widely accepted biopsychosocial model argues that biological, psychological, and sociocultural variables interact to shape an individual’s experience of chronic pain [30]. However, how psychosocial information may influence observer judgments of pain has received insufficient examination in the literature to date [16]. Initial work suggested that less personal distress is felt for a patient with psychosocial stressors (e.g., “job stress” or “stress at home”) [13] and that there is a tendency to downgrade a patient’s pain when their symptoms are associated with psychological distress [5]. Subsequently, De Rudder et al. [16] operationalized psychosocial features with “anxiety and job stress” or “depression and relational difficulties” and demonstrated this information had a wide ranging effect on health professionals’ judgments of patients in terms of perceived pain, self-efficacy, sympathy, and higher beliefs in deception. This is an emerging literature, and there is a need for other psychosocial features to be explored [13,16]. Tait and colleagues suggest that while factors aside from medical evidence are likely to influence pain judgments, there has been insufficient study of such variables to allow for meaningful conclusions to be made [5].

The present study seeks to build on the exploration of psychosocial features. Work suggests that the validity of a patient’s symptoms and pain experience is questioned when their presentation is associated with psychological distress and that patients are concerned about the implications of psychological factors in their pain [5,24]. Yet to our knowledge, no work has considered how a psychological referral may cue provider judgments. Importantly, examining the role of a psychological referral enhances our understanding of how multidisciplinary involvement may influence pain judgments. This has implications for
clinical practice, where psychology is increasingly involved in pain management [31]. Such an examination also represents a way to bring together concerns of patients described in qualitative literature with the experimental literature.

**Psychosocial Information and Attribution Theory**

Within the social cognitive model proposed by Tait and colleagues, attribution theory is a particularly useful framework to apply to psychosocial information. Attributional analyses suggest that in response to a situation, a search is undertaken to determine the cause of the outcome [32]. It then moves beyond this to consider affective reactions, expectancies regarding (successful) outcomes, and behavioral responses [32]. For example, attributions about a person's responsibility for their condition have been demonstrated to decrease pity, increase anger, and influence decisions to help or neglect a person with physically and mentally based illnesses [32,33]. This framework can help to account for why patients may be sensitive to implications of psychological factors in their pain; perceptions of causality influence emotional and behavioral responses to their pain.

In addition to psychological involvement, from an attribution framework, the sense of responsibility for the initial incident (onset controllable), or blame, may affect pain judgments [33]. For example, research manipulating perceptions of the patient's responsibility for their condition (AIDS) has shown that the more an observer blamed the patient, the less pain and empathy they attributed to them [34]. In research specific to people with persistent pain, a content analysis revealed that when there is insufficient medical pathology to account for pain, patients emphasized that they were not culpable for the onset of their pain [35]. Specifically, the patients stressed that they were not responsible or in control of the cause; it was uncontrollable and random [35]. Hence, considered in the present study is whether control over the initial injury does indeed decrease intensity and distress ratings, and increase doubts about patient motive.

The present study extends research in the area to explore contextual variables that encompass psychosocial information of the patient previously unconsidered. Firstly, the study aims to establish the role of medical evidence and consider if pain behaviors increase observer judgments of pain intensity and emotional distress, and decrease judgments of perceived malingering. Secondly, the study aims to investigate psychosocial information, specifically whether referral to a psychologist and responsibility (onset control) for the initial injury may increase an observer's ratings of the likelihood of malingering, and influence views of pain intensity and emotional distress. Also of interest is how pain judgments may differ depending on the combination of variables as it is important for effects to be considered together in terms of their interaction, rather than in isolation [12,16].

**Methods**

**Participants**

Australian medical and nursing students (Mage = 23.57 years, age range = 18–44 years) were recruited through contacting each medical school listed in Australia's medical student representative body. Eighty percent of representative bodies (N = 20) indicated their willingness to disseminate information about the project. Interested students followed an online link where they were provided with more information about the research and the opportunity to participate. Additionally, convenience sampling recruited nursing students through the dissemination of information to the two nursing programs in the researchers' region. Financial incentive was provided for participation, with gift vouchers drawn at random. Approval from relevant Institutional Review Boards was granted, and participants provided informed consent.

**Design**

The study adopted a balanced and orthogonal full factorial design. This follows Anderson's [36] methodology, where participants evaluate combinations of all possible factors. This design allows for the effect of independent variables to be assessed, as well as the way variables interact [37]. All variables are within subjects, with 16 vignettes representing a 2 x 2 x 2 x 2 design: medical evidence (present, absent), responsibility for initial injury (onset controllable, not controllable), referred for psychological assistance (yes/no), and pain behavior (present, absent). The presentation order was counterbalanced across participants. Other variables were held constant: All patients referred to in the vignettes were described as experiencing persistent low back pain, duration was over 1 year, and patients were identified by two initials rather than a name so as to avoid confounds such as gender, ethnicity, or age [9,11,38,39].

**Materials and Procedure**

Participants completed the survey electronically in one sitting using the online software program, QUALTRICS (Provo, UT, USA). Prior to viewing the 16 vignettes, participants provided brief demographic information. Specifically, participants indicated their age, sex, ethnicity, field and current year of study, and personal experience of persistent pain. The initial vignette instructions, examples of the patient vignettes, and the manipulation check are outlined in Appendix A.

Previous research has suggested the utility of considering different types of illness-related judgments [12,33]. As such, after reading each vignette, the participants responded to the set of dependent variables, with all responses indicated on an 11-point numerical rating scale (0–10) [7,16,29]. Participants estimated the likely intensity of the patient’s pain (on a scale anchored with the words “no pain” to “pain as bad as you can imagine”) and the level of emotional distress the patient would be...
experiencing (anchored "no emotional distress" to "high level of emotional distress"). Participants also rated the likelihood that the patient was malingering (defined to participants as exaggerating their pain for other gains, e.g., financial benefit or access to pain killers [anchored "unlikely" to "likely"]).

To ensure participants had attended to the information, a multiple-choice manipulation check was included after each vignette.

Statistical Analyses

Multilevel modelling (MLM) was chosen for analysis. This approach was selected because MLM does not rely on assumptions of sphericity and allows consideration of the relationships to vary for different people. Importantly, the technique has the advantage of being able to estimate the fixed and random effects in one model. That is, associations between variables can differ for different participants within the sample. A random intercepts model was run to analyze the data using the linear mixed effects model (MIXED) procedure in SPSS (IBM Corp., Armonk, NY, USA).

Each analysis consisted of three steps. Firstly, analysis involved partitioning the variance in the outcome into the within and between group components in order to calculate the intraclass correlation (ICC). Secondly, one random-effects factor (participant) associated with the sampling procedure was entered. The four independent variables were entered in the model as fixed factors as they were assumed to be the same for all participants. The relationship between these variables and four outcome variables was considered. In all models, maximum likelihood estimation was used. In the third step, the Fixed Factor table was inspected in order to test specific hypotheses about possible main effects or interactions. Effect sizes are not reported given the lack of agreement for obtaining this information and the ambiguities in the ill-defined methods available for MLM [40,41].

Results

The data were screened and cleaned prior to analysis. Assumptions were checked, and the distributions for variables were acceptable. Manipulation checks were reviewed for each vignette (N = 1,581). Participants (N = 7) who failed the manipulation check for all vignettes were removed from analysis. Subsequently, N = 116 participants remained for analysis with N = 1,069 vignettes. As missing data (N = 512, 32%) can be handled flexibly with MLM [42], analysis was able incorporate all available data rather than exclude a participant who was failed the manipulation check on a single vignette. Sample characteristics are provided in Table 1.

Participants were asked to indicate whether they had personally experienced persistent pain. While N = 16 indicated that they had done so, the substantive results did not differ between the groups, and thus, cases were retained for analysis. Analysis controlled for participant judgment.

The value of the chosen analytical technique was considered by partitioning the variance in the outcome into the within and between group components. Calculations were performed, and the ICC ranged from 0.40 to 0.47 (malingering = 0.40, intensity = 0.43, emotional distress = 0.47), suggesting that the variation in groups was indeed a compelling illustration of the need for a multilevel analysis.

Analysis turned to testing the study's predictions. The results revealed a significant main effect of medical evidence for all ratings. As shown in Table 2, when the patient was described as having medical evidence for their persistent pain (as opposed to no identifiable pathology), the average participant reported higher pain intensity, F(1, 971.51) = 216.41, P < 0.001, greater emotional distress, F(1, 974.82) = 170.66, P < 0.001, and lower likelihood of malingering, F(1, 977.39) = 227.72, P < 0.001.

Furthermore, analysis showed two main effects for pain behavior. Specifically, it indicated that patients with pain behavior were ascribed greater pain intensity, F(1, 969.28) = 328.33, P < 0.001, and greater emotional distress, F(1, 972.94) = 214.28, P < 0.001, with means displayed in Table 2. No main effect was found for likelihood of malingering (P = 0.511).

Table 1  Summary of sample characteristics (N = 116)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>85</td>
<td>73</td>
</tr>
<tr>
<td>Male</td>
<td>31</td>
<td>27</td>
</tr>
<tr>
<td>Age (years)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>23.57</td>
<td>4.11</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>35</td>
<td>30</td>
</tr>
<tr>
<td>European/Anglo-Saxon</td>
<td>73</td>
<td>63</td>
</tr>
<tr>
<td>Indigenous Australian or Torres Strait Islander</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Field of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine</td>
<td>107</td>
<td>92</td>
</tr>
<tr>
<td>Nursing</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Number of years in current degree completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>4.78</td>
<td>1.80</td>
</tr>
<tr>
<td>Personal experience with chronic pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>100</td>
<td>86</td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>14</td>
</tr>
</tbody>
</table>

* As two participants did not indicate their age, the mean and SD reflects N = 114 participants. SD = standard deviation.
Judging Pain and the Patient

Table 2  Mean estimates for pain related judgments (N = 116)

<table>
<thead>
<tr>
<th>Variable</th>
<th>ME</th>
<th>PB</th>
<th>PR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td>6.51*</td>
<td>6.63*</td>
<td>6.08*</td>
</tr>
<tr>
<td>Absent</td>
<td>5.39*</td>
<td>5.26*</td>
<td>5.81*</td>
</tr>
<tr>
<td>Present</td>
<td>6.87*</td>
<td>6.93*</td>
<td>6.45*</td>
</tr>
<tr>
<td>Absent</td>
<td>5.76*</td>
<td>5.69*</td>
<td>6.10*</td>
</tr>
<tr>
<td>Yes</td>
<td>6.21</td>
<td>6.34</td>
<td>5.78</td>
</tr>
<tr>
<td>No</td>
<td>6.81</td>
<td>6.93</td>
<td>6.38</td>
</tr>
</tbody>
</table>

* Indicates that the difference between the means is significant at the \( P = 0.01 \) level.

Analysis also revealed two main effects for referral to a psychologist (compared with not being referred to a psychologist). As shown in Table 2, participants ascribed greater pain intensity, \( F(1,974.48) = 12.79, P < 0.001 \), and higher levels of emotional distress, \( F(1,977.51) = 10.91, P = 0.001 \), to patients who had been referred to a psychologist. No main effect was found for likelihood of malingering (\( P = 0.495 \)).

Additionally, the results indicated three significant main effects for responsibility over the initial injury. However, as significant interaction effects were found, separate interpretation is not given to the main effects here as that would be potentially misleading. An interaction was found for control by pain behaviors for both pain intensity, \( F(1,965.83) = 38.83, P < 0.001 \), and emotional distress, \( F(1,969.86) = 40.42, P < 0.001 \). In terms of the effect of responsibility on estimates of pain intensity, Figure 1 reveals that patients were assessed similarly when pain behavior was absent. On the other hand, patients who had control over their initial injury were ascribed lower pain intensity than those without control when pain behaviors were present. As shown in Figure 2, a similar pattern was observed for the effect of responsibility on judgments of emotional distress. A patient’s responsibility for the initial injury had little impact on ratings of emotional distress when pain behaviors were absent; however, those who did not have control over the initial injury were seen as experiencing greater emotional distress than those who had control when pain behaviors were present.

Furthermore, interaction effects were found for control by evidence for pain intensity, \( F(1,966.37) = 23.13, P < 0.001 \), and likelihood of malingering, \( F(1,972.10) = 9.75, P = 0.002 \). As shown in Figure 3, when medical evidence was present, the ratings of pain intensity were similar for patients regardless of their responsibility for the initial injury. However, when medical evidence was absent, patients with no control over the initial injury were ascribed higher ratings of pain intensity than those who were responsible for the initial accident. Similarly, as shown in Figure 4, control over injury elicited greater perceptions of malingering than no control when medical evidence was absent. Although differences in malingering depending on responsibility were observed for both medical evidence conditions, the magnitude of difference was greater in the absent condition.

No other two-way interactions were found. Likewise, none of the three- or four-way interactions were significant (\( P = 0.01 \)).

Discussion

This study considers how medical and nursing students responded to vignettes describing patients with persistent back pain. Following other researchers in the field, for this discussion, the term “bias” reflects the participants’ use of contextual information (a cue) [43]. Analysis examined the variables of medical evidence, pain behavior, patient’s responsibility over the initial injury, and psychological referral, and their interactions, on medical and nursing students’ assessments of pain. In doing so, the study contributes to the literature through enhancing our understanding of information that is used in assessment, exploring how these cues may be combined, and when observers stop searching for further information [44].

Consistent with previous work, the first finding was that in vignettes where identifiable pathology was absent, patients were ascribed lower pain intensity and less emotional distress [14,16,45]. The legitimizing role of medical evidence was demonstrated in our finding that in vignettes where identifiable pathology was absent, patients were more likely to be judged as malingering for secondary gain (such as financial benefit or access to opioids). This builds...
The interaction between pain behavior and patient responsibility on mean ratings of pain intensity. When pain behaviors were present, those who were responsible for their initial injury were ascribed less intense pain than those whose onset was uncontrollable. However, when the pain behaviors were absent, responsibility over the injury did not significantly decrease ratings of pain intensity. Error bars represent standard errors.

A second set of findings relates to psychosocial information. A patient’s responsibility for their initial injury, as described in the vignette as occurring over a year ago, was found to influence judgments. However, this occurred in interaction with medical evidence and pain behavior. Firstly, responsibility had little effect on ratings when pain behaviors were absent, suggesting that when pain behaviors are absent, observers are satisfied with the information and do not search for further cues [44]. However, when pain behaviors were exhibited, those who were not responsible for the initial injury were seen as experiencing even greater pain and emotional distress than those who were to “blame” for the initial injury. Secondly, responsibility mattered when medical evidence was absent; onset uncontrollable patients were ascribed higher ratings of pain intensity, and malingering was perceived as less likely when compared to patients described in vignettes as responsible for the initial injury.
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Figure 3 Pain intensity means representing the interaction between responsibility over initial injury and medical evidence. The influence of control over the initial injury on ratings of pain intensity depended on whether medical evidence was present or absent. Error bars represent standard errors.

Figure 4 The interaction between responsibility for injury and medical evidence on average ratings of perceived likelihood of malingering. Patients whose injury was onset controllable were always assigned a greater likelihood of malingering, but this was especially the case when medical evidence was absent. Error bars represent standard errors.

Finally, the analysis revealed that a referral to a psychologist influenced the judgments of medical and nursing students. Specifically, results revealed an intuitive relationship, such that psychological referral was associated with greater impressions of a patient’s emotional distress. It was also related to higher ratings of pain intensity. This may reflect the assumption that a psychological referral indicates increased severity of a pain presentation due to the role of psychology in providing emotional support and coping strategies for patients with pain. Encouragingly, and contrary to prediction, referral to a psychologist did not significantly influence perceptions regarding the likelihood of malingering. This suggests an understanding of the role of psychology in pain management among medical and nursing students in that stigma or negative patient judgments were not observed. Such a finding is in contrast to concerns raised in qualitative work that a psychological referral is a source of anger or despair, linked to concerns that it will detract from their pain legitimacy [24]. Implications are discussed next.
Interactions were expected between psychological referral and medical evidence but were not found. However, the absence of an interaction is consistent with the work of De Ruddere et al. [16] who suggest the information from medical evidence and psychosocial features independently provide sufficiently meaningful cues so that the absence of medical evidence does not increase an inclination to take psychosocial information into greater account. Our study strengthens this hypothesis, although future work to consider this proposition is required.

The biopsychosocial model is currently the most widely accepted model for the understanding and treatment of persistent pain [47], yet studies suggest a biomedical model is dominant. However, it is possible a cohort effect exists among current practitioners and that shifts in modes of thinking are now occurring in current medical and nursing cohorts. Thus, the present study considered students in schools of medicine and nursing. Mixed results were found. There was some evidence to support the proposition that biopsychosocial models are influencing judgments in terms psychological referral. We found that this did not impact perceptions of malingering and therefore suggests recognition of the role of psychological support in pain management rather than a tendency to stigmatize those referred to a psychologist as less legitimate. However, the other main findings relating to medical evidence, pain behavior, and control over initial injury suggest traditional biomedical conceptualizations may unwittingly or unwittingly persist, operating as legitimizing factors in pain assessment.

Our findings are consistent with the application of a social cognition model to pain assessment [5]. This suggests that the uncertain and ambiguous nature of pain leads observers to unwittingly access intuitive, bias-prone heuristics. For example, our results found that vignettes describing the absence of medical evidence (i.e., a condition of greater uncertainty) produced higher ratings regarding the likelihood of patient malingering. This reflects an experience-based assumption that a lack of medical evidence indicates a patient is feigning; however, in the case of chronic pain, this reasoning is suboptimal. Thus, enhanced monitoring [48] may be beneficial in addressing the unwitting biases found in this study. Yet naturally, a balance must be found as processing needs to occur in an efficient and timely manner.

**Limitations**

While this study has made some important contributions to understanding contextual variables in pain assessment, some caveats need to be considered when evaluating the results. It is possible that in presenting multiple vignettes, participants formed their own impressions regarding the hypotheses for the study. This may have influenced the way in which they responded and thus has implications for the present study’s validity. This limitation has been similarly described by other authors in the field [7] who argue it is difficult to counter and likely requires designs such as behavioral observation.

It is also worth noting that the vignettes provided to participants had two levels, rather than multiple values. For some variables (e.g., referral to psychologist), this is less of a concern as even in actual treatment settings, these factors are often dichotomous. However, other variables are likely to be on a spectrum rather than assuming two values. This simplification was necessary due to the study’s design; greater levels increased the number of vignettes required.

Another limitation was the use of vignettes rather than real patients in actual health settings or video recordings of patients. The use of vignettes is typical in this field [37] but nevertheless reduces the ecological validity of the study. However, this limitation may actually suggest that the effects found would be magnified in more realistic settings, where additional pressures for attention increase cognitive load and therefore the likelihood of more automatic, biased judgments [12]. A further limit relating to the study design was that it was completed in private, rather than a university laboratory or tutorial environment. This raises the possibility that participants may have been distracted or less engaged in the task. Similarly, the large number of participants who failed manipulation checks is worth noting. This raises the possibility of participant disengagement and/or inappropriate difficulty level. Further, while the study conditions were counterbalanced, the attrition rate following the manipulation check meant that equal numbers of participants were not exposed to the different orders. Finally, males were underrepresented in our medical student sample, with approximately three quarters of our sample female, despite females representing 50.5% of medical students in the population that we recruited from [49].

**Clinical Implications**

The present study supports the need for a greater focus on how contextual variables can affect pain assessment among medical and nursing students, particularly perceptions of malingering that may be primed by our sociocultural context. Changes in attribution can result in changes in a person’s affective responses and behavioral judgments [32]. Following the work of Hirsch et al. [50], we suggest the potential benefit of individualized strategies that identify the variables that influence assessment. Once identified, feedback could be provided to the assessor including strategies such as considering objective and subjective reports, and consultation with colleagues to calibrate judgment.

A key implication relates to patient education regarding biopsychosocial formulations of pain. In considering psychological referral, we introduced a new psychosocial feature that to our knowledge had not previously been empirically examined. We found that a psychological referral did not increase perceptions of malingering, which was contrary to concerns raised by patients in qualitative work. In fact, the increased perceptions of pain intensity and distress suggested psychological referral as a legitimizing factor. Therefore, we suggest a role for community
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education and messaging at the point of referral (e.g.,
general practitioner) to emphasize that current treatment
models acknowledge the role of psychological factors in
pain management. Such an approach would seek to
encourage patients to consider psychological input into
their pain management, more confident in the knowledge
that this will not lead to judgments that pain is "in their
head."

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Appendix A

Initial Instructions

You will be asked to read a scenario describing a patient, before answering questions about this patient. Each scenario will be different. Please read each scenario carefully before answering the questions. You will not be able to return to the scenario after you have read it. ... We are now interested in your perception of [the patient]. Please indicate your level of agreement with each statement by
selecting one number on the scale below. There is no right or wrong answer—we are simply interested in your impressions.

Vignette Example One

History: One year ago, Patient CX ran a red light and struck a pole. CX has reported persistent lower back pain since this time.

Medical findings: Consistent with CX's lower back pain, diagnostic tests have revealed a bulging disc. CX's GP has referred them to a psychologist in relation to their pain. CX walks with a cane and looks to be in pain.

Note: This scenario reflects the manipulation of medical evidence (present) x responsibility for initial injury (onset controllable) x pain behavior (present) x psychologist referral (yes).

Manipulation Check

Did patient CX have control over the initial cause of their injury?

Did CX have some medical explanation for their pain?

Could people visibly see that CX was in pain?

Did CX's doctor refer CX to a psychologist in relation to the pain?

Vignette Example Two

History: One year ago, Patient AS was injured when a rock fell unexpectedly during a bushwalk. AS has reported persistent back pain since this time.

Medical findings: Medical testing has revealed no clear cause of the pain, and you wouldn't be able to tell by looking at AS that they are in pain. AS has not been referred to a psychologist for their pain.

Note: This scenario reflects the manipulation of medical evidence (absent) x responsibility for initial injury (uncontrollable) x pain behavior (absent) x psychologist referral (no).
Chapter 6: Discussion

6.1 General Overview of Findings

The results of this research may be considered on multiple levels. The four studies have utilised a variety of experimental methodologies to examine stigma and pain judgments from two perspectives: personal feelings related to being stigmatised and judgments about pain imputed to another person. To address the research questions outlined in Chapter 1.11, the findings of correlational research in the community, prospective research, a quasi-experimental exploratory treatment trial, and an experimental manipulation, have been presented in a series of manuscripts.

At the most general level, the findings of this research indicated that the experience of internalised stigma is endorsed by people with pain, at comparable levels to the mental health literature (Brohan et al., 2011; Lysaker, Roe, & Yanos, 2007). This is a novel finding and suggests that beyond the consequences of persistent pain, additional harm can be suffered as a result of the experience, perception, or anticipation of negative social reactions about pain (Drapalski et al., 2013). This speaks to the hurt of living with a condition that can attract negative social perceptions such as disbelief. Having demonstrated the prevalence of internalised stigma among people with pain, this thesis has moved to identify associations between internalised stigma and measures of psychosocial functioning. In particular, it demonstrated the damaging nature of internalised stigma through the interrelationships with measures of self-concept, psychological well-being, and unhelpful pain cognitions, which have been associated with maladaptive behaviour (Boyd et al., 2014; Foster et al., 2010; Nicholas, 2007; Sullivan, 2012; World Health Organization, 2004). Therefore, findings provide support for the first and second
research questions through indicating that internalised stigma is indeed a feature of the experience of people with persisting pain. For some, negative attitudes about pain are absorbed in a process that leads to a sense of personal devaluation and demoralisation. This is associated with negative psychological outcomes including lower self-esteem and less confidence in the ability to perform a behaviour or task despite pain.

Beyond interrelationships and associations, an examination of pathways and prospective research emerged as the logical next step in this field of work. The third research question of this thesis examined whether internalised stigma among people with pain is able to predict aspects of self-concept. While clearly more work is required to consider pathways by which internalised stigma may occur, the findings presented a potentially fruitful area by considering predictive relationships. Associations with outcome, specifically self-esteem, emerged. This suggested that a vicious cycle develops for people with pain, where the anticipation or experience of negative social reactions leads to social withdrawal, which in turn reduces self-esteem. Therefore, people are left feeling less confident in themselves, which can produce a range of maladaptive behaviours and lost opportunities, such as self-defeating attitudes, risky behaviours, poorer social outcomes, and mental health problems (Mann, Hosman, Schaalma, & de Vries, 2004; Sharma & Sharma, 2010). However, contrary to the prediction of social-psychological framework, a predictive relationship with pain self-efficacy was not found (Corrigan & Watson, 2002; Link & Phelan, 2001; Link et al., 2001). Thus, while the consequence of stigma for the self-esteem of people with pain was supported, questions remain about whether confidence in one's general ability to approach future life tasks is impacted. Thus, the findings of this prospective work indicate that future research is warranted to
elucidate the relationship between stigma and self-efficacy, and consider whether social psychological applications of stigma theory to a pain population require refinement.

A key purpose of considering internalised stigma in a persistent pain population was to examine the experience of people with pain in a way that may help to improve pain management. The fourth research question therefore focused on the application of internalised stigma to a treatment setting and asked whether internalised stigma is static or changeable in nature. Findings indicated that internalised stigma decreased following a multidisciplinary cognitive-behavioural group pain program. Correlates of change were pain-related disability and pain self-efficacy, but not depression. This finding does suggest interrelationships with confidence in approaching tasks despite pain. Interestingly, not all participants experienced improvement post-program, and in fact, some participants reported increased stigma post-program. Therefore, the promising answer to the fourth research question is that internalised stigma among pain does appear to be modifiable and can improve following treatment; but new questions emerged about which elements of the program were beneficial and for which participants, and therefore how content can be adjusted to maximise change. This reflects the universal difficulties encountered with interventional research where multiple pathways of intervention are included in a single program.

Taken together, the studies suggest that internalised stigma presents an additional burden for those who already suffer from the debilitating effects of persistent pain. From here, the present research program moved to examine the other aspect of stigma: judgments of others about pain, as outlined in research question 5. Future healthcare providers were the focus of this consideration, given their pivotal
role as gatekeepers for health and in the management of persistent pain (Glenton, 2003). Findings demonstrated that biomedical explanations of pain persist in a way that can affect judgments about patient motive and legitimacy. Attributions about perceived responsibility (blame) were also seen to affect judgments of the patient, although this occurred in interaction with pain behaviour and identifiable pain pathology. Contrary to prediction, referral to a psychologist was not found to increase perceived malingering, which suggests the growing recognition of psychological factors in the experience of pain. Given work in the qualitative literature signals patients’ reluctance to focus on psychological aspects of pain due to concerns about this as delegitimising their pain experience, this finding presents implications for future clinical work as outlined in Section 6.3.

6.2 Theoretical Contributions and Implications: Links to Literature

6.2.1 Biopsychosocial formulations of pain. The biopsychosocial model is the most widely accepted framework for conceptualising and treating chronic pain. This model is advantageous in that it accounts for pain’s fundamental complexities and guides treatment strategies (Bosco, Gallinati, & Clark, 2013). The series of studies presented here contribute to a broadened understanding of the psychosocial correlates of pain. Authors such as Blyth, Macfarlane, and Nicholas (2007), and Nielsen (2007), have argued that although many studies of people with persisting pain argue for the importance of psychosocial factors, they typically look just at the “psycho” aspect of this. This thesis has demonstrated that for some people, absorbing negative social perceptions about their condition is associated with decreases in their psychological well-being and unhelpful cognitions in relation to their experience of pain itself, thereby reflecting a bi-directional psychosocial relationship. The effect of negative sociocultural encounters was seen through
impacts on psychological factors (self-esteem) six months later. Further, the role of medical pathology and blame for initial injury in the judgments of medical and nursing students speaks to the importance of biopsychosocial models in education programs, to emphasise a multidimensional perspective on pain and draw attention to the role of contextual factors in shaping judgments during medical encounters. Together, these findings give weight to the importance of examining the psychosocial context in which pain occurs, both in terms of conceptualising the pain experience and informing treatment approaches. Importantly, this study introduces a new construct to address the intersection of psychological and sociocultural factors in the experience of pain.

6.2.2 Social psychological framework. As discussed in the social psychological application of stigma theory, a person who believes that they will be devalued and discriminated against due to their condition (chronic pain) will likely fear the possibility of personal rejection (Link & Phelan, 2001; Link et al., 2001). Link et al. (2001) further argue that this fear of rejection in turn leads to negative consequences, including avoiding social contact, strained social interactions, and loss of employment. It is suggested that self-esteem will be challenged with those affected by internalised stigma feeling less able and worthy than others (2001). Consistent with Link et al.’s (2001) framework, the findings presented in Chapter 2 and 3 supported the model that self-esteem decrement and distress are predicted by the absorption of negative stereotypes about pain. The results demonstrated that a consequence of internalised stigma among people with pain is a subsequent sense that the person has little to be proud of and feels less worthy than others (Link et al., 2001). Results provided support to Link et al.’s (2001) framework, through the
finding that social withdrawal from internalised stigma does indeed predict self-esteem at six-month follow-up, even with adjustment for baseline levels.

The associations in Chapter 2 suggested people with pain who internalised stigma also felt less able than others to approach behaviours or tasks despite pain. However, this relationship was not significantly demonstrated in prospective research following this study. Therefore, support was not found for the sense of feeling less able depending on the level of internalised stigma although findings were tentative given study limitations as discussed in Chapter 3. Overall, the work does suggest the vicious cycle that can arise from experiencing internalised stigma in terms of isolation and decreased confidence in oneself. Future directions for research emerge in terms of considering the role of identity in greater detail, with a focus on how implications of internalised stigma may vary for general and pain-specific self-efficacy.

6.2.3 Social Cognitive Model and Attribution Theory. This research also sought to consider how psychosocial factors influence the assessment of pain among medical and nursing students. The findings were consistent with the social cognitive model relating to pain assessment in suggesting that the uncertain and ambiguous nature of pain may lead healthcare providers to unwittingly access intuitive, bias-prone heuristics. In the case of chronic pain, the application of experience-based assumptions relating to the legitimising role of medical evidence is sub-optimal and may indeed lead to the underassessment and therefore differential treatment of patient’s pain. Additionally, factors pertaining to the social context such as responsibility for the initial injury were also found to inform pain-related judgments of persistent pain in terms of malingering. It is argued this relationship reflects a sociocultural context that primes healthcare providers to attend to such features
(Hadjistavropoulos, 2013), particularly under conditions of uncertainty or ambiguity. Moreover, consistent with predictions of attribution theory, the role of responsibility for an initial injury was found to be significant, suggesting that negative attributions such as blame lead to differential judgments about pain and distress. One caveat that could be addressed in future research is that a sample of experienced healthcare providers may have produced differences in results to the use of students employed in the present program of research.

6.2.4 Augmenting qualitative work. Qualitative work considers the lived experience of the person with pain. This thesis sought to augment qualitative literature with quantitative work, to allow for the objective measurement of outcomes. The implications of pain judgments are discussed at length in qualitative work, which has emphasized the need for medical providers to be cognizant of patients' beliefs and sensitivities, such as avoiding unintentional implications about their pain being feigned due to the absence of identifiable pathology (Frohm & Beehler, 2010; Gillmore & Hill, 1981; Glenton, 2003; Kool et al., 2010; Kouyanou et al., 1998). Chapter 5's findings provided evidence to suggest that biomedical models and beliefs around patient malingering can influence aspects of pain assessment. Yet on the other hand, in contrast to qualitative work, psychological referral was not observed to be a validating factor in pain assessments, which suggests that perceptions outlined in qualitative work may not necessary match actual provider judgments. While the difference between perceived and encountered discrimination based on such factors was not a focus of this thesis, this does suggest the role of educating both parties in terms of communication styles to ensure that the impact of messages are not unintended, and also that the intent of medical providers
is placed within increased recognition of biopsychosocial role for patients (Ha & Longnecker, 2010; Hirsh, Jensen, & Robinson, 2010).

Qualitative literature suggests that pain judgments not only influence provider assessments and interactions, but also occur more broadly to affect a person’s sense of self. In this way, the thesis augments qualitative work by considering the psychological hurt of isolation and withdrawal, perceived discrimination based on pain, loss of self-esteem, and the potential of stigma to influence patient outcome (Glenton, 2003; Goldberg, 2010; Holloway et al., 2007; Slade et al., 2009). Overall, the findings presented in Chapters 2 through 4 supported the suggestion that a proportion of those people living with pain experience alienation, social withdrawal, and disempowerment. In this way, it is hoped the recurrent themes in qualitative work such as disbelief and alienation, which suggest the experience of pain goes far beyond the physical to encompass a range of sociocultural experiences, have been empirically supported.

6.2.5 Complementing internalised stigma research. The thesis expands current work on internalised stigma with its application to a new population. Internalised stigma has been established in work over the past two decades as an important construct in chronic illness literature (Taft, Riehl, Dowjotas, & Keefer, 2014). The literature in this field has consistently demonstrated the presence of internalised stigma in a variety of mental health and physical conditions, and shown links to poorer outcome (Boyd et al., 2014; Drapalski et al., 2013). Consequently, promising work is emerging in a clinical domain that aims to reduce internalised stigma; this remains an emerging literature with further investigations into the development of effective interventions being required (Griffiths, Carron-Arthur, Parsons, & Reid, 2014; Roe et al., 2014).
However, no work had evaluated the internalised stigma among people living with persistent pain. This thesis advances the literature and suggests that internalised stigma occurs among people with pain. Moreover, the proportion of participants who endorsed internalised stigma was comparable to the frequencies observed among traditional populations of examination such as schizophrenia spectrum disorder, bipolar or depressive disorder (Brohan et al., 2011; Lysaker et al., 2007). In addition to health conditions such as HIV/AIDS and epilepsy that have been empirically examined to date, future research among a persistent pain population is warranted. Given the high prevalence of chronic pain, and high comorbidities with mental health conditions, it suggests a new research, clinical and preventative application for the field to consider. The results of Chapter 4 provide the beginnings of work that suggest cognitive behavioural based group interventions are linked to reductions in internalised stigma. This finding could be integrated with existing knowledge of interventions for internalised stigma (e.g. Roe et al., 2014), to consider optimising effective interventions for internalised stigma within a persistent pain population. In presenting this work, it is hoped that as it has in the mental health field (Boyd Ritsher et al., 2003), this construct may encourage researchers and clinicians working in the field of chronic pain to attend to internalised stigma. Through having a reliable measure of internalised stigma, the reduction of internalised stigma can be encouraged as a concurrent treatment goal.

6.2.6 Contributing to the pursuit of goals within the National Pain Strategy. This program of research incorporates several primary goals put forward in Australia’s National Pain Strategy (2010). Through aligning itself with these goals, this series of papers makes a contribution to efforts to improve pain management and effectiveness in Australia (National Pain Summit Initiative, 2010).
Firstly, Goal 1 of people in pain as a national health priority, and within this, de-stigmatising the predicament of people with pain, has been contributed to by the focus of all four studies. Central to each paper is a focus on the intersection between a patient’s pain experience and their social interactions, including judgments within the healthcare system. Further, to work effectively towards key objectives it is imperative to be able to quantitatively measure and thus understand the experience of stigma for the perspective of those living with pain. The absence of research in internalised stigma reflected an information gap underpinning the National Pain Strategy objective that this thesis has addressed. Secondly, this thesis has contributed to efforts to ensure knowledgeable, empowered and supported consumers (Goal 2). It has added to the current literature through its focus in Chapter 4 on the capacity to decrease a sense of devaluation and demoralisation, and increase stigma resistance, among people with pain. Further, through introducing the construct of internalised stigma, this thesis presents a way for identifying people who experience the other end of this spectrum, ‘righteous anger’, whose characteristics may inform future efforts to better support consumers.

Goal 3 reflects efforts to ensure skilled professionals and best-practice evidence-based care for people with pain. Best-practice evidence-base care begins with the ability to accurately assess and therefore formulate a patient’s experience in order to inform treatment strategies. Chapter 2 has contributed to efforts in this area through the introduction of a psychometric assessment tool and Chapter 4 presents an initial exploration of applying evidence-based care in a large metropolitan healthcare setting. Additionally, the focus of Chapter 5 builds on existing literature in the field to ensure skilled professionals in terms of the way in which provider judgments may contribute to biases in assessment. Finally, perhaps self-explanatory
is the contribution of this thesis to research. As outlined in detail in Section 6.4, this thesis presents a potentially fruitful area for further research with multiple options warranted in terms of future empirical examination.

6.3 Clinical Implications

While each study presented in this thesis has discrete clinical implications, a number of broader themes stemming from the work will be reviewed below. Perhaps most significantly is the capacity of internalised stigma to be used as an assessment tool and verifiable treatment outcome measure for people with pain. This construct has not been reported in the pain literature and does not seem prominent in clinical practice, suggesting the need for greater consideration of the sociocultural context in this way.

The findings presented here have indicated that internalised stigma is not a static construct; it was changeable following multidisciplinary intervention. Therefore, clinical implications centre on the potential to explore the experience of absorbing negative sociocultural attitudes towards chronic pain as an important aspect within the rehabilitation process. This work could be informed by the developing approaches in the mental health field, such as group based narrative enhancement and cognitive therapy (Lucksted et al., 2011; Roe et al., 2014; Yanos, Roe, & Lysaker, 2011; Yanos et al., 2012). Such an approach could encompass: psycho-education to replace stigmatizing views about persistent pain; cognitive restructuring techniques to assist in challenging negative beliefs about the self based on pain; and narrative work to enhance the ability to narrate one’s life story (Roe et al., 2014).

Another clinical implication is to focus on people with pain who did not experience reductions in internalised stigma following treatment, given findings
showed some participants experienced no improvement or in fact increased stigma post-multidisciplinary pain program. Considering this subset in greater detail would enable the development of more tailored interventions. This essentially reflects an exploration of which aspects of current multidisciplinary pain program interventions are most effective in targeting internalised stigma, for which participants, and why? Such questions are consistent with the broader direction of psychological research in pain management (Williams, Eccleston, & Morley, 2012).

The role of preventative efforts is another implication flowing from the findings presented in this thesis. The role of brief, early interventions in protecting people with persistent pain from internalised stigma is a new direction for clinical work to consider. On an individual level, this work could encompass initial strategies to increase stigma resistance, ensure empowered and supported consumers, and facilitate communication techniques in response to perceived discrimination experiences. One point of capture could be through general practitioners in the community given their role in ongoing medical management. Patients identified in the early stages of persisting pain (i.e. less than 1 year) could be provided with resources or brief intervention in the hope of inoculating against a sense of devaluation or demoralisation due to internalised stigma.

Finally, beyond the individual level, approaches need to be multifaceted and multilevel to produce internalised stigma change (Link & Phelan, 2001). As stigma of pain has been demonstrated to be an alienating experience, then part of the solution may be to help reduce suffering through bringing the pain sufferer back to a sense of community, rather than isolation (Goldberg, 2010). Goldberg (2010) refers to the notion of “repatriating” people who are living with chronic pain. This reflects interventions at the community level, not just strategies targeted at the individual. As
demonstrated in the results of Chapter 4, participants did not experience reductions in discrimination experience. Intervention is necessary at the level of the person, but also for those who they interact with in order to be most effective.

Consistent with the need to focus clinical interventions at the social level, discussion in Chapter 5 suggested the need for education to both healthcare providers and patients in terms of biopsychosocial formulations of pain. Yet while multidisciplinary frameworks have received most support in the literature, these are difficult to convey in a short, sharp form to the public (Hinshaw & Stier, 2008). Nevertheless, multilevel efforts are required for change to occur (Link & Phelan, 2001). An example of how this might be achieved is demonstrated through a population based primary prevention intervention which targeted knowledge of back pain (Buchbinder, Jolley, & Wyatt, 2001). This public health campaign significantly improved beliefs about back pain held by both doctors and the general community, with positive increases in knowledge and awareness maintained three years after the campaign had finished (Buchbinder & Jolley, 2004). This intervention offers hope for the ability to produce significant change through coordinated messaging in terms of pain’s biopsychosocial context. In turn, this could provide corrective experiences for negative sociocultural encounters among people with pain.

6.4 General Limitations and Future Directions

Limitations of each of the studies have been discussed within the specific manuscripts and thus are not repeated here. However, focus is given to ways for extending and improving the current program of research based on broad limitations. Beyond the specific discussion offered in each study, presented below are a range of future directions that flow from this thesis.
Firstly, having now applied the internalised stigma scale to a persistent pain population, future work could examine the applicability of the instrument to different cultural and linguistic groups. In addition to the construct’s application across diverse demographic groups, work could consider how internalised stigma may vary depending on pain site or diagnosis. This could include psychometric evaluation of the adaptation for a pain population, to further assess construct validity and measurement invariance. The focus of the present thesis was a heterogeneous pain population but a more nuanced analysis could explore whether certain conditions are more likely to lead to the experience of internalised stigma.

Secondly, the prospective research presented here failed to show a significant relationship in some of the hypothesised areas. This does not detract from the strong results of the other studies and a potentially fruitful area of research. Instead, it signals the need for larger prospective research with greater power and sample size to test the predictive relationships outlined in social psychological theory, but particularly considering global outcome measures in contrast to pain specific measures. Moreover, a general limit of this research program was also the lack of consideration of behavioural outcomes that might be associated with internalised stigma (e.g. employment status). Therefore, future work could examine the predictive relationship between internalised stigma and behavioural consequences particularly in critical areas of employment status, frequency of health care visits, and social engagement.

A third direction for future research stems from the limitation that outcome variables were negative processes in the present work, such as self-esteem decrement, catastrophising, disability, and reduced pain self-efficacy. Positive outcomes represent the other side of the continuum worth exploring. This is
particularly the case given that internalised stigma was not endorsed by all participants. This finding is consistent with the paradox of stigma, whereby not all people who encounter stigma internalise the stigma (Corrigan & Watson, 2002; Link & Phelan, 2001). Therefore, examining factors that differentiate between those who endorse high internalised stigma, those who are neutral in the face of negative sociocultural experiences, and those who react with righteous anger and are energised to act, presents an area of interest. Such work could be used to inform the use of training to facilitate resiliency or other protective factors among people with pain.

Finally, the quasi-experimental design of the cognitive behavioural intervention study presents a limitation that could be addressed through the use of a randomised control trial to target internalised stigma. Qualitative work has discussed the pivotal role of stigma in the lives of those with pain and suggested strategies for coping with this stigma would be beneficial addition to pain management programs (Holloway et al., 2007). The findings of this thesis suggest that the incorporation of strategies to deal with internalised stigma into pain management outcomes is worthy of consideration given the changeability in the construct. In particular, it would appear that strategies to explore pain communication with healthcare providers and the role for dual community education and support would be warranted. For example, one moderating factor in the experience of internalised stigma may be strong social support. A limit of the studies presented here was that they did not consider judgments beyond the health care, such as interactions with significant others. The interplay between the pain related judgments of close others, and internalised stigma, presents a future direction for research. Overall, the present series of papers offers a way for such treatment targets to be assessed in a verifiable
manner through the use of the internalised stigma scale and a starting point for the development of treatment work in this field.

6.5 Concluding Statement

This thesis presents a series of studies which are grounded within a biopsychosocial formulation of pain. It has sought to empirically examine how the psychosocial context may influence a person with pain, and the judgments of healthcare providers within this context. Through this investigation, findings have suggested that for some, negative stereotypes about people with pain can come to be internalised in process that leads to personal devaluation and demoralisation. A harmful feature of living with persistent pain can be turning sociocultural stereotypes inward. The results suggest that for some people, the disheartening experience of isolation, lack of belonging, and alienation due to the sense that judgments will be made about one's character based on their pain condition.

The findings of the longitudinal study help to improve understanding and reveal fruitful directions for research. Similarly, a quasi-experimental treatment study paves the way for clinical implications to improve effective management of people with pain. Furthermore, results suggest the need for further education at multiple levels of healthcare provider and patient to guard against unwilling biases in pain assessment. A person's pain experience does not occur in isolation and thus the assessment, treatment and exploration of how interpersonal interactions affect the self and future outcomes presents a promising area of research. This body of work seeks to contribute to efforts in the psychological field of pain management with the hope of offering an avenue to improved understand and therefore more effectively responding to the experience of those with pain.
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(Contextual Statement & Discussion)


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