

University of Alberta

Social Stigma Perceived by Patients with Chronic Pain Attending a Cognitive  
Behavioral Pain Management Program (Pain 101)

by

Pravesh Vallabh

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## **Abstract**

There are limited data on the stigma perceived by patients with chronic pain and there are no data on the effect of cognitive behavior therapy (CBT) on stigma in chronic pain patients. The purpose of this study was to examine perceived stigma in adults with chronic pain and the effects of a cognitive-behavioral pain management program (PAIN 101) on stigma. The sources of stigma assessed, were the patients' physicians, family members and the public.

Perceived stigma was experienced the most from the public, followed by the physicians and then by family members. CBT had no effect on stigma perception while the pain management program was successful in reducing anxiety and pain-related disability in patients. It was found that depression, pain, and pain-related disability predicted stigma.

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## **List of Abbreviations**

AIDS	Acquired Immunodeficiency Syndrome
CBT	Cognitive Behavior Therapy
CFS	Chronic Fatigue Syndrome
CPSS	Chronic Pain Stigma Scale
FM	Fibromyalgia
fMRI	Functional Magnetic Resonant Imaging
HAD	Hospital Anxiety and Depression Index
HIV	Human Immunodeficiency Virus
IBS	Irritable Bowel Syndrome
MPQ	McGill Pain Questionnaire
MPC	Multidisciplinary Pain Center
NSCLBP	Non - Specific Chronic Low Back Pain
PDI	Pain Disability Index
15D	Quality of Life Questionnaire
QOL	Quality of Life
UAH	University of Alberta Hospital

## **I. Introduction**

The author has been involved in the management of chronic pain patients and his experience has led to observations of strained patient-physician interactions secondary to perceived stigma. These observations culminated in the development of a research project to detect the sources of stigma and to utilize cognitive behavior therapy (CBT) to address the stigma perceived.

The most frequently cited definition of stigma is that of Erving Goffman (1963). The term was originated by the ancient Greeks to refer to bodily marks whose purpose was to reveal something discrediting about the moral status of the marked person. The marks were cut or burned into the body to identify the marked person as a slave, criminal or traitor. The marked person was to be avoided, especially in public. In the current era, the bodily evidence of stigma is not used, but stigma is applied more to the disgrace than to the bodily evidence of it (Goffman, 1963). Goffman identified 3 types of stigma. The first are physical, such as deformities, disabilities and chronic diseases. The second are blemishes of one's character such as the person's weakness, illness, or dishonesty. The third are tribal stigmas of race, nationality and religion (Goffman, 1963).

The research on mental illness stigma is relevant to many medical conditions including chronic pain (Reed, 2006). In patients with chronic pain, one would postulate that stigma exists because there is evidence that there is a tendency to ascribe chronic pain to psychological causes rather than to physical illnesses, especially if there is no clear organic cause (Wright, 1983; Weiner, 1993). It has been suggested that stigma in chronic pain may be associated with the attribution of psychosomatic causes that are seen as at least partially under the control of the individual (Marbach et al., 1990).

It is difficult to ignore the importance of chronic pain. The cost of chronic pain to society is great (Turk, 2002), with prevalence studies indicating that as much as 44% of the population experience pain on a regular basis, and that in one quarter of this group the pain is severe (Birse & Lander, 1998; Smith et al., 2001). Chronic pain affects the ability to work, sleep and perform other activities essential to leading a full life, and these changes generally worsen over time (Wincent et al., 2003). Chronic pain has a significant negative impact on a variety of factors related to an individual's quality of life (Shifren et al., 1999).

The evolved definition of pain has its origins when the philosophers Aristotle and Plato described pain as "a passion of the soul", and this idea was accepted for almost 2000 years (Bonica, 1990). In 1644, Descartes (a philosopher and mathematician) proposed that pain is a signal fired off by a disease or injured body part (Reed, 2006). This led to the concept of mind body dualism and the basis for the biomedical model. Pain was categorized as either physical/somatic or psychological/psychosomatic (Reed, 2006). To address the limitations of the biomedical model, Melzack and Wall published their Gate Control Theory of pain in 1965. This highlighted how dynamic brain processes filter and modulate pain, whether originating from an emotional or physical cause (Melzack, 1993). This theory allowed that anything causing changes in the brain, whether originating from an emotional or a physical state, could potentially influence the perception and experience of the pain (Reed, 2006). Incorporating these concepts, pain was later defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (Mersky, 1986). This definition is used by clinicians and scientists today.

This definition emphasizes that pain is a complex perceptual experience composed of several components and that physical injury may or may not adequately explain it. Psychological factors have become recognized as integral parts of the pain experience. This has led the author to postulate that the Bio-Psycho-Social-Spiritual model become the accepted model for understanding pain. In the author's experience, patients have reported feeling stigmatized by treating physicians, their family and the general public because of their condition. The complex interaction of pain and psychosocial factors has been observed by the author. Stigma is a psychosocial factor related to chronic pain that is associated with negative effects such as depression, decreased self esteem, strained interpersonal relations and lowered quality of life (Jones et al., 1984).

Chronic pain in psychiatry is classified in the DSM IV-TR as being secondary to a general medical condition or a pain disorder found under the somatoform disorders. In the DSM IV-TR (APA, 2000), the criteria for Pain Disorder include pain at more than one anatomical site, it being the predominant focus of the clinical presentation and being of sufficient severity to warrant clinical attention. In addition the pain needs to be causing clinically significant distress or impairment in social, occupational, or other important areas of functioning. Psychological factors are judged to have an important role in the onset, severity, exacerbation, or maintenance of pain. The symptom or deficit is not intentionally produced (as in factitious disorder or malingering). The pain is not better accounted for by a mood, anxiety, or psychotic disorder and does not meet criteria for dyspareunia. Pain that has a duration of six months or longer is classified as chronic and that of duration less than six months is classified as acute. The other available classification is Pain Disorder Associated with Psychological Factors and Pain Disorder Associated With Both Psychological

Factors and a General Medical Condition (APA, 2000). In the author's experience, this evolved attempt at describing chronic pain has left both health care providers and patients with some ambiguity on how to describe chronic pain consistently.

There is evidence that chronic pain and psychiatric illness can be linked on a neurobiological basis (Borsook et al., 2003). The reason this is important is that it can then be postulated that stigma can have a neurobiological effect on an individual with chronic pain. Borsook et al. (2003) describe the inter-relationship of the reward-aversion circuitry in analgesia and pain and the implications for psychiatric disorders. They used neuro-imaging in humans to investigate sensory changes and affective components of painful stimuli. Their analysis of central nervous system activation provided evidence that putative reward circuitry can be differentiated from classic pain circuitry. These regions include the sub-lenticular extended amygdala, the ventral tegmental area, the peri-aqueductal gray area, the orbitofrontal cortex and nucleus accumbens. Dopamine transmission from the ventricular tegmentum area to the nucleus accumbens is associated with behavioral response to rewards. Other brain regions implicated in the brain reward function are the amygdala, which is connected to the ventral tegmentum area and the nucleus accumbens. The importance of this is emphasized by the known relationship of anxiety and depression to chronic pain.

Chronic depressive symptoms have been shown to correlate with chronic pain. Studies have indicated that structures like the amygdala and the prefrontal cortex may be important in depressive symptomology (Borsook et al., 2003). Anxiety about pain can exacerbate the pain sensation (Borsook et al., 2003). Recent neuro-imaging has described a relationship between anxiety and activation of specific neural circuits, particularly the entorhinal cortex and the

parahippocampal cortex (Borsook et al., 2003). Opioids may modulate the affective component by acting on the amygdala and the cingulate gyrus (Borsook et al., 2006). It has been proposed that changes to the reward-aversion circuitry are likely contributors to the psychiatric disorders that develop in many patients with chronic pain (Borsook et al., 2006). Recent data suggest that reward and aversive stimuli affect similar pathways in the CNS. Networks have been highlighted and a summary of this is seen in this model postulated on neuro-imaging findings. Pain pathways involve the amygdala, the prefrontal cortex and dopamine receptors (Borsook et al., 2003). This is the same pathway that involves the reward circuitry in the brain. There is alteration in motivation, emotion and behavior in chronic pain, and there is a functional modulation of sensory and reward-aversion circuits following nerve damage. Allodynia and “wind-up”, increased pain unpleasantness and suffering as well as the development of a functional illness (like depression) may co-exist with chronic pain. The combination of altered pain sensation (nociception) and altered reward-aversion circuits resulting in anxiety, depression and fear determines pain unpleasantness, hence the emotional reaction to pain. Thus chronic pain potentially predisposes individuals to a functional illness and vice versa. Their shared clinical presentation suggests that at least some of the underlying circuitry is similar across disease states.

In "The blame game: The effect of responsibility and social stigma on empathy for pain", Decety et al. (2010) examine the functional neuro-imaging aspects of stigma. This investigation combined behavioral and functional neuro-imaging measures to explore whether the perception of pain is modulated by the target's stigmatized status and whether the target bore the responsibility for that stigma. During functional magnetic resonance imaging (fMRI) scanning,

participants were exposed to a series of short video clips featuring age-matched individuals experiencing pain who were similar to the participant (healthy), stigmatized but not responsible for their stigmatized condition (namely infected with Acquired Immunodeficiency Syndrome (AIDS) as a result of an infected blood transfusion), or stigmatized and responsible for their stigmatized condition (infected with AIDS as a result of intravenous drug use). These participants were asked to rate their pain intensity. Participants were significantly more sensitive to the pain of AIDS transfusion subjects, compared to healthy and AIDS drug subjects, as evidenced by significantly higher pain and empathy ratings during video evaluation and significantly greater hemodynamic activity in areas associated with pain processing (right anterior insular area, anterior mid-cingulate cortex and peri-aqueductal gray area). In contrast, significantly less activity was observed in the anterior mid-cingulate cortex with AIDS drug targets, as compared to healthy controls.

The above mentioned study that describes the relationship of perceived stigma on a neurobiological level, adds to the rationale that managing chronic pain is important. Pain is the most common symptom for which patients seek medical care (Miller & Krause, 1990). According to the National Institutes of Health (2003), the cost associated with chronic pain in the United States is estimated to be over \$100 billion per year.

In the literature regarding stigma and chronic pain, the experience of stigma in chronic pain patients has been clearly established (Holloway et al., 2007; Friedl et al., 2008). Stigma has its own sequelae on the individual and this impacts the management of the patient from a biopsychosocial level. The studies highlighting the effects of stigma reveal a correlation with depression (Holloway et al., 2007; Friedl et al., 2008) and as a result there is a delay in seeking help

(Holloway et al., 2007; Friedl et al., 2008). The reason for depressed patients not seeking help could be attributed to fear of judgment from physicians, feeling morally too weak to manage their health and suffering from poor motivation secondary to the illness itself.

The current study was undertaken to highlight the presence and effects of stigma in people with chronic pain and to further add to current literature. Most pain centers in Canada use cognitive behavior therapy (CBT), an empirically validated therapy, for chronic pain (Morley et al., 2003) It has been suggested that CBT could be used to address stigma (Reed, 2006). To the best of the author's knowledge there are no published studies that examine the impact of CBT on stigma in chronic pain. In view of this, this study was undertaken to assess if CBT would address stigma in the patient experiencing chronic pain.

#### 1.1 Review of the literature on stigma and chronic pain

The complex relationship of stigma in relation to chronic pain is best understood when the relation of stigma and various illnesses is first reviewed. Thereafter there is a comment on stigma and its relationship to mental illness as well as opioid usage. The impact of stigma is also commented on. Finally this review concludes with an analysis of the studies that specifically investigated socially perceived stigma in the chronic pain population. The latter is pertinent to this study and led to both the development and refinement of this study.

The relationship of stigma in various illnesses was shown in a study by Weiner et al. (1988). Subjects with ten conditions presumably associated with stigma (AIDS, Alzheimer's disease, blindness, cancer, child abuser, drug addiction, heart disease, obesity, paraplegia, and Vietnam War syndrome) were included. The authors studied the relationship between stigma, perceived responsibility (onset-controllability), emotions of anger and sympathy and reports

of intention to help. Weiner et al. (1988) concluded that physically-based conditions tended to be perceived as onset-uncontrollable and were linked with the affective reactions of pity, and anger-free help giving behavior. Conversely, mentally-based conditions were perceived as onset-controllable and linked with blame, dislike, and anger. Health care providers are trained to diagnose an organic condition and to then treat it. Thus, when no organic lesion can be detected, there is often a perception that the symptom is psychiatric and the patient can consequently be stigmatized. Weiner et al. (1988) found that there is an unwillingness to assist when the illnesses were perceived to be within the individual's control.

Further supporting these findings is a large body of evidence that consistently identifies mental illness as more stigmatizing than physical illness (Crocetti et al., 1974, Dovidio et al., 1985; Link & Bruce, 1990; Markowitz, 1998; Corrigan et al., 2000). Mental illness stigma is often explained by the idea that reactions to stigmatized persons are in part based on moral principles (Reed, 2006). Mental Illness has a tendency to be perceived as being somewhat under the control of the individual. (Brewin, 1984; Link & Bruce, 1990).

As mentioned, it has been suggested that stigma in chronic pain may be associated with the attribution of psychosomatic causes that are seen as, at least partially, under the control of the individual (Marbach et al., 1990). It is not uncommon to note in clinical practice, both in the setting of pain clinics and otherwise, that if a procedure is unable to fix the pain, then the etiology of pain is assumed to be psychological.

In the literature, it has also been repeatedly noted that patients with chronic pain are stigmatized for using opioids. Individuals taking opioid analgesics are vulnerable to stigmatization because of the fear of addiction and negative

attitudes towards substance abuse (Reed, 2006; Diwan et al., 2010). Society at times fails to distinguish between the legitimate and illegitimate use of opioids (Hill, 1993). A study in United States showed that more than half (54%) of physicians believe that addiction (which is characterized by psychological dependence with drug-seeking behavior), is a frequent result of legitimate prescription (Weinstein, 2000). The authors argue that physicians are confused regarding the difference between physical dependence, tolerance and addiction. Physical dependence consists of a withdrawal syndrome on abrupt drug discontinuation. Tolerance results in the need for increasing drug doses to maintain the same effect. Both tolerance and dependence are psychophysiological phenomena and are properties of the drug, not the user. Addiction is a behavioral syndrome of drug use despite harm. It is suggested that physicians often mistake the patient's intense focus and seeking relief for their pain as a sign of aberrant drug-seeking behavior (Reed, 2006). This is sometimes referred to as "pseudoaddiction". Nearly half of physicians (49%), also believed that too many opioid prescriptions would lead to external review. Further, 26% believed that prescribing narcotics for chronic pain is likely to trigger a Drug Enforcement Agency investigation. The triplicate prescription process is monitored by the College of Physicians and Surgeons in most jurisdictions. This is a good way of monitoring total opioid prescriptions, but it may lead to physician reluctance to prescribe opioids.

A recent review of methadone and its stigma as a barrier to its use in the treatment of chronic pain was performed by Diwan et al. (2010). The study reviewed the opinions of physicians who were members of the American Pain Society. The physician names were obtained from the American Pain Society's membership list. Of 124 physicians included in the study, 111 prescribed

methadone. Of these, 55 stated that social stigma was the most common reason patients refused to take methadone for the treatment of pain.

Saunders (2010) reviewed the patient's perspective of barriers to chronic opioid therapy for non-malignant pain and state that the prescription of opioid analgesics for managing chronic nonmalignant pain is a highly contentious treatment modality. This debate has resulted in stigma being associated with both the treatment (using opioids) and in those individuals receiving it. As a result of the stigma, many barriers exist for those individuals using opioids to control their pain. Some qualitative research exists that reflects patients' perspectives regarding the stigmatization and the barriers that they encounter when using this treatment option. The barriers appear to arise from family, the health care system and society at large (Saunders, 2010). Since controversy exists regarding opioid use for benign chronic pain conditions, stigma develops and this strains doctor-patient relationships, since not all physicians believe in the use of long term opioids for chronic pain.

There is substantial literature highlighting the negative impact of perceived stigma on the well being of persons with an illness or disability. The impact can be conceptualized as occurring within two broad categories. The categories are intra-personal and interpersonal effects (Reed, 2006). The intra-personal effects of stigma are most identified as being decreased self-esteem, depression and reduced quality of life. There is abundant literature describing co-morbid depression and stigma in somatoform illnesses (Friedl et al., 2008, Walker et al., 2007). As a result, one can expect delays in accessing appropriate health care. Most chronic pain clinic programs are set up to improve the functioning of an individual. However, stigma is not factored into these programs.

Researchers suggest that it is more meaningful to conceptualize self-esteem as a situationally constructed trait rather than as a stable and global trait carried by individuals across all situations (Crocker & Major, 1989). Self-esteem has been negatively associated with perceived stigma in illnesses such as mental illnesses (Fabrega, 1991; Markowitz, 1998; Link et al., 2001), Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Disease Syndrome (AIDS) (Herek, 1999; Fife et al., 2000; Berger et al., 2001), epilepsy (Sneider & Conrad, 1980; Scrambler & Hopkins, 1990), psoriasis (Gupta et al., 1998; Perrott et al., 2000), and asthma (Becker et al., 1993; Vamos & Kolbe, 1999).

Depression has been found to be frequently present in conditions like HIV (Herek, 1999; Fife & Wright, 2000), asthma (Vamos & Kolbe, 1999), cancer (Stahly, 1992), and skin disorders (Richards et al., 2001). These studies have found that stigma makes a significant contribution in predicting depression, when disease severity, social support, history of psychological problems, gender and age are controlled for (Reed, 2006). Again, this highlights the importance of detecting and addressing stigma to ensure effective treatment.

In somatoform pain disorders, the relationship between stigma and depression has been studied. Friedl et al. (2008) performed a survey on the attitudes of 115 patients with the diagnosis of somatoform pain disorder regarding perceived discrimination and mental illness stigma and how they are influenced by depressive symptoms. Somatoform pain patients showed a high perceived stigma score and a significant correlation of stigma with depressive symptoms. Nearly 70% thought that most employers would pass over the application of the psychiatric patient in favor of another applicant. The authors concluded that the fear of stigma increases with the presence of depressive

symptoms and both risk treatment delay. The authors also state that the goal of future research should be to question how to reduce subjective stigma experiences of the patients affected, in order to help them into psychiatric treatment, thereby gaining self-confidence and improving mental health. The negative effect of stigma on quality of life has the largest body of research in studies of patients with mental illness (Markowitz, 1998; Link et al., 2001; Yanos et al., 2001).

The interpersonal effects are noted when non-stigmatized persons' reactions to individuals with stigmatized health conditions are related to feelings of hostility, anxiety and ambivalence (Crandall & Moriarty, 1995). Weiner (1993) revealed that hostility may result from belief that the person is responsible for the condition. Hostility also occurs if someone feels threatened. An example of this is frequently seen when the stigmatizer is in the proximity of a person with a contagious condition (Crandall & Moriarty, 1995). There is fear of acquiring the illness. Alternatively, anxiety may occur in the interaction. Anxiety may be secondary to a lack of experience and knowledge of the health condition (Hebl et al., 2000). Specifically, with respect to health care professionals, the inability to manage the patient leads to anxiety and even possibly hostility and anxiety combined. Katz (1981) describes ambivalence that occurs as people feel conflicted, and they blame the stigmatized person for their own ambivalence. As a result, the stigmatized person is avoided or there may be mixed messages given that lead to strained relations. It is the author's experience that in chronic pain settings, patients may leave a consult meeting feeling confused, lost and not validated. The author's observation is patients who respond poorly to a particular treatment regime tend to induce frustration in their health care providers.

In studies of patients with physical illnesses (Kleck, 1968; Kleck 1969; Sigelman et al., 1986), biased behavior towards them has been noted. The patients were spoken to at a distance, there was decreased touching and there were more gestural behaviors (Kleck, 1968; Kleck 1969; Sigelman et al., 1986). The language used was simpler when interacting with the physically disabled (Gouvier et al., 1994). This may give the impression of decreased intellect and inferiority being experienced in the stigmatized individual. It has been hypothesized that these types of behaviors may lead to strained interactions (Reed, 2006). Patients in qualitative studies describe being made to feel inferior intellectually as a result of these strained interactions. This is important since strained social interactions may disrupt the physician-patient relationship and lead to decreased support (Fife et al., 2000).

Studies that investigated socially perceived stigma in chronic pain subjects are outlined in the tables that follow (**Tables 1-11**).

**Tables 1-11 : Review of Studies on Chronic Pain and Stigma**

**Table 1:**

<b>Author/ Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Lennon et al. (1989)	USA	Age(mean): 38yrs Gender: Female Number: 151 Disease States: Tempomandibular Pain & Dysfunction Syndrome (TMPDS)	Perceived stigma was analyzed Stigma scale	<ul style="list-style-type: none"> <li>• 81% felt most people have no idea what it is like to have facial pain</li> <li>• Large majority of patients feel totally “alone”</li> <li>• Large majority of patients feel estranged &amp; misunderstood</li> <li>• 52% told pain was imaginary</li> <li>• 37% felt that people associated pain with psychiatric problems</li> <li>• 46% felt pain person is perceived as less emotionally stable.</li> <li>• 58% felt people did not believe they hurt</li> </ul>	<ul style="list-style-type: none"> <li>• Cross sectional</li> <li>• Subjective report</li> <li>• Only white females included</li> </ul>

**Table 2:**

Author/ Year	Country	Patient Demographics	Study Method	Results	Limitations
Marbach et al. (1990)	USA	Age(mean): 38yrs Gender: Female Number: 151 Disease States: Tempomandibular Pain & Dysfunction Syndrome (TMPDS)	<ul style="list-style-type: none"> <li>• Used 25 item Likert scale</li> <li>• Factor analyzed using principal component analysis</li> <li>• 2 scales derived using :               <ul style="list-style-type: none"> <li>i. Estrangement scale</li> <li>ii. Attribution to psychological problems.</li> </ul> </li> </ul> <p>% agreement for each was utilized.</p>	<p>Reliability of</p> <ul style="list-style-type: none"> <li>i. estrangement scale = 0.84</li> <li>ii. attribution to psychological problems scale = 0.82</li> <li>iii. Intercorrelation = 0.52</li> </ul> <ul style="list-style-type: none"> <li>• Estrangement significantly correlated to number of doctors consulted (<math>p &lt; 0.001</math>) &amp; to being told that pain is imaginary (<math>p = 0.001</math>)</li> <li>• Attribution scale significantly related to number of doctors consulted (<math>p = 0.001</math>) and related to being told that pain is imaginary (<math>p = 0.001</math>)</li> <li>• Narcotic use significantly related to estrangement (<math>p &lt; 0.001</math>) and significantly attributed to personality problems (<math>p &lt; 0.09</math>)</li> </ul>	<ul style="list-style-type: none"> <li>• Study of patient perceptions.</li> <li>• Items used in the stigma scale were adapted from measures designed to assess stigma associated with mental illness.</li> <li>• Cross sectional</li> </ul>

**Table 3:**

<b>Author/Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Borkan et al. (1995)	Israel	Age(mean):39.5yrs 65%: Male 35%: Female Number: 76 Disease state: Low Back Pain	Content analysis done	Subjects frequently found delegitimization of their lower back pain @ hands of doctors, co-workers, spouses & families.	<ul style="list-style-type: none"> <li>• Cross sectional</li> <li>• Subjective report</li> </ul>

**Table 4:**

<b>Author/Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Osborne et al. (1998)	UK	Age: 25-55yrs Number: 9 Disease State: Chronic Back Pain	Semi-structured interviews Analysis using IPA	Participants felt obliged to appear ill to satisfy the requirements of others.	<ul style="list-style-type: none"> <li>• Qualitative study using semi-structured interview</li> <li>• Cross sectional design</li> </ul>

**Table 5:**

<b>Author/Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Rhodes et al. (1999)	USA	Age(mean): 47yrs Number: 54 Gender: Male = 20 Female = 34 Disease State : Chronic Back Pain	Semi-structured interviews Thematic analysis	52% reported medical profession did not believe their pain 33% reported invisibility of pain problematic	<ul style="list-style-type: none"> <li>• Qualitative study</li> <li>• Cross sectional design</li> </ul>

**Table 6:**

<b>Author/Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Asbring et al. (2002)	Sweden	Number: 25 Gender: female Disease State: Chronic Fatigue Syndrome and Fibromyalgia	Data collected through interviews. Systemic Analysis of interviews was performed.	<ul style="list-style-type: none"> <li>• Moral characters called into question</li> <li>• Distress from being psychologized by others, viz. doctors.</li> </ul>	<ul style="list-style-type: none"> <li>• Relied on the experiences of the participants</li> <li>• Healthcare providers and family members were not assessed or observed to ascertain what they had said to participants.</li> <li>• Only female subjects</li> </ul>

**Table 7:**

<b>Author/Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Lillrank (2003)	Finland	Age: 20-66 yrs Gender : Female Number : 30 Disease State : Chronic Back Pain	Autobiography writing Narrative analysis	<ul style="list-style-type: none"> <li>• Doctors appointments were disappointing</li> <li>• Doctors who indicate pain was “unreal” or psychological were experienced as very stigmatizing.</li> </ul>	<ul style="list-style-type: none"> <li>• Cross sectional design</li> <li>• Subjective Report</li> </ul>

**Table 8:**

<b>Author/ Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Looper et al. (2004)	Canada	Age(mean): CFS = 40 yrs. FM = 49.6 yrs IBS = 35.6 yrs  Number: 265  Gender: CFS = 66% female; 33.3% male IBS = 71% female; 23% male FM = 91% female; 9% male  Disease State: Functional Somatic Syndrome (FSS) Chronic Fatigue Syndrome (CFS) Irritable Bowel Syndrome (IBS) Fibromyalgia (FM)	Patients with Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Irritable Bowel Syndrome (IBS) were compared to patients with Multiple Sclerosis (MS), Rheumatoid Arthritis (RA) and Inflammatory Bowel Disease (IBD)	<ul style="list-style-type: none"> <li>• Perceived stigma was higher in patients with FSS&gt; (P&lt;0.005)</li> <li>• CFS had higher level of stigma compared to other matched conditions.</li> </ul>	<ul style="list-style-type: none"> <li>• Used Pain Stigma Scale in this study for patients with facial pain.</li> <li>• Self-report</li> <li>• Cross sectional design</li> </ul>

**Table 9:**

<b>Author/ Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Holloway et al. (2007)	England	Age(mean): 53 yrs. Number: 18 Gender: 12 Males; 6 Females Disease State: Chronic Back Pain	Qualitative Study  Interpretative Phenomenological Approach (IPA)  Narrative interview and analyzed thematically.	<ul style="list-style-type: none"> <li>• Stigmatizing responses by family, friends, health professionals and the general public.</li> <li>• Effect on the perceptions, self-esteem and behaviors of those interviewed.</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative study</li> </ul>

**Table 10:**

Author/Year	Country	Patient Demographics	Study Method	Results	Limitations
Friedel et al. (2007)	Austria	<p>Age(mean): 43 yrs.            Number : 101            Gender: -42% male; 58% female            Diseases            States:</p> <ul style="list-style-type: none"> <li>• 45 patients with Epilepsy</li> <li>• 14 patients with Dissociative Disorder</li> <li>• 42 patients with Somatoform Disorder</li> </ul>	<ul style="list-style-type: none"> <li>• Cross sectional study</li> <li>• 12-item perceived stigma questionnaire utilized to assess beliefs about discrimination towards persons with mental illness.</li> </ul>	<p>60% of participants felt that:</p> <ul style="list-style-type: none"> <li>i. Most people would not allow mental patients to take care of their children.</li> <li>ii. Most young ladies would be reluctant to date a man with mental illness.</li> <li>iii. Most employers would pass over the application of a psychiatric patient.</li> <li>iv. Most people think less of a person who has been hospitalized in a mental hospital.</li> </ul> <p>More than 50% felt that psychiatric patients are less intelligent, less trustworthy and that their opinion is taken less seriously by others.</p>	<ul style="list-style-type: none"> <li>• The questionnaire focused mainly on mental illness.</li> <li>• In this study 20% of the answers were incorrect.</li> </ul>

**Table 11:**

<b>Author/ Year</b>	<b>Country</b>	<b>Patient Demographics</b>	<b>Study Method</b>	<b>Results</b>	<b>Limitations</b>
Slade et al. (2009)	Australia	Age(mean) : 51.2 yrs Number : 18 Gender : 6 = Males 12 = Females Disease State : Chronic Low Back Pain	Grounded theory was applied in the analysis  Predetermined Questions utilized in study	<ul style="list-style-type: none"><li>• Majority were not satisfied with healthcare providers.</li><li>• Participants described stigma from family and personal relationships.</li><li>• Workplace stigma</li></ul>	<ul style="list-style-type: none"><li>• Qualitative Study</li><li>• Cross sectional</li></ul>

Although the literature addressing the issue of stigma in persons with chronic pain is limited, it does provide evidence that perceived stigma is an important factor in the experience of individuals coping with pain (Reed, 2006). Of note, existing studies that were conducted in different parts of the world found similar feelings of stigma in patients. The predominant theme was having the cause of pain attributed to psychological problems.

An early study conducted by Lennon et al. (1989) and Marbach et al. (1990) looked at pain in females. In the first study (Lennon et al., 1989) the hypothesis was that patients would be perceived to not have an organic cause and would be stigmatized by physicians and others by having their chronic pain attributed to psychological problems. Patients had seen an average of six different medical professionals before being seen at a pain clinic. Patients who felt others would think their pain to be secondary to personality problems were more likely to be secretive about their pain. Patients who had a mate felt estranged in the relationship if their pain was severe. Physicians were reported to be the primary source of labeling. Patients reported that they were frequently told that their pain had a psychological basis and this led to a sense of estrangement. The major limitation of the study was that only white females were included. Another limitation was that the sources of stigma asked about were limited to physicians or the general public.

Four studies were later conducted in different countries but identified similar findings with respect to stigma. The predominant theme was having the cause of pain attributed to psychological problems. The studies all had qualitative designs.

A study in Israel by Borkan et al. (1995) revealed that amongst patients who have back pain, stigmatization of pain occurred by spouses, families, co-workers and physicians. Delegitimization occurred through psychologizing symptoms. Patients reported feeling trapped between the pressure to hide their pain to avoid stigma as well as to show and communicate about their pain to justify their decreased functioning. Patients reported feeling a continual need to justify their pain as real. Once again, the limitation of this study was its restriction to patients with chronic back pain.

In another study from the UK by Osborne and Smith (1998) on patients with back pain, there was a tendency for patients to withdraw from social contact out of fear of being misunderstood or rejected. Since patients may pass as normal, the legitimacy of healthcare seeking was questioned. When patients have to prove they are ill, the likelihood of improving is low. This is known as “social iatrogenesis” (Wessley, 2002). Again, the limitation of the study by Osborne and Smith (1998), was its sole use of patients with back pain.

In the study of patients with chronic back pain by Rhodes et al. (1999), patients described a sense of doubt about themselves, feeling alienated by physicians yet being driven by pain to seek medical treatment. The patients were relieved when given a medical diagnosis since such a diagnosis provided an escape from stigmata that a psychological problem existed. A limitation was that only patients with chronic back pain were surveyed.

In another study, the experience of stigma was assessed amongst females with chronic fatigue syndrome and fibromyalgia (Asbring et al., 2002). Patients with perceived stigma kept a distance from others, they concealed their illness, and withdrew from co-patients. This led to anxiety, doubt, shame and decreased self-esteem. The study was limited by its inclusion of only female subjects.

A study by Lillrank (2003) studied females with chronic back pain. The findings were that doctors indicated pain as "unreal" or psychological. Patients reported feeling that doctors viewed them as crazy or lazy. They described anger, hopelessness and shame. Being given a diagnosis was seen as acceptable. The limitation was it was not reflective of back pain patients as they were all female.

A study in Canada by Looper and Kirmayer in 2004 reviewed stigma amongst patients with Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Irritable Bowel Syndrome (IBS) and Multiple Sclerosis (MS). Patients with organic illnesses were not subjected to perceived stigma compared to those patients where no diagnostic test could be used to diagnose their illness (namely, CFS, IBS and FM). It is worth noting that not long ago, MS patients were treated as psychiatric patients because their disorder could not be diagnosed.

Another study was also conducted examining the stigmatization of people with chronic back pain (Holloway et al., 2007). Stigmatization emerged as a key theme from the narrative accounts of participants. The finding suggest that patients with chronic back pain feel stigmatized by the time they attend the pain clinic and this may affect their attitudes and behaviors towards those offering professional help. Pain management programs, the authors concluded, need to address the realities and practicalities of dealing with stigma in everyday life.

Another study looked at the stigma of mental illness, specifically the anticipation of attitudes to stigmatization among patients with epileptic, dissociative or somatoform pain disorder (Friedl et al., 2007). In this study it was noted that the fear of being stigmatized is more pronounced among somatoform pain patients compared to patients suffering from epileptic or dissociative disorders with particular reference to close personal relationships. A limitation of

this study is that the Link's questionnaire used pointed more to mental illness stigma rather than stigma secondary to chronic pain.

Slade et al. (2009) studied stigma experienced by people with nonspecific chronic low back pain (NSCLBP). Their objective was to determine participant experience of exercise programs for NSCLBP. It was shown that people with NSCLBP experienced both subtle and overt stigma. The following sub-themes emerged: Stigma is applied by healthcare providers, by friends, family, the community, and the workplace. Once again, it was concluded that chronic pain clinics need to be aware of the impact of stigma. The limitation of this study included its narrative nature and like previous surveys, the fact that the responses were based on patient recall of their experience.

In summary, chronic pain is conceptualized according to the bio-psycho-social-spiritual model. Illness stigma is one psychosocial factor associated with depression (Fife et al., 2000), decreased self esteem (Berger et al., 1998), strained relationships (Gouvier et al., 1994; Jones et al., 1984), and decreased quality of life (Asbring et al., 2002). Illness stigma develops in the context of psychological cause, perceived controllability and severity of significant factors. These factors are relevant to understanding the potential for stigma related to chronic pain. Due to the fact that the cause of the pain is frequently unknown, chronic pain is often associated with a psychological cause as a fall back for many health care providers and others around the patient. Illnesses associated with psychological causes are highly stigmatized (Weiner et al., 1993). Stigma is related to the failure to control one's pain, thereby being seen as weak willed. Stigma from disability arises from many aspects of daily life including lack of paid work productivity. The bias against opioid usage is another source of stigma. In existing research, physicians are repeatedly found as a cause of stigmatization.

In light of the many sequelae of stigma, the effectiveness of chronic pain clinic programs will be limited if stigma is not addressed.

The studies thus far have supported the existence of perceived stigma amongst patients with chronic pain (Marbach et al., 1990; Asbring et al., 2002; Reed, 2006; Decety et al., 2010). Upon review of these studies, they are all qualitative studies with the exception of the study by Reed (2006), it being the only one with a subjects with varied chronic pain syndromes and the first to develop and use the CPSS. Unfortunately, despite the high quality of the Reed dissertation methodology and reporting of results, that dissertation was never published for reasons unknown to this author.

#### I.2 Development of Chronic Pain Stigma Scale by Reed (2006)

The unpublished dissertation conducted by Reed (2006) led to the development of the Chronic Pain Stigma Scale (CPSS). The CPSS was developed to identify perceived stigma from several sources (viz. from physicians, family and the public). The study revealed perceived stigma from physicians in 51% of patients, from the public in 62% of patients and from family in 23% of patients. The strengths of this study were its implementation of the CPSS, the inclusion of subjects with different chronic pain syndromes and its inclusion of both genders. Reed (2006) in her unpublished study, conducted a comprehensive review of perceived stigma in chronic pain patients. The sample population consisted of 150 adults with moderate to severe chronic pain due to low back pain or osteoarthritis. Subjects were randomly selected from a private practice pain management and orthopedic medical offices in the San Francisco Bay area. Participants completed several self-administered questionnaires including the Beck Depression Inventory- II (BDI-II), medical outcomes survey short form - 36 (SF - 36) and the CPSS. The CPSS was a 30-item Likert-type

self-administered questionnaire designed for this study and designed to evaluate the degree of perceived stigma across sources and hypothesized dimensions of chronic pain stigma. Each item on the scale was a statement of a hypothesized attitude toward people with chronic pain. Twenty items were worded to express negative attitudes and 10 items had positive or neutral wording. There were 6 response options: strongly agree (6), agree (5), somewhat agree (4), somewhat disagree (3), disagree (2) and strongly disagree (1). A composite score was obtained by summing the values of each source subscale (public, physicians and family). Stigma score, which was the mean of the subscale scores, was then calculated. The CPSS was designed to measure the degree of stigma from three potential sources (the public, physicians and family). Each of these subscales contain 10 items. The items on the CPSS were developed to address the hypothesized chronic pain stigma dimensions of estrangement, attribution to psychological cause, bias against opioid analgesics, malingering and general negative attitudes. The items were reviewed by a group of health psychology doctoral students, a health psychology faculty member, a postdoctoral student specializing in health psychology and a physician specializing in pain management in order to evaluate clarity, level of reading required (approximately sixth grade level) and face validity.

Construct validity of the CPSS was evaluated by principal component factor analysis. A factor loading of 0.40 was chosen as the lowest acceptable loading for items to be included in the interpretation of each factor. A factor loading of 0.40 is considered appropriate for exploratory factor analysis.

Criterion validity was assessed by correlating composite scores of the CPSS with scores on the BDI-II and the MCS of the SF - 36. The BDI-II and the MSC of the SF - 36 were chosen because previous research has shown a

positive correlation between perceived stigma and depression (Fife & Wright, 2000; Herek, 1999; Richards et al., 2001) and a negative correlation between perceived stigma and quality of life (Asbring & Narvanen, 2002; Link et al., 2001; Perrott et al., 2000).

Discriminant validity was evaluated by correlating CPSS composite scores with physical function impairment as measured by the PCS of the SF - 36. This scale was utilized because several studies have provided evidence that there are no correlations between actual physical impairment and perceived stigma in people with a variety of medical conditions (Fife & Wright, 2000; Perrott et al., 2000; Vamos & Kolbe, 1999). Internal consistency was assessed by Cronbach's alpha and corrected item total correlations. High alpha reliability was found for the total CPSS (0.91), as well as for each of the subscales (Public = 0.81, Physician = 0.83 and Family = 0.91).

Construct validity was evaluated by principal components factor analysis with Varimax rotation, resulting in factors with Eigen values greater than 1.0. The factor structure of the CPSS was consistent with the hypothesized sources (general public, physicians, family), but did not support the hypothesized dimensions of Chronic Pain Stigma (estrangement, attribution to psychological cause, bias against opioids, malingering and general negative attitudes). The highest degree of mean perceived stigma was from the general public with a mean agreement response of 62%, compared to 51% from physicians and 23% from family. No differences were found for the variables of age, gender, marital status, level of education, type of pain condition or severity. The strengths Reed's (2006) study included the development and validation of the CPSS in a fairly heterogenous population profile and its inclusion of both genders. The limitations were its cross sectional design, and the dependence on patient recall. Reed's

study concluded that CBT may be an effective intervention to target stigma. The author designed this study using CBT to address targeting stigma. Stigma was assessed using the CPSS at various time intervals. Subjects were broadly reflective of patients attending a pain clinic, namely both genders and patients experiencing various types of pain syndromes, were included. This study had the strengths of Reed's study compared to previous studies done, namely the mixed sample population and the utilization of the CPSS, as well as a cross-sectional design with the exception that the CPSS was measured at various points during this study with the intention of detecting any changes in the CPSS scores.

### I.3 Objectives & Hypotheses

The purpose of this study was to track changes in perceived stigma in individuals receiving CBT at the University of Alberta Hospital Multidisciplinary Pain Centre (UAH-MPC) for chronic pain. The intention was to reveal trends in clinical outcomes that could be used to improve general clinical practice and to tailor clinical practice to meet the identified needs of clinical clients (quality control).

- 1) The primary hypothesis was that patients with chronic pain syndromes who completed eight standardized CBT sessions would report decreased stigma for having chronic pain.
- 2) Secondary hypotheses were that patients would:
  - Report decreased disability post CBT.
  - Report decreased depression post CBT.
  - Report decreased anxiety post CBT.
  - Report improved quality of life post CBT.

## **II. Methods**

A sample of 101 patients was recruited from the UAH-MPC and they were divided using a randomization protocol set out before the study into three groups of participants. Of these patients, 71 completed the entire study, giving a completion rate of approximately 69%. The 30 subjects who did not complete the study did not submit one or both of their questionnaires. Participants were randomized into one of two groups that included: 1) patients attending with a family member for the first session, 2) attended the first session on their own. A third group was recruited from individuals on the pain centre's wait list who had not yet received Pain 101 programming. Individuals randomized to the family group who either did not have a significant other, family member, or friend who could attend the first group session with them, we allocated to the treatment group whose family members did not attend. This occurred in seven instances for a variety of reasons including that family members were unable to attend a group session at the last minute. Patients were screened by the primary investigators for suitability to attend a CBT-based, standardized pain management group (named PAIN 101). CBT was planned for a weekly basis to a total of eight sessions. The CPSS was filled out at the beginning of the therapy and again at the end of the final group session for all three groups. The wait-list group also had the CPSS filled out at the beginning of the first week and again after 8 weeks time frame to coincide with the CBT groups' time frame. Other measures were also included that assessed depression and anxiety (Hospital Anxiety & Depression Index - HAD), pain severity (McGill Pain Questionnaire - MPQ), pain-related disability (Pain Disability Index – PDI) and quality of life (15D) in these patients. The data also collected were gender, age, medical history including a diagnosis and etiology of pain (if known), and the chronicity of pain. Informed

consent was obtained from all participants in accordance with the University of Alberta's Faculty of Medicine & Dentistry's Human Research Ethics Board requirements. Questionnaires were either distributed in person at the time of the first CBT session or at a scheduled clinic follow-up visit in the first two groups or mailed to the wait-list group at the appointed measurement time. Questionnaire packages that were mailed to patients and their families included a self-addressed stamped envelope to cover the cost of return postage.

### II.1 Inclusion/Exclusion criteria

Inclusion criteria were:

- 1) Patients between ages 18+ years with a chronic pain syndrome.
- 2) Patients with chronic pain referred for group cognitive behavior therapy.

Patients excluded from this study were:

- 1) Patients who were assessed as experiencing a psychotic disorder.
- 2) Patients acutely suicidal.

All patients were screened for exclusion criteria by a registered psychologist or psychiatry resident.

The following questionnaires were distributed to all patients at the time of initial assessment (baseline measure) and at eight weeks.

- i. Chronic Pain Stigma Scale (CPSS; Reed, 2006): This is a 30-item Likert-type instrument measuring patients perceptions of stigma from 3 sources (general public, physicians and family) and across several hypothesized dimensions of chronic pain stigma (estrangement, attribution to psychological cause, malingering, bias against opioid analgesics and general negative attitudes). Patients were required to circle their response. The items were rated on a continuum of strongly agree to strongly disagree.

- ii. Hospital Anxiety & Depression Index (HAD; Zigmond, & Snaith, 1983): This questionnaire consists of a list of 14 situations that describe how a person might feel on a regular basis, of which 7 items query depressive symptoms and 7 items query symptoms of anxiety. The patient is required to place a tick in the box next to the reply that comes nearest to how they have been feeling in the past week. Items are rated on a 4-point scale (0-3). Scores on each subscale range from 0-21.
- iii. McGill Pain Questionnaire (MPQ; Melzack, 1975): The MPQ provides measures of the sensory, affective, and evaluative aspects of pain. This questionnaire is widely used because of its ability to measure these different aspects of pain and its sensitivity to differences in different qualities of an individual's pain. Patients are asked to place a check mark beside each word that best describes their pain, from a selection of 78 adjectives. In a drawing, they are asked to shade in the areas that correspond to where they feel pain. In addition, the patient rates the overall intensity of pain on a visual-analogue scale (1 to 10), and a "present pain intensity" by choosing an appropriate word (this is a 0 to 5 scale).
- iv. Pain Disability Index (PDI; Pollard, 1984): Measures difficulty and disability in everyday functioning due to pain. The PDI examines respondents' levels of perceived disability due to pain in 8 domains of daily living. The patients were asked to circle the number on the scale of 0 to 10 that best describes the level of disability they typically experience due to their pain.
- v. Quality of Life Questionnaire (QOL) (15 D; Sintonen & Pekurinen, 1993): This 15-item measure provides information regarding health-related areas that include limitations in physical activities because of health problems,

limitations in social activities because of physical or emotional problems, limitations in usual role activities because of health problems, general mental health (psychological distress and well-being), limitations in usual role activities because of emotional problems, vitality (energy and fatigue), and general health perceptions. Patients were asked to place a cross against the response which best describes his/her present health status.

In brief, the eight standardized CBT sessions that were carried out focused on the following content with the aim of increasing function, reducing pain-related disability, and improving quality of life. Pain intensity reduction was not a primary focus of the program.

The content of session one involved pain education. There was an overview of common problems related to having a chronic pain syndrome (physical effects including de-conditioning, family changes, social changes, employment issues, dealing with relevant professionals, emotional effects) and an introduction of the bio-psycho-social model of chronic pain. 'Hurt versus harm' and differences in acute versus chronic pain were described. The Gate Control Theory was reviewed as were the bio-psycho-social factors that amplify pain. The definition of differences between addiction, physical tolerance, and physical dependence regarding medication was described. A strong emphasis was placed on the importance of the patient controlling life, not pain controlling life.

A brief overview of the sessions to follow was done. The goals were validation of the biological nature of chronic pain syndrome, discussion of psychological and social implications of chronic pain syndromes and an introduction of key concepts and aims of psychological pain management sessions at MPC. The initial session homework involved discussing session content with a family member or a close friend.

The second session dealt with the vicious cycle of chronic pain, stress and muscle tension. The content included a brief review of the previous session, an introduction to the vicious cycle of pain, an introduction of relaxation techniques (diaphragmatic breathing, progressive muscle relaxation, imagery) to break this vicious cycle and an instruction on use of a relaxation diary. The vicious cycle entails the impact of stress and depression on chronic pain and vice versa. The goals were to increase patients' awareness of the vicious cycle and help them understand the importance of consistent practice with relaxation techniques. The session homework included 4 to 6 relaxation exercises per day and completion of a relaxation diary.

The third session dealt with pacing. The content included a review of relaxation diaries, an introduction of concept of activity cycling (over-activity on good days and under-activity on bad days), a review and elaboration of the vicious cycle of pain, inactivity, and de-conditioning, a review and elaboration of the concept of hurt versus harm, a review and elaboration of the concept of acute versus chronic pain, an emphasis on prioritizing, planning and pacing. The concept of physical tolerance levels and how to calculate them was introduced and examples of successful pacing programs for patients with chronic pain were given. The goals included helping patients notice if they are engaged in activity cycling and helping patients see the value of reconditioning using pacing. The session homework involved considering three activities that patients would like to increase in their lives, calculating tolerance times for these activities and experimenting with pacing in everyday activities. Patients were provided with another relaxation diary and asked to continue to keep this diary.

The fourth session dealt with depression and negative thoughts. The content involved a review of relaxation diaries, a review of tolerance times

calculated for pacing, problem solving homework assignments and an introduction of a cognitive behavioral model where thoughts, mood, and behaviors affect each other and affect pain in a reciprocal manner. There was a review of the vicious cycle between thoughts, mood, behaviors, and pain. There was also an introduction of the concept of monitoring and challenging negative thoughts and a provision of alternative ways of thinking to challenge negative thoughts. A simple thought diary was given to patients to challenge negative thoughts. The goal was to increase patient's awareness of effects of the vicious cycle between thoughts, mood, behaviors, and pain. Another goal was to help patients see the value of monitoring and challenging negative thoughts. The session homework was completion of a thought diary, experimenting with pacing in everyday activities, continuing with relaxation exercises and recording progress in a relaxation diary.

The fifth session dealt with coping with stress and anxiety. The content involved a review of relaxation diaries, a review of tolerance times calculated for pacing (gradual increases in time levels discussed), a review of thought diaries, problem solving with homework assignments, a discussion of effects of stress and anxiety on muscle tension and pain, a discussion of physical effects of stress and anxiety including muscle tension, headaches, gastrointestinal changes and others, a discussion of common daily hassles, a discussion of specific idiosyncratic stressors, a discussion of importance of preparing for stressful situations, and a discussion of coping strategies for dealing with stress and anxiety. The goals included increasing patients' awareness of effects of stress and anxiety on pain and increasing patients' awareness of general and specific personal stressors. The session homework involved making a list of personal stressors.

The sixth session dealt with communication and pain behavior. The content included a review of relaxation diaries, a review of tolerance times calculated for pacing and a review of a setback plan. Problem solving with homework assignments was done. There was a discussion of common problems with communication in patients with chronic pain and a discussion of strategies for discussing one's pain appropriately. The goal was to help patients contemplate the importance of effective communication for issues related to pain and more general life issues. Patients also had to set 1 to 2 goals aimed at helping them improve their communication with people around them. The session homework included goals as mentioned above.

The seventh session dealt with planning for and dealing with setbacks. The content involved a review of relaxation diaries, a review of tolerance times calculated for pacing, a review of thought diaries, a review of personal list of stressors, problem solving with homework assignments, a discussion of how to deal with setbacks using previously introduced coping strategies, a discussion of other individual strategies developed by patients to deal with bad pain days and a discussion of how to make a setback plan. The goals included helping patients realize that bad days are a normal part of life and helping patients formulate a personalized setback plan. The session homework involved complete a setback plan.

The eighth session dealt with pain and everyday life. The content included a review of previously discussed topics and coping strategies, a review of tolerance times calculated for pacing, discussion of progress with communication goals from session seven, problem solving with homework assignments, a discussion of a variety of topics involving work, leisure activities, everyday challenges and sleep difficulties, a re-emphasis of the nature of chronic pain, a

re-emphasis of life despite pain, a review of hurt versus harm and a re-emphasis of importance of the patient controlling life, not pain controlling life. The goals were to remind patients of general concepts emphasized during previous sessions and to help patients view chronic pain within the broader context of life. The session homework included the use of techniques discussed in previous sessions.

A research assistant was responsible for organizing the mail-out and collection of forms for the patients who were not actively receiving treatment (the wait-list group). Data was collected from patients prior to their involvement in Pain 101. These data were collected by the research assistant and computed. The data had been anonymous and kept in storage before analysis (anonymously). The data were checked for coding errors. Thirty patients did not submit their questionnaires, and unfortunately the 15 D questionnaires were omitted in the waitlist control group.

The primary hypothesis was to track changes in perceived stigma in individuals receiving CBT at the University of Alberta Hospital Multidisciplinary Pain Centre (UAH-MPC) for chronic pain. The intention was to reveal trends in clinical outcomes that could be used to improve general clinical practice and to tailor clinical practice to meet the identified needs of clinical clients (quality control). Analysis of changes in questionnaire outcome results was carried out using SPSS - Version 17. Repeated measures ANOVAs were carried out. Post-hoc analysis used Bonferroni corrections to control for the inflation of alpha. Forward stepwise multiple regression techniques were used to investigate variables that predicted stigma and disability.

### III. Results

In this study, the sample population ranged from 18-71 yrs. Subjects were experiencing pain from a variety of body sites. They included males and females and had experienced chronic pain for an average of 10 years (Table 12).

**Table 12: Descriptive Characteristics of Sample**

	<b>Group 1 (CBT alone) n=26</b>	<b>Group2 (CBT with family) n=23</b>	<b>Group3 (Waitlist control) n=22</b>
<b>Age (Mean, range)</b>	47.8 yrs; 18-69 yrs.  (SD = 6.3)	42.6yrs.; 18-70 yrs.  (SD = 17)	49.7yrs; 27-71 yrs.  (SD = 12.3)
<b>Gender M:F</b>	9:17	6:17	7:15
<b>Duration of Pain at initial CPSS/Pain 101 (Date, year, median range in years; each month = 0.83)</b>	9.8 yrs; 1-19 yrs.  (SD 13.9)	12.1 yrs; 2-36 years  (SD = 10.9)	11.6 yrs; 0.5-36 yrs.  (SD = 8.5)

A forward stepwise regression was carried out to ascertain whether pre-treatment perceived stigma was predicted by one or more of pre-treatment levels of pain, pain-related disability, anxiety, depression, or quality of life. While depression ( $r = .50$ ,  $p = .001$ ), anxiety ( $r = .39$ ,  $p = .006$ ), and quality of life ( $r = .47$ ,  $p = .001$ ) were all significantly correlated with perceived stigma, only depression ( $p = .001$ ) significantly predicted perceived stigma before treatment

(Tables 13 and 14). Pre-treatment depression accounted for 24.6% of variance in pre-treatment levels of perceived stigma.

**Table 13: Correlation of Pre-treatment Stigma with other Variables**

	<b>CPSS</b>	<b>McGill</b>	<b>PDI</b>	<b>HAD-A</b>	<b>HAD-D</b>	<b>15-D</b>
<b>CPSS</b>		0.164 0.155	0.066 0.344	<b>0.393</b> <b>0.006</b>	<b>0.496</b> <b>0.001</b>	<b>-0.469</b> <b>0.001</b>
<b>McGill</b>	0.164 0.155		0.069 0.337	<b>0.266</b> <b>0.048</b>	<b>0.330</b> <b>0.019</b>	<b>-0.437</b> <b>0.002</b>
<b>PDI</b>	0.066 0.344	0.069 0.337		0.072 0.329	<b>0.433</b> <b>0.003</b>	<b>-0.342</b> <b>0.015</b>
<b>HAD-A</b>	<b>0.393</b> <b>0.006</b>	<b>0.266</b> <b>0.048</b>	0.072 0.329		<b>0.414</b> <b>0.004</b>	<b>-0.526</b> <b>0.000</b>
<b>HAD-D</b>	<b>0.496</b> <b>0.001</b>	<b>0.330</b> <b>0.019</b>	<b>0.433</b> <b>0.003</b>	<b>0.414</b> <b>0.004</b>		<b>-0.655</b> <b>0.000</b>
<b>15-D</b>	<b>-0.469</b> <b>&lt;0.001</b>	<b>-0.437</b> <b>0.002</b>	<b>-0.342</b> <b>0.015</b>	<b>-0.526</b> <b>0.000</b>	<b>-0.655</b> <b>0.000</b>	

**Table 14: Multivariable Correlation of Pre-Treatment Indices with Pre-Treatment CPSS**

<b>Variable</b>	<b>Beta (B)</b>	<b>P&lt;B</b>
PRI /McGill	0.01	0.997
PDI	-0.184	0.244
HAD-A	0.227	0.145
<b>HAD-D</b>	<b>0.496</b>	<b>&lt;0.001</b>
15-D	-0.252	0.179

There were no significant overall changes in perceived stigma levels found in the pre- vs. post-test results examining percent agreement for perceived stigma related to physicians, the general public, or from family members (Table 15). A subsequent post-hoc t-test showed that perceived stigma was significantly reduced in the Family group at the time of post-testing ( $p = .026$ ). This finding suggested that for patients who had a family member attend the first session of Pain 101, the perceived level of stigma from physicians was significantly decreased.

**Table 15: Effect of Treatment on Stigma Perception**

		<b>Group 1 (CBT) n=26</b>	<b>Group 2 (Family) n=23</b>	<b>Group 3 (Waitlist control) n=22</b>
<b>Stigma from Physicians (%, <math>\pm</math>, SD)</b>	<i>Baseline</i>	54.2 $\pm$ 27.2	61.3 $\pm$ 26.2	42.3 $\pm$ 26.7
	<i>Post</i>	56.2 $\pm$ 30.2	50.9 $\pm$ 26.4	45.5 $\pm$ 30.4
	<i>Pre-Post (p-value)</i>	.688	<b>.026</b>	.374
<b>Stigma from Public</b>	<i>Baseline</i>	73.5 $\pm$ 21.5	76.5 $\pm$ 19.4	57.7 $\pm$ 29.6
	<i>Post</i>	71.9 $\pm$ 26.1	71.7 $\pm$ 26.4	59.5 $\pm$ 29.7
	<i>Pre-Post (p-value)</i>	.603	.298	.751
<b>Family</b>	<i>Baseline</i>	26.9 $\pm$ 29.0	31.3 $\pm$ 26.9	18.2 $\pm$ 26.5
	<i>Post</i>	33.1 $\pm$ 33.9	31.7 $\pm$ 26.4	20.9 $\pm$ 25.2
	<i>Pre-Post (p-value)</i>	.103	.928	.572

The effect of the Pain 101 program on other indices is shown in Table 16. The pain disability index ( PDI) significantly decreased after attending the CBT program. There had been a significant reduction in the anxiety scores as evident on the HAD-A scores.

**Table 16: Effect of Treatment on Other Indices**

		<b>Group 1 (CBT)</b>	<b>Group 2 (Family)</b>	<b>Group 3 (Waitlist control)</b>
PRI /McGill	<i>Baseline</i>	42.3 ± 19.3	42.4 ± 17.0	37.8 ± 17.8
	<i>Post</i>	38.8 ± 21.5	43.0 ± 14.8	40.4 ± 17.7
	<i>Pre-Post (p-value)</i>	<b>.368</b>	<b>.649</b>	.317
PDI	<i>Baseline</i>	9.0 ± 1.7	9.57 ± 1.3	7.86 ± 1.9
	<i>Post</i>	6.0 ± 2.4	5.9 ± 1.6	8.79 ± 2.3
	<i>Pre-Post (p-value)</i>	<b>.033</b>	<b>.013</b>	.723
HAD-A	<i>Baseline</i>	19.0 ± 4.4	18.0 ± 4.2	18.8 ± 4.7
	<i>Post</i>	11.4 ± 4.2	11.8 ± 4.2	19.1 ± 5.0
	<i>Pre-Post (p-value)</i>	<b>.024</b>	<b>.016</b>	.898
HAD-D	<i>Baseline</i>	12.1 ± 3.2	12.7 ± 2.6	7.8 ± 4.4
	<i>Post</i>	10.1 ± 4.1	10.1 ± 3.9	9.1 ± 5.0
	<i>Pre-Post (p-value)</i>	<b>.079</b>	<b>.061</b>	.350
15-D	<i>Baseline</i>	0.6 ± 0.1	0.6 ± 0.1	Questionnaire omitted
	<i>Post</i>	0.6 ± 0.14	0.5 ± 0.19	Questionnaire omitted
	<i>Pre-Post (p-value)</i>	<b>.146</b>	<b>.410</b>	Questionnaire omitted

#### **IV. Discussion**

This study has its origins in the management of chronic pain patients with an intention to improve their outcome. The primary hypothesis was that a cognitive behavior program which targeted perceived stigma would improve clinical outcomes. We also factored other variables into the study, namely the relationship of stigma with pain related disability, depression, anxiety and quality of life. We found that depression predicts stigma (Tables 13 and 14). Perhaps the fact that our Pain 101 outcomes did not include a significant improvement in depression, is one possible explanation for why stigma did not improve overall (Table 16). We have validated Reed's (2006) findings of stigma from all sources (namely the public, physicians and family members). Reed's study revealed perceived stigma from the general public to be 62%, from physicians to be 51% and from the family to be 23%. Our study mirrors these results in that perceived stigma from the general public is 69%, from physicians to be 52% and from the family to be 25%. Our study also included a varied chronic pain population and, qualitatively, patients of different ethnic backgrounds, although we did not record the latter in our study. Reed (2006) used percentage agreement of the responses to the CPSS in her data analysis. This study did the same to compare data. These findings suggest that the CPSS may be useful in future studies and also add to the current literature of stigma existing amongst chronic pain patients. There is also an element of refinement that was undertaken in the present study in that we have shifted away from the earlier narrative qualitative studies, by using the CPSS, thereby facilitating comparison, not only for this study, but also for future studies. This strengthens the replicability of this study. My findings are consistent with previous research suggesting that people with chronic pain feel stigmatized by the public, their health care providers, and family members. The

current study further supports the idea that stigma is likely very prevalent in patients with chronic pain in various countries including Canada as well as the USA (Reed, 2006). There is no physical and organic cause to be found in many patients with benign chronic pain conditions and this leads to strained relationships between the patient and their treating physicians as well as within their family units (Marbach et al., 1990; Borkan et al., 1995).

Chronic pain syndromes tend to result in stigma for the same reason as mental illnesses, i.e. is because no physical cause is often found for the condition. Hence, chronic pain syndromes are frequently stigmatized. The hypothesis of CBT leading to a change in perceived stigma was studied. To address stigma from families, participants were randomized into a family member group, whereby a family member was invited to the initial psycho-education session of CBT, a second wait-list group (that served as a control group in the study), and a third group of patients who attended the entire program on their own. The strength of the study is the diversity of patients involved, and the various other factors that were studied in addition to perceived stigma (namely, anxiety, depression, pain related disability, and quality of life). There was no significant change in stigma in the pre- and post-CBT perceived stigma ratings. The reason for this could be the lack of a formal session that targeted stigma being included in the CBT program. This is the first study undertaken to address stigma using a CBT program. Despite the lack of an overall significant change between groups pre- and post-CBT, an interesting finding in the analysis of data is the significant decrease (Table 15) in perceived stigma in the family group towards physicians. A postulate is that family members attending the first session improve the alliance of their affected family members by strengthening the “buy in” into the treatment team’s credibility. As already stated, including a family

member in treatment improves outcomes, particularly on a key outcome measure, perceived stigma from physicians. This could possibly improve the affected individuals' strained interpersonal relationships at home. This validation would facilitate improvement and adherence to treatment. Families would be less likely be antagonistic towards treating physicians if they were invited to be part of the treatment program. It also appears to have the potential to decrease stigma. We propose that this could be a function of improved therapeutic alliance.

Studies have shown that strained relations arise within the context of perceived stigma (Gouvier et al., 1994). The significant finding of decreased perceived stigma from family members is worth noting as it could be postulated that taking time to educate family members on chronic pain may improve relationships at home and could possibly improve the outcomes of treatment programs. Studies have explored the relationship of stigma and depression (Friedl et al., 2008). Improved interpersonal relationships were found to lead to improved self esteem and improvement in mood. This is an area that future studies should examine.

We have also extended the literature. Based on the experience and sequelae of stigma in patients with mental illness, namely strained interactions (Jones et al., 1984; Gouvier et al., 1994), poor quality of life (Asbring et al., 2002), and depression (Friedl et al., 2008). I investigated the relationship of these variables and stigma. In this study, I did notice that in the family groups there was a significant worsening of depression. Previous research has shown that patients' with depression experienced stigma in patients with somatoform illnesses ( Friedl et al., 2008). We did not show this relationship but our limitation could have been study size.

Another hypothesis was a reduction in anxiety after CBT. Anxiety was significantly decreased across participants (Table 16). This could be attributed to the CBT program as CBT is an evidence based treatment option for anxiety. A limitation of my study is the lack of clarifying the type of anxiety disorder the participants were experiencing. It would seem reasonable to assume (based on clinical experience) that generalized anxiety symptoms/disorder would be highly prevalent in patients with chronic pain. Since stigma was not significantly reduced pre- and post-CBT, it could be postulated that the anxiety response was not related to stigma in this study. This is the first study to review the relationship of stigma and anxiety.

Friedl et al. (2008) looked at depression and somatoform pain disorder but not anxiety. The current study included an investigation of depression but did not show a significant change in response to treatment (Table 16). Stigma, and even the chronicity of patient's illness, could pose a confounder to response to CBT (although this relationship was not looked at). As noted already, our CBT program was also found to be effective in reducing anxiety in our patients, a pervasive issue in chronic pain (in more than eighty percent of patients (Asmundson et al., 2009). Anxiety and depression are often co-morbid with chronic pain conditions (Friedl et al., 2008). CBT is helpful for anxiety and, having targeted this in the program, we aimed to improve the overall well being of the individuals affected. The neurobiology discussed earlier described psychiatric conditions like depression and anxiety affecting patients' with chronic pain (Borsook et al., 2003). Hence, effective anxiety treatments including CBT and psychotropic medication could help patients with chronic pain but only if the treatment team reflect this as an important component of the treatment versus

the pain being “all in the patient’s head”. Perceived stigma could lead to suboptimal outcomes in rehabilitation programs.

The CBT program’s primary focus is empowering patients on a self management model to reduce disability and improve their quality of life. This was detected in our study. Table 16 shows a significant difference in the PDI post Pain 101. The control group showed an increased level of pain related disability after 8 weeks of no treatment. This supports the construct around which this program is conducted, namely to reduce pain related disability. Reduced pain related disability would certainly have an impact on a patient’s overall well being. There would also be a greater motivation to participate in programs. This could have a positive impact on reducing depressive symptoms, anxiety symptoms, and improve quality of life and reduce stigma. To strengthen the efficacy of Pain 101, a session on stigma could be considered in future studies. This is a limitation of our study.

Studies on stigma in chronic pain have revealed a poor quality of life outcomes (Asbring et al., 2002), and our study attempted to show the relationship between stigma and quality of life. Unfortunately the 15 D - QOL questionnaires were omitted in the questionnaire package in the control groups, thus there was no comparison group.

Our study did look at any prediction that could be made by performing a regression analysis on the key variables and stigma. The pre-CBT factors that predict stigma revealed depression to be of significance (Table 13 and 14). This supports the findings of Friedl et al. (2008) of a significant relationship between depression and somatoform pain disorder. This also fits with the findings of Reed (2006) of a positive correlation between depression and stigma. This phenomenon has already been described, whereby individuals with stigma have

decreased self esteem and strained relations that lead possibly lead to their depressive symptoms (Jones et al., 1984).

In my study, patients had chronic pain for about 10 years before being involved in treatment. Patients with chronic pain would most likely benefit from early referrals to multidisciplinary pain clinics and from early involvement in a CBT program like Pain 101.

My data also shed light on key factors to target in treatment and indicate that stigma may be one of these primary factors. Other important targets should include reducing disability, improving quality of life, and effective pain management. Stigma leads to poor self esteem and poor quality of life. Thus targeting stigma would help improve both of these, although this study did not have a session dedicated to targeting stigma in the CBT program. Despite this, there was an improvement in disability. We could further enhance this effect by refining our CBT program and including a session targeting stigma.

My study aimed to review the effects of CBT on perceived stigma. However, it is unknown how the therapeutic alliance with the multidisciplinary team affected stigma. Future research could identify the potential effects of early referral to a chronic pain service. With early referrals to the multidisciplinary chronic pain service, stigma may be reduced and thereby improve the outcome. My program looked at helping target stigma in the individual but, having a wider educational program educating health professionals on the realities of stigma in the chronic pain patient could improve treatment outcomes.

The strengths of this study are its design and the fact that it is the first published data describing the relationship of stigma, chronic pain and other associated factors that have a relationship with stigma. This is the first and only study of a CBT program being used to address stigma. The population used in

the program is generalizable to the chronic pain patients who may attend most multidisciplinary pain clinics. This research adds to the current limited data on stigma, serves as a possible template for further research and has highlighted areas of improvement/refinement to address stigma. The study, despite being held in Edmonton, Canada, found similar results of perceived stigma to a study done on chronic pain patients in the USA (Reed, 2006).

As mentioned, Reed (2006), did not publish her data except in dissertation form. Interestingly, the current study mirrors her findings on perceived stigma. It is the first study that attempted to study factors that could predict and target treating stigma. The CBT program has revealed significant clinical utility that further adds to the literature that CBT is an important treatment modality for chronic pain.

#### IV.1 Limitations

This study only looked at stigma on a cross-sectional basis at different points. The report of stigma depended on patient recall that may not be completely accurate. The CPSS lacks of a cut-off rating for stigma on the rating scale. Hence, we cannot assess if the stigma has completely resolved. Our intervention aimed at targeting the perception of stigma. Unfortunately the CBT program did not dedicate sessions specifically targeting stigma. Future research is warranted and it is recommended to include a session targeting stigma.

Limitations of our CBT program were that we did not use a completely scripted program and there was a small amount of variability that existed in the content of sessions between groups. However, it is a part of standard clinical care to tailor the therapy to groups. The heterogeneity of the sample is a strength from a generalizability standpoint but it may have negatively affected the results because of the considerable inter-individual variability. Another limitation is that

we did not measure therapeutic alliance, and the effect of this factor therefore remains unknown. Both quantitative and qualitative future studies could add a great deal in finding out what other factors play a role in perceived stigma. I also did not control for medication use, and there was a great deal of variability in this aspect.

## **V. Conclusion**

My study highlights that stigma is very prevalent in chronic pain patients. This is a phenomenon that is often overlooked but may be an important factor in treatment outcome. The fear of stigma and the lack of self esteem increases the likelihood of patients failing to adhere to treatment recommendation. It is proposed that health care providers, pain management programs, and society in general consider the reality of stigmatizing interactions in everyday life of individuals with chronic pain. Confronting stigmatizing interactions in management programs is recommended. The goal of future research should be to refine techniques to target stigma in order to help improve clinical outcome.

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