

# Prevalence of Stigmatization and Poor Self-esteem in Chronic Pain Patients

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## Abstract

**Objective:** Stigma and poor self-esteem (defined as the internalized cognitive, emotional, and behavioural impact of others' negative attitudes on a person) are associated with many chronic health conditions and have indirect but strongly negative implications for clinical prognosis. We sought to estimate the prevalence of perceived stigmatization and self-esteem in chronic pain patients and its relationship with general health markers.

**Methods:** All adult patients (n=160, >18 years old, chronic pain >3 months) completed a set of validated questionnaires; Stigmata Scale for Chronic Illness (SSCI), Rosenberg's Self-esteem Scale (RSES); Hospital Anxiety Depression Scale (HADS); Brief Pain Inventory short form (BPI); and the General health survey (SF12v2). Data was recorded using Microsoft Excel and analyzed using SPSS.

**Results:** The mean pain intensity score (Visual analogue score (VAS)) was  $6.1 \pm 1.7$ . 77% of patients (123/160) had a lowered self-esteem (RSES score= $17.2 \pm 14.5$ ) with a mean SSCI score of  $50.8 \pm 19.0$  (normal range 24-120). An inverse relationship between (a) stigmatization and self-esteem (Pearson correlation,  $r=.58$ ,  $p<0.001$ ) and (b) self-esteem and pain interference ( $r=.48$ ,  $p<0.001$ ) was identified. A positive correlation between stigmatization and anxiety ( $r=.228$ ,  $p<.05$ ) and an inverse relationship between self-esteem and depression existed ( $r=.234$ ,  $p<.05$ ).

**Conclusions:** A high prevalence of stigmatization was identified in individuals experiencing chronic pain and a significant correlation exists between the type of stigma experienced, the level of pain intensity and other psychological factors including self-esteem, anxiety, and depression

**Keywords:** Chronic pain; Stigmatization; Self-esteem

## Introduction

Stigma is defined as social devaluation or discrediting of an individual as abnormal, and has been identified as an important construct in the outcome of many chronic health conditions [1] such as mental illness epilepsy, inflammatory bowel disease and HIV infection [2-5].

Typically the process of stigmatization evolves from an individual's awareness of a negative stereotype to an acceptance that the negative stereotype applies to them and ultimately ends in lowered self-esteem [6]. In addition, stigma has indirect but strongly negative implications for psychological stress, quality of life and for public health efforts to combat the diseases as illustrated by conditions HIV and mental health.

The nature of chronic pain as a lifelong, concealable illness, indiscriminate of age or gender that is associated with a significant burden in terms of both symptoms and treatments places individuals at risk for stigmatization. Clinical outcome in chronic pain patients is often objectively measured by changes such as symptoms, frequency of socialization, and employment [7] as well in terms of more internally experienced and subjectively measured domains such as perceived quality of life and sense of purpose in life [8,9]. Self-esteem and the factors associated with chronic pain and stigmatization have not been examined to date.

The objective of this study is to (a) report the prevalence of stigmatization in chronic pain patients and (b) to explore how anticipated stigma undermines the individual's self-esteem and quality of life in those diagnosed with chronic pain syndromes. Our hypothesis is that the personal experience of suffering chronic pain and the transformation of identity that will accompany this experience would alter the way people perceive and feel about themselves and potentially be an inhibitor of recovery among those with this long term medical condition.

## Methodology

### Study participation

With local research ethics committee approval and using a cross-sectional, anonymous and convenience sampling study design, all adults (>18 years) attending a chronic pain clinic were asked to complete a set of questionnaires before their appointment. Exclusion criteria included (i) a diagnosis of mental illness from a mental health professional, (ii) the inability to read English, (iii) age <18years or, (iv) the individuals refusal to participate in the study. A single investigator (MW) explained the questionnaires to each person in turn, ensured that all elements of each questionnaire were completed fully, and was available to answer any issues that arose. All participants were asked to complete the questionnaires in a quiet waiting room setting. No time limitation was enforced but individuals were told the process would take between 10-15 minutes.

### Demographic data

Demographic measures collected included date of birth, diagnosis, duration of pain condition, marital status and employment status.

### Brief Pain Inventory (BPI)

The Brief Pain Inventory assesses pain severity (sensory dimension)

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and interference with function (the reactive dimension). Using a numeric rating scale (NRS) from 0 to 10 the BPI also asks questions about pain relief, pain quality, and the patient's perception of the cause of pain. The BPI asks for ratings of the degree to which pain interferes with mood, walking and other physical activity, work, social activity, relations with others, and sleep. The mean of these scores can be used as a pain interference score. High test-retest reliability has been demonstrated; severity ranging from 0.83 to 0.98, and interference 0.97. Severity correlations range from 0.83 to 0.88 [10]. The Cronbach's alpha coefficient is reported as >0.70 [11].

### Stigma Scale in Chronic Illness (SSCI)

The Stigma Scale in Chronic Illness is a 24-item scale where individuals are asked to score the impact their illness has on functional and emotional elements. It has demonstrated good internal consistency, convergent validity, and IRT model fit. Confirmatory Factor Analysis produced high-standardized loadings on an overall stigma factor (0.68 to 0.94) [12].

### Rosenberg's Self-esteem Scale (RSES)

This is a 10-item Likert scale to assess positive or negative feelings about the self. Scores range from 0 to 30 and are computed by summing the responses. Previous research in a Canadian population with chronic illness has used scores of 0-20 as representing low-moderate self-esteem, and 21-24 indicating high self-esteem. The original reproducibility of the scale was 0.92, with a scalability of 0.72 [13]. Cronbach's alpha coefficients for internal consistency range from 0.77 to 0.88 [14].

### Hospital anxiety and depression scale

Depression and anxiety were assessed using the respective subscales of the Hospital Anxiety and Depression Scale. This is a widely used, well-validated questionnaire consisting of 7 items each for anxiety and depression, scored on a 4-point Likert scale from 0-3, with a maximum score of 21. A threshold score of 8+ for both depression and anxiety has been suggested, sensitivity and specificity in the range of 0.70 to 0.90 [15]. Cronbach's Alpha Coefficients range from 0.83 to 0.93. Retest reliability (2 weeks) demonstrates a high correlation,  $r > 0.80$ . The HADs was used to assess for co-existing anxiety and depression, which may act as potential confounders [16].

### General health status: SF 12v2

The SF12v2 provides a measure of general health status allowing participants with co-existing morbidities which may act as confounders to be excluded. It is an abbreviated version of the SF-36v2 Health Survey that uses 12 questions to measure functional health and well-being. The 12 items reflect 8 sub-domains: self-perceived general health, bodily pain, physical functioning, physical role, vitality, social functioning, mental health and emotional role. Both physical and mental component summary scores are generated [17]. Higher scores indicate better functioning and well-being. The mean population score for each is 50 with a SD of 10, based on US norms [18]. US-based norm scoring has been shown to have very little impact when data is collected in Western European countries, and the use of US-derived standard scoring algorithms is recommended [18].

### Data analysis

All replies were documented in writing, transferred to a secure excel database and subsequently stored in keeping with local data protection guidelines. Data analysis was performed using SPSS version 12 (SPSS, Inc., Chicago, IL.) and included normality assessment,

bivariate and partial correlation. Significance was set at  $p < 0.05$ . Scores were calculated for all of the above measures. In order to examine the relative importance of each domain of the stigmata scale index scores were calculated for each subscale by taking the actual score and dividing by the total score possible for that domain. This computation standardized each subscale to allow for direct comparisons of their importance.

### Results

Over a period of 3 months 178 individuals were invited to participate and 160 complete sets of questionnaires were recorded (90% success rate). Overall this represented 22% of all chronic pain outpatients' contacts during this period at the clinic.

### Social demographics

Our study population was predominantly female (67%); the age distribution, chronicity of pain, and pain intensity is represented in Table 1. The majority of individuals were married or had a partner and 58.7% were unemployed.

The mean duration of chronic pain was 7.3 years (range 0.5-56 years). A summary of the origin of the chronic pain is represented in Table 2. The majority of patients reported that pain interfered significantly with daily function as indicated by a high BPI score ( $6.2 \pm 2.0$ ) and a low physical capacity score (Table 3). The Physical component sub-scale assessment on the SF12v2 was reduced by 38% compared to the expected normal range (SF12v2: Physical component  $32.2 \pm 8.2$ ) (Table 3). The total mean stigmatization score was  $49.7 \pm 18.9$  and sub-scale analysis showed that internal stigmatization prevailed to a greater extent compared to external stigmatization with index stigmatization scores of 0.49 and 0.35 respectively (Table 3). 77% of patients (123/160) had a lowered self-esteem (RSES score= $17.2 \pm 14.5$ ). No relationship between patient age ( $r = -0.03$ ,  $p = 0.6$ ) or gender and stigmatization was identified.

A significant inverse relationship was identified between the total stigmatization, the internal and external stigmatization subscales and self-esteem. (Pearson correlation,  $r = -.48$ ,  $p < 0.001$ , (Table 4)). A low but significant correlation existed between self-esteem and pain interference (Pearson correlation:  $r = .27$ ,  $p < 0.001$ ). Partial correlation analysis failed to demonstrate a statistically significant relationship between stigmatization and self-esteem ( $r = .174$ ,  $p = 0.04$ ). A positive correlation between stigmatization and anxiety ( $r = .23$ ,  $p < 0.05$ ) and an inverse relationship between self-esteem and depression existed ( $r = .23$ ,  $p < 0.05$ ).

### Discussion

The key findings of this study are (i) prevalence of stigmatization was identified in individuals experiencing chronic pain was high, and (ii) a significant correlation exists between the type of stigma experienced, the level of pain intensity and other psychological factors including self-esteem, anxiety, and depression. We also report no significant differences in the levels of experienced stigma based upon age, duration of chronic pain or gender.

To our knowledge this study uniquely identified the presence of stigmatization in chronic pain patients. This result indicates that the internalized cognitive, emotional, and behavioral impact of others' negative attitudes on a person who possesses a devalued characteristic (i.e. chronic pain) is a real clinical entity. The clinical impact chronic pain has on the psychosocial elements including a lowered self-esteem, depression, and anxiety are consistent with the associations previously

Variable		Total	Male	Female
Age (years)	18-34	8.1% (12)	2.3% (1)	10.9% (11)
	35-44	20.9% (31)	30.2% (13)	16.8% (17)
	45-54	23.0% (34)	16.3% (7)	25.7% (26)
	55-64	23.0% (34)	27.9% (12)	19.8% (20)
	65-74	16.9% (25)	20.9% (9)	15.8% (16)
Duration of Pain (years)	75+	8.1% (12)	2.3% (1)	10.9% (11)
	<1 year	10.7% (16)	13.3% (6)	9.1% (9)
	1-5 years	43.0% (64)	44.4% (20)	41.4% (41)
	5-10 years	21.5% (32)	17.8% (8)	24.2% (24)
	>10 years	24.8% (37)	24.4% (11)	25.3% (25)
Highest level of Education achieved	Primary School	19.9% (29)	25.0% (11)	18.2% (18)
	Junior Certificate or Equivalent	27.4% (40)	31.8% (14)	24.2% (24)
	Leaving Certificate or Equivalent	15.1% (22)	11.4% (5)	16.2% (16)
	Vocational or Technical School	17.8% (26)	22.7% (10)	16.2% (16)
	Diploma, Degree, Masters or higher	19.9% (29)	9.1% (4)	25.3% (25)
Marital Status	Single	18.2% (28)	13.0% (6)	20.4% (21)
	Partner	5.2% (8)	6.5% (3)	4.9% (5)
	Married	61.0% (94)	67.4% (31)	58.3% (60)
	Divorced	6.5% (10)	6.5% (3)	5.8% (6)
	Widowed	9.1% (14)	6.5% (3)	10.7% (11)
Employment Status	Unemployed	63.9% (94)	52.4% (22)	68.3% (69)
	Employed	21.1% (31)	26.2% (11)	18.8% (19)
	Retired	15.0% (22)	21.4% (9)	12.9% (13)
Pain as a factor in occupation	No	18.4% (23)	15.4% (6)	20.7% (17)
	Yes	81.6% (102)	84.6% (33)	79.3% (65)
Annual Income (Euros)	<10,000	46.8% (32)	33.3% (12)	53.4% (39)
	10,000-20,000	30.6% (34)	30.6% (11)	30.1% (22)
	20,000-40,000	14.4% (16)	25.0% (9)	9.6% (7)
	40,000-60,000	5.4% (6)	8.3% (3)	4.1% (3)
	>60,000	2.7% (3)	2.8% (1)	2.7% (2)

Note: The terms "primary schooling" refers to 5-11 years of age; "Junior Certificate or Equivalent" refers to education up to 15yrs old; "Leaving Certificate or Equivalent" refers up to 18 years; "Vocational or Technical School" refers to individuals between 16-18 years; "Diploma, Degree, Masters or higher" refers to third level education where individuals are >18 years

**Table 1:** Shows the demographic details on the cohort for age, duration of pain, and socio-economic status.

Diagnosis	Number (n=160)	%
Lower Back Pain ± radicular pain	80	50%
Neck Pain ± radicular pain	32	20%
Peripheral neuropathy/neuralgia	24	15%
Musculoskeletal Pain (e.g. Fibromyalgia/Arthritis/Chronic Pelvic Pain/ Myofascial Pain)	24	15%

**Table 2:** Summary of chronic pain conditions reported.

reported in areas such as mental illness epilepsy, inflammatory bowel disease and HIV infection [2-5,19]. For example elevated internalized stigma appears to be a clinical issue that affects a substantial number of persons (36%) with severe mental illness such as schizophrenia [20-23]. Likewise 84% of Inflammatory Bowel disease sufferers reported perceived stigma. In fact hierarchical regression demonstrated that perceived stigma accounted for 10%-22% of the variance in health-related quality of life scores, 4%-16% for psychological distress, 5% for medication adherence, 19% for self-esteem, and 8% for self-efficacy [5]. These results suggest that perceived stigma is a significant predictor of poorer outcomes in patients with IBD when controlling

for illness and demographic variables. Perceived stigma is a potentially important psychosocial factor in IBD patient care and warrants further investigation [5].

Self-stigmatization is a dynamic process whereby public attitudes lead to personal responses [12,24]. Initially, when a person with a stigmatizing condition experiences discrimination they become aware of negative stereotypes around their illness. The awareness of the stereotype (i.e. perceived stigma), and the actual experience of a discriminatory behavior, such as social exclusion, is called enacted stigma [13]. In the final step of the process, the person accepts that negative stereotypes apply to them and then internalizes the stereotype (termed internalized stigma). This internalization has negative consequences for the individual (e.g. lowered self-esteem). Our results support the hypothesis that chronic pain can be regarded as a medical condition that alters the way people perceive and feel about themselves and their likelihood to plan and meet their life goals.

This relationship is clinically significant firstly because it may be one factor explaining why some individuals respond better than others to similar treatment protocols and secondly, it highlights the need to assess, and manage, this psychological factor in conjunction with the physical and pharmacological options in those with chronic pain conditions.

The duration of the pain condition does not seem to influence the degree of stigmatization. Individuals in our study report having chronic pain reported at least for 6 months. All types of chronic pain were included with the exception of cancer pain past or present (Table 2). The rate of transition from the enacted to the internalized sub-type of stigmatization needs to be examined because intervening early may prevent the development of the negative consequences. Attention to the stage of the individual treatment and diagnosis should be considered in any future analysis.

Unlike patients with mental illness, where individuals in the 35-54 year age group are reported to have a higher stigmatization score, there was no dissimilarity in the level of stigmatization across the age groups in chronic pain patients.

Item	Mean (± SD)	Range
<b>Pain Intensity (VAS)</b>	6.1 (1.7)	2.5-10
<b>Brief Pain Inventory (BPI)</b>	6.93 (2.0)	2-10
<b>SSCI</b>	49.7 (18.9)	24-118
Internal	31.9 (12.0)	-
Enacted	12.3 (8.6)	-
<b>RSES</b>	17.2 (14.95)	5-30
<b>HADS</b>		
Anxiety	10.7 (4.7)	0-21
Depression	8.6 (4.2)	1-19
<b>SF12v2</b>		
Mental Component	41.5 (10.9)	8.48-70.61
Physical Component	32.2 (8.2)	17.77-53.46

**Table 3:** Shows pain intensity, pain interference, stigmatization (SSCI), Rosenberg's Self-esteem scale (RSES), Hospital anxiety and depression score (HADS) and General health scores (SF12v2) for patients with chronic pain (n=160, mean (SD)).

	SSCI Total	SSCI Internal	SSCI Enacted	RSES
BPI	-.27*	-.31*	.09	-.27*
RSES	-.48*	-.52*	-.39*	-

**Table 4:** Shows the Pearson's Correlation coefficient (r) between stigmatization (total, internal & external SSCI), self-esteem (RSES) and pain interference (BPI) in chronic pain patients (n=160, \*p<0.05).

## Study Limitations

In light of the results it may be that a repeated-measures or a longitudinal design would provide better understanding of the enduring effects of perceived stigma in chronic pain patients. Improved pain phenotyping should be considered as stigmatization may vary with the type of pain experienced. It is also acknowledged a control group was not included and it would have been informative if an indirect comparison to the general population was presented at the same time.

As the population sample studied was predominantly female and Caucasian the results of this study should be interpreted with caution when evaluating African American, Hispanic, or other ethnic minority groups. The skew in gender mix needs to be a balanced in future studies to explore this impact has on stigmatization and self-esteem. While the study used validated and anonymous questionnaires it is recognized that self-reporting may be towards the positive, especially of more sensitive topics.

## Conclusion

These findings reinforce the importance of regularly addressing stigma in the clinical setting. With 77% of chronic pain patients having a lowered self-esteem, it is likely that this maybe a key factor in the psychological morbidity associated with chronic pain and suggests that healthcare providers should include psychosocial screening and counseling related to stigma at all visits. The degree to which the stigma of chronic pain influences clinical outcome needs to be evaluated. Failure to address this element will more likely prolong the patient's recovery, which in turn will be associated with significant economic cost to the health service.

## Conflict of Interests and Funding

Dr. Mary Wall was the holder of the HRB Summer Student Scholarship while completing this research as part of her final year medical project. There were no other funding sources. There are no other conflicts of interest to disclose.

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