ISCTE IUL
REPOSITÓRIO
INSTITUTO UNIVERSITÁRIO DE LISBOA

Repositório ISCTE-IUL

Deposited in *Repositório ISCTE-IUL*:
2025-08-26

Deposited version:
Accepted Version

Peer-review status of attached file:
Peer-reviewed

Citation for published item:
Van Alboom, M., Bernardes, S. F., Baert, F. , Bracke, P. & Goubert. L. (2025). Two-wave study on intrapersonal stigma, social isolation, well-being, and functioning in individuals with chronic pain: A structural equation modeling approach. The Journal of Pain. 35

Further information on publisher's website:
10.1016/j.jpain.2025.105479

Publisher's copyright statement:
This is the peer reviewed version of the following article: Van Alboom, M., Bernardes, S. F., Baert, F. , Bracke, P. & Goubert. L. (2025). Two-wave study on intrapersonal stigma, social isolation, well-being, and functioning in individuals with chronic pain: A structural equation modeling approach. The Journal of Pain. 35, which has been published in final form at https://dx.doi.org/10.1016/j.jpain.2025.105479. This article may be used for non-commercial purposes in accordance with the Publisher's Terms and Conditions for self-archiving.

Use policy

Creative Commons CC BY 4.0
The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a link is made to the metadata record in the Repository
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Serviços de Informação e Documentação, Instituto Universitário de Lisboa (ISCTE-IUL)
Av. das Forças Armadas, Edifício II, 1649-026 Lisboa Portugal
Phone: +(351) 217 903 024 | e-mail: administrador.repositorio@iscte-iul.pt
https://repositorio.iscte-iul.pt

Manuscript (revised, clean) Click here to view linked References

Two-wave study on intrapersonal stigma, social isolation, well-being, and functioning in individuals with chronic pain: A structural equation modeling approach

Van Alboom Maité*, Bernardes Sónia F.**, Baert Fleur*, Bracke Piet***, Goubert Liesbet*

*Ghent University, Faculty of Psychology and Educational Sciences, Department of Experimental-Clinical and Health Psychology

** ISCTE, Instituto Universitario de Lisboa, School of Social Sciences, Department of Social and Organizational Psychology

***Ghent University, Faculty of Political and Social Sciences, Department of Sociology

Corresponding author: Maité Van Alboom - Address: Ghent University, Faculty of Psychology and Educational Sciences. Henri Dunantlaan 2, 9000 Ghent, Belgium. - Email: maite.vanalboom@ugent.be – Tel: +32473353773

Running title: stigma, social isolation, and well-being/functioning in the context of chronic pain

Abstract

Stigmatization poses significant challenges for individuals living with chronic pain (CP), particularly when pain complaints lack a clear pathophysiological basis, referred to as primary CP. Although the negative impact of stigmatization on well-being and functioning of individuals with CP is acknowledged, its systematic and theory-driven investigations are sparse. Moreover, the underlying mechanisms linking CP stigmatization to adverse outcomes have yet to be examined. This study conducted an online, two-wave prospective questionnaire, collecting data from 332 individuals with chronic pain in the first wave (271 women, M age = 50y) and a subset of the same sample (N= 295; 241 women, M age = 54y) in the second wave (1 year later). Structural equation modeling revealed several key findings: (1) Individuals with primary CP perceived higher intrapersonal stigma compared to those with secondary CP. (2) Higher perceived stigma was related to increased mental distress and to decreased functioning/participation, both via higher levels of social isolation. 3) The structural relationships were not statistically equivalent across primary and secondary CP, suggesting moderation. 4) Finally, changes in perceived stigma were related to changes in functioning/participation in daily life and changes in mental distress, but only the model with mental distress was mediated by changes in social isolation. The findings underscore the importance of addressing perceived stigma and social isolation to improve mental health outcomes in CP patients. Clinically, tailored interventions that consider the unique needs of patients with primary versus secondary CP are necessary.

Perspective: This paper presents results of a two-wave questionnaire study on perceived stigma, social isolation, well-being, and functioning. The role of chronic pain type, namely primary versus secondary chronic pain is being examined.

Key words: perceived stigma, social isolation, well-being, functioning, structural equation modeling

Introduction

Stigmatization poses significant challenges for individuals with chronic pain (CP) [1,2]. Stigmatizing responses are devaluing and discrediting reactions of observers towards people having a characteristic (herein CP) that deviates from societal norms [3]. In the context of illness, society expects clear symptoms, an underlying pathophysiology, and observable signs of the complaints. Additionally, people expect people expect the sick role to be temporary [4]. CP and especially pain for which no clear pathophysiology can be detected (i.e., primary CP) deviates from these societal norms [5] and as such, may elicit stigmatizing responses [6]. Indeed, qualitative research has shown that observers tend to suspect that individuals with CP feign pain [7,8]. Further, studies have shown that people from the general population are more suspicious towards individuals with primary CP [9–12]. Also, individuals with fibromyalgia (primary CP) report more invalidation as compared to individuals with rheumatoid arthritis (secondary CP) [13]. However, other studies did not find differences regarding perceived stigma between the two groups after controlling for pain intensity [14,15]. This divergence in findings needs further research.

A recent review and meta-analysis showed that higher perceived CP stigmatization was associated with poorer well-being [16], but theory-driven research is sparse. Moreover, previous studies do not distinguish between various types of stigma. The current study draws upon the Stigma Mechanisms in Health Disparities Model [17] to examine stigma and well-being/functioning in depth. The model describes how public stigma (i.e., stereotypes motivating individuals to fear, reject, avoid, or discriminate people [18]) influences mental and physical health. The model depicts stigma mechanisms at multiple levels: (1) intrapersonal level (e.g., self-stigma), (2) interpersonal level (e.g., less social support), and (3) institutional level (e.g., access to health services). The present study investigates the associations between perceived stigma at the intrapersonal level, social isolation as an indirect assessment of the interpersonal level, and well-being/functioning. The institutional level will not be assessed, as measuring this from an individual's perspective can be highly interpretative, which is not a problem when you are aiming to assess subjective stigma experiences. According to Chaudoir et al [17], there are three distinct types of intrapersonal stigma. Internalized stigma refers to "the degree to which individuals feel shame

or self-loathing (by internalizing the public's perspective)". Anticipated stigma refers to "the degree to which individuals anticipate or expect to be the target of discrimination or social rejection". Enacted stigma refers to "the degree to which individuals actually have experienced discrimination in the past" (p. 76).

Research has not yet explored the underlying mechanisms explaining associations between stigma and mental distress and functioning [2]. Based upon Chaudoir and colleagues' model [17], changes in social networks and dyadic interactions (i.e., interpersonal level) are proposed as processes by which stigma impacts upon mental distress and functioning. Indeed, research focused on the negative impact of social isolation on well-being of individuals with CP [19–25]. Social isolation can be defined as a state in which the individual lacks a sense of belonging and engagement with others, and has a minimal number of social contact [26]. A systematic review has highlighted the role of social isolation into causing and maintaining chronic health conditions, such as depression and cancer [27]. Social isolation may be crucial in the context of CP stigmatization as patients often isolate themselves to avoid stigma [14]. Also, individuals with CP often struggle to join or enjoy social activities because of their pain [28,29]. Conversely, members of their social network may also avoid them, further exacerbating their isolation [2,30].

Using structural equation modeling, the current two wave study aimed to investigate the following objectives: (1) examine cross-sectionally whether intrapersonal stigmatization (internalized, anticipated, enacted) was higher in individuals with primary CP compared to those with secondary CP; (2) Investigate cross-sectionally whether social isolation mediated the relationship between intrapersonal stigmatization and mental distress, as well as, functioning/participation in daily life; (3) Examine cross-sectionally whether the type of CP (primary vs. secondary) moderated the mediation model between stigmatization, social isolation, and outcomes; (4) Assess whether changes in intrapersonal stigma were related to changes in social isolation, and in turn, to changes in mental distress and functioning/participation in daily life.

Methods

Patient and public involvement

Participants were not involved in the design phase of the study. The research team provided all participants and patient organizations with a written report about the results in lay terms. Patient organizations assisted in disseminating these study results.

Participants and recruitment

The current study is part of a project on stigma and social networks in the context of chronic pain. The project focuses on differences between primary and secondary CP and examines the associations between stigma or social network characteristics on one hand, and well-being and functioning on the other. A previously published paper related to this project focused on the structural and functional social network characteristics of individuals with CP [30]. In contrast, the current study focuses solely on CP related stigma, marking a significant difference in scope from the previous study. The participants in the current stigma study are the same individuals who participated in the social network study. They were recruited through three patient organizations, namely the Flemish Pain League (FPL), the League for Rheumatoid Arthritis (LRA), and the Flemish League for Fibromyalgia Patients (FLFP). All members (N= 1983) of the FPL and the LRA (N= 319) were sent an invitation letter to participate in an online study regarding negative reactions towards individuals with CP and the relationship with patients' wellbeing. Members of the LRA were also informed via Facebook and their personal magazine 'RAAM'. Members of the FLFP were reached via an announcement on their Facebook page and their personal magazine 'Fibrozine'. Two hundred nighty seven members of the FPL, 91 of the LRA, and 94 of the FLFP (N= 481) agreed to get informed about the study and were contacted by phone by one of the members of the research team. Further information about the study was provided and the following inclusion criteria were checked: (1) having non-cancer CP (i.e., persistent or recurrent pain for at least three months), (2) speaking Dutch fluently, and (3) being older than 18 years. Sixteen people could not be reached. Four hundred sixty-two members met the inclusion criteria and 452 members agreed to participate in the study. Reasons for not taking part in the study (N= 10) were experiencing a hard time because of personal or family problems, surgeries, or not being able to concentrate for half an hour. Participants without a computer or with too little computer knowledge (N=37) were offered a home visit by a research assistant to fill out the questionnaires on paper. Due to the COVID-19 pandemic, only

eight home visits could be carried out. In total, 335 participants completed the first survey. Eighty-eight people who received the weblink did not or only partially completed the first survey. For some of them, it was too exhausting to fill out the questions, but most of them did not reply to the reminder e-mails. Further, data from three participants were excluded because they had a diagnosis of cancer, which is not within the scope of the current study. One participant was excluded because there was no CP present. For the first wave, data of 332 individuals with CP were included in the analyses. The second wave took place one year after the first one. People who did not complete the first survey were not approached to take part in the second wave. Eight participants could not be reached for the second wave, 16 did not want to participate, and eight agreed to participate but did not or not completely fill out the survey. For the second wave, complete data of 295 individuals with CP were included in the analyses. The retention rate was 89%.

Study design and procedure

This study is a prospective two-wave questionnaire study. Data collection took place between September 2019 and June 2021. After the phone call by a member of the research team, participants were sent a weblink via e-mail to complete the online self-report questionnaires. This e-mail also included a personal login code to get access to the survey. Data were pseudonymized. Informed consent was obtained online before the start of the survey. All questionnaires were included in a protected web-based survey tool, i.e., LimeSurvey. If the survey was not completed within one week, a reminder was sent via e-mail. The completion of the survey took, on average, 25 minutes. Upon completion of the survey, participants received a cinema ticket or Fnac-voucher (11.50 euro). Eighty participants preferred not to receive a compensation.

One year later, participants were contacted via e-mail to inquire about their willingness to participate in the second wave. The remainder of the procedure mirrored the first survey, with the exception that a lottery was conducted to distribute 50 cinema tickets among the participants; hence, not all participants received a compensation. The study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of Ghent University.

Questionnaires

Sociodemographic information regarding gender (i.e. "Which gender do you identify with?"), age, nationality, civil status, education, and work status were collected at the beginning of the survey.

The Dutch *Graded Chronic Pain Scale* (GCPS) [31] was included to assess pain intensity and disability. Three items of the GCPS assess current, worst, and average experienced pain intensity during the past six months and were rated on an 11-point scale from 0 (= No pain) to 10 (= Worst imaginable pain). Pain disability was assessed by four items of the GCPS, i.e. the reported days in which the person was prevented from carrying out his/her usual activities (work, school or household duties) during the past six months and three items measuring whether the participant was prevented from carrying out daily activities, recreational/social/familial activities, and work during the past six months. These items were answered on an 11-point scale from 0 (= No difficulties at all) to 10 (= Impossible to execute activities). The GCPS is a reliable and valid instrument in CP samples [31,32]. In this study, Cronbach's alpha was .82 and .84 for pain intensity, and .90 and .92 for pain disability in the first and second wave. In line with Von Korff and colleagues [31], participants were classified into 5 grades based on the scores for mean pain intensity and disability: grade 0 'no pain', grade 1 'low intensity and low disability' (disability points <3 and pain intensity <50), grade 2 'high intensity and low disability' (disability points <3 and pain intensity ≥50) and, grade 3 'moderate disability, regardless of pain intensity' (disability points = 3 or 4), grade 4 'high disability, regardless of pain intensity' (disability points = 4 or 5).

The Dutch version of the *Stigma Scale for Chronic Illness – Short Form* (SSCI-SF) [33,34] was used to assess internalized and enacted stigma. The scale consists of 8 items: 2 items assess internalized stigma (e.g., "I felt embarrassed about my illness"), 4 items assess enacted stigma (e.g., "Because of my illness, some people avoided me"), one item loads on both subscales ("Because of my illness, I felt left out of things") in the original article, though it was used as an indicator for internalized stigma. Items were rated on a 5-point scale from 0 (= Never) to 4 (= Always). Internalized and enacted subscale scores, and a total score were calculated. The good reliability and validity of the SSCI has been demonstrated in a sample of neurological disorders [33], neuromuscular disease [34] and in a sample of patients with CP [35]. The short form was validated, for instance in multiple sclerosis [36], neurological disorders [37], and

chronic pain [38]. In the current study, Cronbach's alpha was respectively in the first and second wave, .82 and .77 for internalized stigma, .86 and .88 for enacted stigma, and .88 and .88 for the total score.

Anticipated stigma was measured with the 12 item Dutch version of the *Chronic Illness Anticipated Stigma Scale* (CIASS) [39]. By means of a back-translation procedure, we developed the Dutch version of the CIASS. The translation was approved by the original author of the scale. The CIASS assesses stigma from three different sources, i.e. friends and family (e.g. "A friend or family member will think that your illness is your fault"), work colleagues ("Someone at work will think that you cannot fulfill your work responsibilities"), and healthcare providers ("A healthcare worker will blame you for not getting better"). Items were answered on a scale ranging from 1 (= Very unlikely) to 5 (= Very likely). A total sum score was calculated. Because most participants were not working, we did not include the scores on the subscale about the work colleagues. The CIASS is a reliable and valid instrument in samples of chronic illness [39]. In the current study, Cronbach's alpha was .91 in the first and .93 in the second wave. Intrapersonal stigma was specified by the sum score on the subscales internalized, enacted stigma (SSCI) and anticipated stigma (CIASS).

The 8-item short-forms of the Patient-Reported Outcomes Information System [40–42] (PROMIS®) were used to assess depression, anxiety, anger, ability to participate in social roles and activities, physical functioning and pain interference: PROMIS item bank v1.0 Emotional Distress-Depression – Short Form 8a (e.g., "I felt worthless"); PROMIS item bank v1.0 Emotional Distress-Anxiety – Short Form 8a (e.g., "It is very hard for me to focus on anything other than my anxiety"); PROMIS item bank v1.1 Anger – Short Form 5a (e.g., "I felt angry"); PROMIS item bank v2.0 Ability to Participate in Social Roles and Activities – Short Form 8a (e.g., "I have a hard time doing all my regular leisure activities with others."); PROMIS item bank v1.1 Pain Interference – Short Form 8a (e.g., "To what extent did the pain interfere with your daily activities?"): PROMIS v1.2 item bank Physical functioning – Short Form 8b (e.g., "Are you able to run errands and shop?"); PROMIS item bank v2.0 Social Isolation – Short Form 8a (e.g., "I feel left out"). The sum scores were converted into T-scores (mean of 50 and standard deviation of 10). Two latent constructs were constructed. The latent construct mental distress was indicated by the T-scores on the PROMIS subscales depression, anxiety and anger.

The latent construct functioning/participation in daily life was indicated by the T-scores on the PROMIS® subscales pain interference, physical functioning, and ability to participate in social role and activities. In this way, indicators for the latent constructs were defined as sum scores. This approach, known as 'item parceling', is a valid technique for reducing the number of indicators in SEM models [43].

All PROMIS items were answered about the past 7 days on a 5-point scale from 0 (= Never) to 4 (= Always). A total sum score was calculated for each subscale. The PROMIS subscales are reliable and valid in clinical samples [41,44,45]. In the current study, Cronbach's alpha was respectively for the first and second wave: .95 and .95 for depression, .95 and .95 for anxiety, .91 and .92 for anger, .95 and .95 for ability to participate in social roles and activities, .94 and .94 for pain interference, .92 and .92 for physical functioning, and .95 and .96 for social isolation.

Analytical strategy

Analyses were conducted in R version 2023.09.1. Cronbach's Alpha reliability statistics (see 'Methods') were used to examine internal consistency for all scales. No missing values were present in the participants' responses as the software made them complete all questions.

For the research question regarding the comparison of stigma levels and the moderated mediation measurement invariance (MI) was tested across both types of diagnosis (i.e., primary and secondary CP) to make sure that differences were not due to differences in measurement across groups. For the research question about the mediation model over time MI was tested across both waves. MI verifies that the measurement instrument performs consistently across different groups and time points. Specifically, we tested whether the instrument is invariant between the primary and secondary CP groups and whether it remains consistent across both waves. Researchers often compare means across groups without acknowledging the need for strong factorial invariance [46]. Because of this, invalid conclusions can be drawn from the results as differences can be related to questionnaires measuring constructs in a different way across groups. Confirmatory factor analysis was used to test MI. The following invariance models were tested: configural (equal factor structure), metric (equal factor structure and loadings), scalar (equal factor structure, loadings and intercepts), strict (equal factor structure, loadings, intercepts, and residuals) and more strict (equal factor structure, loadings, intercepts,

residuals, and residual covariances) invariance. Each invariance model represents a more stringent set of assumptions about the measurement instrument. A change in CFI fit >.01 from one model to a stricter model was considered problematic following guidelines from Cheung and Rensvold [47,48]. Scalar invariance should be reached to be allowed comparing latent mean differences [49]. If needed, partial MI was explored to examine which parameters are different across groups.

For the research question regarding the comparison of stigma levels, latent mean differences were analyzed. For the second research question, we tested a mediation model using structural equation modeling (SEM) in wave 1. SEMs were performed using the Lavaan package [50] in R (version 0.6.16). In the current study, the following fit indices were used in line with recommendations of Kline [51] and Hooper et al. [52]: Chi-square (χ^2, p-value > .05), Root Mean Square Error of Approximation (RMSEA, <.08), Comparative Fit Index (CFI, >= .90), and Standardized Root-Mean-square Residuals (SRMRs, <.08). As sample size increases χ^2 tests are often significant (N>200), indicating a misfit of the model. Therefore, χ^2 tests will be reported, but interpreted with caution. We first assessed the measurement model, followed by the structural model. Bootstrapping was used to determine whether indirect effects were significant. Bootstrapping is a non-parametric method for assessing indirect effects. Normal distribution may only be found in large samples, but bootstrapping overcomes several problems with non-normally distributed variables. Confidence intervals are reported for the significant indirect effects. For the third research question, we tested the same mediation model at baseline and examined whether this mediation model is moderated by the type of CP, i.e. primary versus secondary. Scores were standardized for this research question. Specifically, we compared the groups by calculating the differences in estimates for the a-path, b-path, and ab effect and evaluated whether these differences were significant. We first tested a configural model in which all path coefficients were freely estimated across groups to establish a baseline. Next, we tested a constrained model where the structural paths were held equal across groups. Model fit indices were compared using the chi-square difference test to determine whether constraining the paths significantly worsened model fit, which would suggest moderation. For the fourth research question, Selig and Preachers [53] and Mackinnon's [54] recommendations regarding mediation analyses in longitudinal studies using latent mean differences

scores were followed. Difference scores were calculated by subtracting the scores in wave 1 from the scores in wave 2. These difference scores were used as indicators for the latent variables in the model.

Results

Sample characteristics

Sample characteristics are shown in Table 1. Of the final sample, 81.6% (N=271) were women and 95.8 % (N=320) had a Belgian nationality. One hundred thirty-one participants had a diagnosis of fibromyalgia (FM), four had a diagnosis of chronic fatigue syndrome (CFS), 71 had a diagnosis of rheumatoid arthritis (RA), 12 had arthrosis, 19 had Ehler Danlos Syndrome (EDS), eight reported to have an auto-immune disease or an inflammatory disease, and 18 had a hernia, scoliosis or failed back surgery. Twenty-three participants had FM as well as RA, 12 participants had no diagnosis and 39 had other diagnoses, e.g., nerve pain, polyneuropathy. Participants were divided into two groups depending on whether their CP was primary or secondary. The secondary chronic pain group (N=131) consisted of participants with RA, arthrosis, EDS, auto-immune diseases, inflammatory diseases, hernias, scoliosis or failed back surgery. The primary CP group (N= 137) consisted of participants with FM or CFS. A final group consisted of participants with primary as well as secondary CP and participants for whom it was inconclusive whether there was a clear pathophysiology for their pain. These participants were included in the analyses regarding the mediation model and the mediation model over time. They were not included in the analyses regarding the comparison of stigma between primary and secondary CP and regarding the moderated mediation model.

Preliminary analyses and measurement invariance testing

Table 1 in the Supplementary files presents the means, SD and Cronbach's alpha and Pearson intercorrelations for each of the variables.

Further, it was examined whether the sociodemographic variables were correlated with outcome variables. Gender was not related to internalized, enacted or anticipated stigma. Gender was also not related to depressive symptoms, anxiety, anger, pain interference, ability to participate in social roles and activities, and physical functioning. Younger participants reported more internalized ($r = -.29$, $p <$

.01), enacted (r= -.18, p< .01) and anticipated (r=-.35, p< .01) stigma. They also reported more depressive symptoms (r= -.17, p< .01), anxiety (r= -.17, p< .01), anger (r= -.27, p< .01), and pain interference (r= -.15, p< .01) and lower ability to participate in social activities and roles (r=.13, p< .05). Civil status was only associated with any of the outcome variables. Participants with more years of education reported higher ability to participate in social activities and roles (r=.11, p< .05) and physical functioning (r=.19, p< .01) and lower levels of pain interference (r=-.17, p< .01). Based on these analyses, we controlled for age and years of education in the mediation model and in the moderated mediation. In RQ1, latent mean differences were inspected, not allowing us to add control variables in the model (only measurement equations in the model). In the fourth research question, we did not add control variables as the interpretation of the estimates is not straightforward because of the use of difference scores.

For the first research question regarding the comparison of stigma between primary and secondary CP, measurement invariance (MI) was separately tested for internalized/enacted stigma and anticipated stigma as they are measured using different questionnaires. For internalized and enacted stigma MI was established up to the metric model (see Table 2 in Supplementary files). Subsequently, we freed two parameters (two intercepts) resulting in a higher fit and indicating partial scalar invariance. This means that all intercepts except two are equal across both groups, however partial scalar invariance suffices to compare latent mean differences. For anticipated stigma MI was established until the strict model, allowing us to inspect latent mean differences (see Table 3 in Supplementary files).

For research question 3 regarding the moderated mediation, MI across both groups was tested. MI was established up to the scalar model, allowing us to conduct a moderated mediation (see Table 4 in Supplementary files). Partial strict invariance was reached by freely estimating the variance for physical functioning in both groups.

For research question 4 regarding changes in the mediation model, we determined whether calculating difference scores is permissible by assessing MI across both waves. The MI was established up to the most strict model for internalized stigma, enacted stigma, anticipated stigma (see Table 5 in Supplementary files), depression, anxiety, anger, ability to participate in social roles and activities, pain

interference, and physical functioning (see Table 6 in Supplementary files). This approach ensured that the estimated model is consistent across both waves, confirming that we are measuring the same model in each wave. This consistency allows us to calculate difference scores by subtracting wave 1 scores from wave 2 scores.

Intrapersonal stigmatization in individuals with primary versus secondary chronic pain.

The measurement model initially showed a poor fit: $\chi 2$ (19)= 146.569 ($p< .001$), RMSEA= 0.142 (90% CI= 0.121 - 0.164), CFI= 0.911, SRMR= 0.070. In line with recommendations from Byrne[55] , we inspected modification indices and considered conceptual justifications for adding additional parameter estimates. We added 7 residual covariances - four between pairs of items within the internalized or enacted subscales, and three between items from different subscales. This resulted in a substantially improved model fit: $\chi 2$ (12)= 30.530 ($p< .01$), RMSEA= 0.076 (90% CI= 0.043 - 0.110), CFI= 0.985, SRMR= 0.036. Latent means were higher for internalized stigma ($p= .030$) in primary CP (B= 0.285) compared to secondary CP (B= 0; reference group). For internalized stigma the absolute mean in primary CP was 23.19 (SD= 11.12) and 18.44 (SD= 10.90) in secondary CP. Also enacted stigma was higher ($p= .018$) in the primary CP group (B= 0.251) in comparison with the secondary CP group (B= 0; reference group). Compared to individuals with secondary CP (B= 0; reference group), individuals with primary CP reported higher anticipated stigma from family and friends (B= 0.590) ($p< .001$) and healthcare workers (B= 0.410) ($p= .002$). For enacted stigma the absolute mean in primary CP was 12.12 (SD= 8.25) and 9.73 (SD= 8.68) in secondary CP.

Social isolation as mediator of the association between perceived stigmatization and mental distress and functioning/participation in daily life (wave 1)

Latent constructs of the observed data were constructed. Intrapersonal stigma as a latent construct was specified by the sum score on the subscales internalized, enacted stigma (SSCI) and anticipated stigma (CIASS). Higher scores represent higher intrapersonal stigma. The latent construct mental distress was indicated by the sum scores on the PROMIS subscales depression, anxiety and anger. Higher scores represent higher mental distress. Following the International Classification of

Functioning, Disability and Health [56], the latent construct functioning/participation in daily life was indicated by the PROMIS® subscales pain interference, physical functioning, and ability to participate in social role and activities. Higher scores represent higher functioning/participation. Social isolation was included as an indicator, as well as the two control variables age and years of education. The results of the mediation model are shown in Figure 1.

INSERT FIGURE 1

The measurement model showed an acceptable fit of the data, $\chi 2$ (17)= 58.592 ($p< .001$), RMSEA= 0.086 (90% CI= 0.063 - 0.111), CFI= 0.974, SRMR= 0.060. The hypothesized structural model showed only an acceptable fit, $\chi 2$ (40)= 152.668 ($p< .001$), RMSEA= 0.092 (90% CI= 0.077 - 0.108), CFI= 0.944, SRMR= 0.093. When examining the factor loadings, we observed that the CIASS did not load sufficiently on the latent variable 'intrapersonal stigma'. As a result, we decided to omit this scale and only include the SSCI as an observed indicator of stigma. We changed the name of the latent variable to 'perceived stigma'. Now the structural model showed a better fit: $\chi 2$ (27)= 77.697 ($p< .001$), RMSEA= 0.075 (90% CI= 0.056 - 0.095), CFI= 0.970, SRMR= 0.046. The results showed that, higher perceived stigma was associated with higher mental distress (c'_1= 0.133, $p< .001$). Higher levels of perceived stigma were related to higher levels of social isolation (a= 0.359, $p< .001$) and higher levels of social isolation were related to higher levels of mental distress (b_1= 0.377, $p< .001$). Social isolation mediated the relationship between perceived stigma and mental distress (ab_1= .135, $p< .001$, CI= 0.094 – 0.179). The total effect was also significant (c_1= .268, $p< .001$), so a partial mediation effect was observed.

Further, higher levels of perceived stigma were associated with lower levels of functioning/participation in daily life (c'_2= -.116, $p< .001$). The association between social isolation and functioning/participation in daily life (b_2= -.206, $p< .001$) was also significant. The results showed that social isolation mediated the relationship between stigma and functioning/participation in daily life (ab_2= -.074, $p< .001$, CI= -0.111– -0.039). The total effect was significant (c_2= -.190, $p< .001$).

Primary versus secondary CP as moderator for the mediation model (wave 1)

The mediation model with perceived stigma, social isolation, and mental distress as the outcome was significant both for individuals with primary and secondary CP. The analysis revealed no significant difference in the indirect effects between the secondary CP group and the primary CP group. The indirect effect for functioning/participation in daily life as outcome was only significant in the primary CP, but the difference with the indirect effect for secondary CP was not significant. The results of the moderated mediation model are shown in Figure 2.

INSERT FIGURE 2

The chi-square difference test indicated that the constrained model showed significantly worse model fit compared to the configural model, $\Delta\chi^2(9) = 19.802$, $p = 0.019$. This suggests that the structural relationships were not statistically equivalent across groups, indicating significant moderation by chronic pain type.

Mediation model over time using difference scores

Again, we estimated the mediation model with perceived stigma as observed predictor, social isolation as mediator, and mental distress and functioning/participation in daily life as outcomes. Differences in the means of all variables between the two waves are shown in Table 2. Descriptive characteristics of the difference scores are shown in Table 3. Difference scores between total scores on wave 1 and wave 2 were used to determine the latent constructs. The results of the mediation model using difference scores are shown in Figure 3.

INSERT FIGURE 3

The measurement demonstrated showed a good fit of the data, χ^2 (8)= 18.073 (p= .021), RMSEA= 0.065 (90% CI=0.024 - 0.106), CFI= 0.975, SRMR= 0.038. Similarly, the hypothesized structural model showed a good fit, χ^2 (16)= 28.471 (p= .028), RMSEA= 0.051 (90% CI=0.017 - 0.082), CFI= 0.977, SRMR= 0.035. It should be noted that in this specific model the factor loading of the physical functioning scale on the latent variable functioning/participation in daily life is relatively low. Changes in perceived stigma were related to changes in functioning/participation in daily life ($c'_{part/funct}$= .119, p< .001), and to changes in mental distress (c'_{mental}= .115, p< .001). Changes in perceived stigma were

related to changes in social isolation (a= .167, p< .001), and changes in social isolation were related to changes in mental distress (b_{mental}= 0.324, p< .001), but not to changes in functioning/participation in daily life ($b_{funct/part}$= 0.068, p= .165). The indirect effect with mental distress as outcome was significant, but the indirect effect with functioning/participation in daily life as outcomes was not (ab_{mental}= .054, p< .01, CI= [0.024 ; 0.093]; $ab_{part/funct}$= 0.011, p= .175, CI= [-.006 ; .028]). The sum of the direct and indirect effects (total score) of stigma on mental distress (c_{mental}= .169, p <.001) and on functioning/participation in daily life ($c_{part/funct}$= .130, p <.001) were significant. In summary, the mediation model for mental distress was supported by evidence using difference scores of two waves.

We conducted an exploratory multiple group SEM analysis to test for moderation effects of CP type. First, we estimated a configural model, in which all parameters were freely estimated across groups. The chi-square difference test indicated that the constrained model did not significantly worsen model fit compared to the configural model, $\Delta\chi^2(16) = 22.73$, p = 0.121. This suggests that the structural relationships were statistically equivalent across primary and secondary CP, indicating no significant moderation.

Discussion

The current study examined intrapersonal stigmatization, social isolation, and well-being/functioning in individuals with primary and secondary chronic pain (CP), drawing upon the Stigma Mechanisms in Health Disparities model [17]. Our findings revealed that individuals with primary CP, in contrast to individuals with secondary CP, report higher levels of internalized biases and negative societal attitudes directed against them, as well as higher levels of past experiences of discrimination and higher expectations of future stigmatization. This is consistent with previous research indicating heightened invalidation in fibromyalgia (primary CP) compared to rheumatoid arthritis (secondary CP) [13,14].

Perceived stigmatization related to CP has been consistently linked to poorer well-being in previous studies [16], yet the underlying mechanisms warrant further investigation. The Stigma Mechanisms in Health Disparities model [17] suggests that changes in social networks and dyadic social interactions are key processes linking stigma to mental and physical health outcomes. In our study, higher perceived stigma was associated to higher mental distress through elevated levels of social isolation, and with worse functioning and participation in daily life, with this association also mediated by social isolation.

Our findings are in line with previous research on stigma in other health conditions. For instance, health-related stigma has been thoroughly examined in the context of HIV. A study in women showed that internalized stigma was related to higher loneliness, which, in turn, was related to increased depression [57]. Loneliness, although closely related to social isolation, represents a different construct reflecting the discrepancy between one's desired and actual social relationships [58]. Social isolation can be viewed from either a structural or functional perspective. Structural social isolation refers to the objective lack of people and interactions within one's social network. In contrast, functional social isolation pertains to the perceived lack of closeness with members of one's network [59,60]. The latter is measured via the PROMIS scale, as applied in this study. Consequently, functional social isolation closely resembles loneliness. Furthermore, a substantial body of research has delved into psychosis-related stigma, showing that stigma-related stress was associated with perceptions of social isolation,

which were in turn related to lower self-esteem and higher depression [61]. In the context of lupus, a cross-sectional study demonstrated that stigma was related to social isolation and that the relationship between stigma and depression became nonsignificant after including social isolation in the model [62]. Also, qualitative research described how stigma is related to feelings of loneliness in the context of depression [63] and among elderly populations [64].

The removal of the CIASS from our models warrants careful consideration. Although the CIASS demonstrated adequate psychometric properties in isolation, its inclusion alongside the SSCI resulted in poor model fit, suggesting potential conceptual overlap or measurement redundancy. This may be related to the fact that, unlike the SSCI, the CIASS was not developed using cognitive interviews and focus groups as recommended by COSMIN guidelines, which could have affected its content validity. From a theoretical perspective, this raises questions about the distinct contribution of anticipated stigma relative to internalized and enacted stigma. It is possible that in chronic pain, anticipated stigma is less salient or that individuals' perceptions of anticipated stigma are closely tied to their experiences of enacted stigma, contributing to multicollinearity. Alternatively, the SSCI's internalized and enacted stigma dimensions may capture the most clinically relevant stigma experiences for understanding social isolation and outcomes in this population.

Furthermore, in the group with secondary CP, social isolation did not significantly mediate the relationship between perceived stigma and daily functioning or participation. However, when comparing these mediation effects between the secondary and primary CP groups, the difference was not statistically significant. Even so, the overall model fit differently for the two groups, suggesting that group type (primary vs. secondary CP) might moderate how these relationships work. This finding suggests that chronic pain type may influence associations between perceived stigma, social isolation, and functioning. It is worth noting that research indicates that patients with secondary CP tend to report higher well-being and functioning compared to those with primary CP [14,65,66]. Additionally, studies have found that individuals with primary CP report higher levels of perceived stigma than those with secondary CP [13,67].

Finally, our study results showed a significant mediation between changes in perceived stigma, changes in social isolation (as the mediator), and changes in mental distress, but not with functioning/participation in daily life. This contrasts with previous research showing that social isolation predicted physical functioning in individuals with CP [68,69] and aligns with research showing an association between social isolation and emotional wellbeing over time [70]. However, another study found a predictive relationship between social isolation and disability, but not between social isolation and depression in people having low back pain [70]. In our study, a direct effect was observed between changes in perceived stigma, and changes in functioning/participation in daily life and mental distress. It is important to acknowledge the debate about the reliability and validity of using difference scores. Gollwitzer, Christ, and Lemmer [71] defend the use of difference scores but argue that their reliability depends on the extent to which the standard deviations (SDs) differ between the two measurement points. The larger the difference in SDs, the higher the reliability. In our study, SD differences were minimal (ranging from 0.07 to 1.14), which may introduce bias in the results. We now believe that the intensity or frequency of stigmatizing events may vary, whereas the awareness or expectation of stigma likely contributes to a more stable sense of being stigmatized. Consequently, when stigma is measured using the SSCI, we do not expect it to fluctuate significantly.

The current study has some limitations to consider. First, two measure moments are insufficient to make inferences about the direction of associations and the mediation models were primarily tested at wave 1. We cannot determine whether stigma affects well-being and functioning, or whether the reverse is true. Second, most of the sample self-identified as women, which limits the generalizability of the findings to all genders. Third, our sample also showed limited diversity in terms of ethnicity, reducing the potential to generalize the findings. Moreover, we did not directly assess participants' ethnicity, presenting an additional limitation. Fourth, although we collected data on education level, we did not assess other indicators of socioeconomic status, such as income. Both ethnicity and socioeconomic status are important intersectional factors in the study of stigma and their omission may limit the generalizability and contextual interpretation of our findings. These variables were not assessed in line with the ethics committee's guidelines at the time of data collection, which advised against

collecting sensitive demographic information unless directly necessary to address the research questions. Fifth, recruiting via patient organizations may have led to a selection bias as it can be assumed that these individuals with CP may have more extensive social networks than other individuals with CP, possibly resulting in lower levels of social isolation. Sixth, the primary CP group only consisted of individuals with fibromyalgia and/or chronic fatigue syndrome, which limits the generalizability to other primary CP conditions. Seventh, exploratory comparisons of baseline characteristics between participants who completed wave 2 and those who dropped out, showed that the latter group had higher baseline levels of disability, social isolation and stigma.

Future research could benefit from simultaneously examining stigma at intrapersonal, interpersonal and institutional levels to provide a comprehensive understanding of CP-related stigma. To do so, different research methods should be combined. This includes conducting observational research in specific settings (e.g., hospital departments), interviewing patients and providers working in those settings, and examining the policy documents used in those settings. Longitudinal studies with more than two measurement points are needed to better infer causality. Additionally, exploring intersections of CP stigma, such as gender, may be crucial as most individuals with CP are women, which may elicit other prejudices than for men [72,73]. While the clinical relevance of the 'unclear diagnosis' group is evident—especially in community-based settings where diagnostic ambiguity is common—a three group model could not be run due to sample size limitations. Future research with larger and more balanced subgroup samples is warranted to explore this further. Future studies could also explore additional mediating pathways between intrapersonal or perceived stigma and well-being. For instance, self-efficacy may be an interesting candidate as a potential mediator. Understanding these explanatory pathways will allow for better targeted interventions for individuals with CP and their social networks. Certain individuals with CP may benefit more from interventions focusing on raising self-efficacy, whereas others may experience greater improvements from interventions addressing social isolation by enhancing social integration. Network analysis, in which interrelationships between variables are being examined, might identify key variables to target in interventions. By identifying these key variables,

interventions can be tailored more effectively to address the specific needs of individuals with CP and ultimately improve their quality of life.

A few clinical implications can be drawn from the study results. Pain-related healthcare should aim to prevent lower well-being levels in individuals with CP. Social isolation may be crucial to proactively address. Healthcare providers may use tools like the short PROMIS® social isolation subscale to identify patients at risk and develop targeted interventions. Tackling social isolation among individuals with CP could serve as an empowering strategy to help them cope with these challenges. Furthermore, peer support from fellow individuals with CP may be beneficial in addressing social isolation and promoting social integration, for instance by encouraging participation in support groups of self-help organizations. However, it is also important to improve patients' integration in their personal social networks in general. At the societal level, interventions aimed at diminishing public stigmatization towards CP are crucial [2,74]. Previous research has shown that individuals from the general population tend to report more stigmatizing responses towards primary CP versus secondary CP [74], highlighting the need for tailored interventions aimed at the general public in which primary CP is differently targeted than secondary CP.

In conclusion, the findings underscore the importance of addressing stigma and social isolation to improve mental health outcomes in individuals with CP. Clinically, tailored interventions that consider the unique needs of patients with primary versus secondary CP are essential.

Disclosures: Research funding: this study was supported by two grants from the Fund for Scientific Research (FWO)-Flanders, Belgium (Grant No. G020118N awarded to Liesbet Goubert and Piet Bracke and grant No. 11K0421N awarded to Maité Van Alboom). Conflicts of interest: There are no conflicts of interest to declare.

Acknowledgements: We thank all participants for taking part in the study.

Author contributions

MVA, PB, SB, and LG conceived the design of the study. MVA collected, processed, and analyzed the data. MVA drafted the paper. All authors reviewed and approved the final manuscript.

Data statement: data are available on request. The study was not pre-registered.

Figure legends

Figure 1. Mediation SEM (structural) model with perceived stigma as latent predictor, social isolation as mediator, and well-being and functioning/participation in daily life as latent outcome variables. Bolding indicates statistically significant associations (all p< .001).

Figure 2. Moderated mediation SEM (structural) model with perceived stigma as latent predictor, social isolation as mediator, and well-being and functioning/participation in daily life as latent outcome variables. Bolding indicates statistically significant associations (all p< .001).

Figure 3. Mediation SEM (structural) model using differences scores with perceived stigma as latent predictor, social isolation as mediator, and well-being and functioning/participation in daily life as latent outcome variables. Bolding indicates statistically significant associations (all p< .001).

References

1. Holloway I, Sofaer-Bennett B, Walker J, et al. The stigmatisation of people with chronic back pain. *Disabil Rehabil*. 2007;29(18):1456-1464. doi:10.1080/09638280601107260.
2. DeRuddere L, Craig KD. Understanding stigma and chronic pain: A-state-of-the-art review. *Pain*. 2016;157(8):1607-1610. doi:10.1097/j.pain.0000000000000512
3. Gilbert T, Fiske S, Lindzey G, Editors. *The Handbook of Social Psychology*. Oxford University Press; 1998.
4. Parsons T. Definitions of Health and Illness in the Light of American Values and Social Structure. In: Jaco EG, ed. *Patients, Physicians and Illness.* Free Press; 1985:165-187.
5. Eccleston C, Crombez G. Worry and chronic pain : A misdirected problem solving model. *Pain*. 2007;132(3):233-236. doi:10.1016/j.pain.2007.09.014
6. Jackson JE. Stigma, liminality, and chronic pain: mind-body borderlands. *Am Ethnol*. 2005;32(3):332-353. doi:10.1525/ae.2005.32.3.332
7. Monsivais DB. Decreasing the stigma burden of chronic pain. *J Am Assoc Nurse Pract*. 2013;25(10):551-556. doi:10.1111/1745-7599.12010
8. Nicola M, Correia H, Ditchburn G, Drummond P. Invalidation of chronic pain: a thematic analysis of pain narratives. *Disabil Rehabil*. 2019;43(6):861-869. doi:10.1080/09638288.2019.1636888

9. McCracken LM, Gutieŕrez-Martínez O, Smyth C. “Decentering” reflects psychological flexibility in people with chronic pain and correlates with their quality of functioning. *Health Psychology*. 2013;32(7):820-823. doi:10.1037/a0028093

10. DeRuddere L De, Goubert L, Stevens M, Amanda AC, Crombez G. Discounting pain in the absence of medical evidence is explained by negative evaluation of the patient. *Pain*. 2013;154(5):669-676. doi:10.1016/j.pain.2012.12.018

11. Salaffi F, Puttini PS, Girolimetti R, Atzeni F, Gasparini S, Grassi W. Health-related quality of life in fibromyalgia patients: A comparison with rheumatoid arthritis patients and the general population using the SF-36 health survey. *Clin Exp Rheumatol*. 2009;27(5):67-74. doi:10.3389/fpsyg.2022.924405

12. DeRuddere L, Goubert L, Vervoort T, Prkachin KM, Crombez G. We discount the pain of others when pain has no medical explanation. *Journal of Pain*. 2012;13(12):1198-1205. doi:10.1016/j.jpain.2012.09.002

13. Kool MB, Van Middendorp H, Lumley MA, et al. Lack of understanding in fibromyalgia and rheumatoid arthritis: The Illness Invalidation Inventory (3*I). *Ann Rheum Dis*. 2010;69(11):1990-1995. doi:10.1136/ard.2009.123224

14. Van Alboom M, DeRuddere L, Kindt S, et al. Wellbeing and Perceived Stigma in Individuals with Rheumatoid Arthritis and Fibromyalgia. *Clin J Pain*. 2021;37(5):349-358. doi:10.1097/AJP.0000000000000929

15. Looper KJ, Kirmayer LJ. Perceived stigma in functional somatic syndromes and comparable medical conditions. *J Psychosom Res*. 2004;57(4):373-378. doi:10.1016/j.jpsychores.2004.03.005

16. Hickling LM, Allani S, Cella M, Scott W. A systematic review with meta-analyses of the association between stigma and chronic pain outcomes. *Pain*. 2024;165(8):1689-1701. doi:10.1097/j.pain.0000000000003243

17. Chaudoir SR, Earnshaw VA, Andel S. “Discredited” versus “Discreditable”: Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic Appl Soc Psych*. 2013;35:75-87. doi:10.1080/01973533.2012.746612

18. Corrigan PW, Penn DL. Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*. 1999;54(9):765-776. doi:10.1037/0003-066X.54.9.765

19. Mellado BH, Falcone ACM, Poli-Neto OB, Rosa E Silva JC, Nogueira AA, Candido-Dos-Reis FJ. Social isolation in women with endometriosis and chronic pelvic pain. *International Journal of Gynecology and Obstetrics*. 2016;133(2):199-201. doi:10.1016/j.ijgo.2015.08.024

20. Leung YY, Teo SL, Chua MB, Raman P, Liu C, Chan A. Living arrangements, social networks and onset or progression of pain among older adults in Singapore. *Geriatr Gerontol Int*. 2016;16:693-700. doi:10.1111/ggi.12539

21. Solé E, Racine M, Tomé-Pires C, Galán S, Jensen MP, Miró J. Social Factors, Disability and Depressive Symptoms in Adults with Chronic Pain. *Clin J Pain*. 2020;36(5):371-378. doi:10.1097/AJP.0000000000000815

22. Walker J, Sofaer B, Holloway I. The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. *European Journal of Pain*. 2006;10(3):199. doi:10.1016/j.ejpain.2005.03.007

23. Clarke KA, Iphofen R. A phenomenological hermeneutic study into unseen chronic pain. *British Journal of Nursing*. 2008;17(10):658–663. doi:10.12968/bjon.2008.17.10.29482

24. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a Fundamental Cause of Population Health Inequalities. *Public Health*. 2013;103:813-821. doi:10.2105/AJPH

25. Van Alboom M, Elmer T, Boersma K, et al. Social integration of adolescents with chronic pain: a social network analysis. *Pain*. 2022;163(11):2232-2244. doi:10.1097/j.pain.0000000000002623

26. Nicholson NR. Social isolation in older adults : an evolutionary concept analysis. *J Adv Nurs*. 2009;65(6):1342-1352. doi:10.1111/j.1365-2648.2008.04959.x

27. Leigh-Hunt N, Bagguley D, Bash K, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017;152:157-171. doi:10.1016/j.puhe.2017.07.035

28. Hengstebeck E, Roskos S, Breejen K, Arnetz B, Arnetz J. Chronic pain disrupts ability to work by interfering with social function: A cross-sectional study. *Scand J Pain*. 2017;17:397-402. doi:10.1016/j.sjpain.2017.09.021

29. Mun CJ, Thummala K, Davis MC, Karoly P, Tennen H, Zautra AJ. Predictors and social consequences of daily pain expectancy among adults with chronic pain. *Pain*. 2017;158(7):1224-1233. doi:10.1097/j.pain.0000000000000903

30. Van Alboom M, Baert F, Bernardes SF, et al. Examining the Role of Structural and Functional Social Network Characteristics in the Context of Chronic Pain: An Ego-centered Network Design. *Journal of Pain*. 2024;25(9):104525. doi:10.1016/j.jpain.2024.104525

31. Von Korff M Von, Ormel J, Keefe FJ, Dworkin SF. Grading the severity of chronic pain. *Pain*. 1992;50:133-149. doi:10.1016/0304-3959(92)90154-4.

32. Von Korff M, Stewart W, Lipton R. Assessing headache severity. New directions. *Neurology*. 1994;44:40-46.

33. Rao D, Choi SW, Victorson D, et al. Measuring stigma across neurological conditions: The development of the stigma scale for chronic illness (SSCI). *Quality of Life Research*. 2009;18(5):585-595. doi:10.1007/s11136-009-9475-1

34. Van Der Beek KM, Bos I, Middel B, Wynia K. Experienced stigmatization reduced quality of life of patients with a neuromuscular disease: A cross-sectional study. *Clin Rehabil*. 2013;27(11):1029-1038. doi:10.1177/0269215513487234

35. Scott W, Yu L, Patel S, McCracken LM. Measuring Stigma in Chronic Pain: Preliminary Investigation of Instrument Psychometrics, Correlates, and Magnitude of Change in a Prospective Cohort Attending Interdisciplinary Treatment. *Journal of Pain*. 2019;20(10):1164-1175. doi:10.1016/j.jpain.2019.03.011

36. Ballesteros J, Martínez-Ginés ML, García-Domínguez JM, Forero L, Prefasi D, Maurino J. Assessing stigma in multiple sclerosis: Psychometric properties of the eight-item Stigma Scale

for Chronic Illness (SSCI-8). *Int J MS Care*. 2019;21(5):195-199. doi:10.7224/1537-2073.2018-053

37. Yoo SH, Kim SR, So HS, et al. The Validity and Reliability of the Korean Version of the Stigma Scale for Chronic Illness 8-Items (SSCI-8) in Patients with Neurological Disorders. *Int J Behav Med*. 2017;24(2):288-293. doi:10.1007/s12529-016-9593-4

38. Lavefjord A, Sundström FTA, Buhrman M, McCracken LM. The role of stigma in health and functioning in chronic pain: Not just catastrophizing. *European Journal of Pain*. 2024;28(4):620-632. doi:10.1002/ejp.2207

39. Earnshaw VA, Quinn DM, Kalichman SC, Park CL. Development and psychometric evaluation of the Chronic Illness Anticipated Stigma Scale. *J Behav Med*. 2013;36(3):270-282. doi:10.1007/s10865-012-9422-4

40. Cella D, Riley W, Stone A, et al. Initial item banks and first wave testing of the Patient–Reported Outcomes Measurement Information System (PROMIS) network: 2005–2008. *J Clin Epidemiol*. 2010;63(11):1179-1194. doi:10.1016/j.jclinepi.2010.04.011.

41. Schalet BD, Pilkonis PA, Yu L, et al. Clinical validity of PROMIS Depression, Anxiety, and Anger across diverse clinical samples. *J Clin Epidemiol*. 2016;73:119-127. doi:10.1016/j.jclinepi.2015.08.036

42. Crins MHP, Terwee CB, Klausch T, et al. The Dutch–Flemish PROMIS Physical Function item bank exhibited strong psychometric properties in patients with chronic pain. *J Clin Epidemiol*. 2017;87:47-58. doi:10.1016/j.jclinepi.2017.03.011

43. Matsunaga M. Item Parceling in Structural Equation Modeling: A Primer. *Commun Methods Meas*. 2008;2(4):260-293. doi:10.1080/19312450802458935

44. Ibaseta A, Rahman R, Andrade NS, et al. Determining validity, discriminant ability, responsiveness, and minimal clinically important differences for PROMIS in adult spinal deformity. *J Neurosurg Spine*. 2021;34(5):725-733. doi:10.3171/2020.8.SPINE191551

45. Bartlett SJ, Orbai AM, Duncan T, et al. Reliability and validity of selected PROMIS measures in people with rheumatoid arthritis. *PLoS One*. 2015;10(9):1-14. doi:10.1371/journal.pone.0138543

46. Cheung GW, Rensvold RB. Evaluating goodness-of-fit indexes for testing measurement invariance. *Structural Equation Modeling*. 2002;9(2):233-255. doi:10.1207/S15328007SEM0902_5

47. Cheung GW, Rensvold RB. Evaluating goodness-of-fit indexes for testing measurement invariance. *Structural Equation Modeling*. 2002;9(2):233-255. doi:10.1207/S15328007SEM0902_5

48. Schmitt N, Kuljanin G. Measurement invariance: Review of practice and implications. *Human Resource Management Review*. 2008;18(4):210-222. doi:10.1016/j.hrmr.2008.03.003

49. Sass DA. Testing measurement invariance and comparing latent factor means within a confirmatory factor analysis framework. *J Psychoeduc Assess*. 2011;29(4):347-363. doi:10.1177/0734282911406661

50. Rosseel Y. Lavaan: An R Package for Structural Equation Modeling. *J Stat Softw*. 2012;48(2):1-36. doi:10.18637/jss.v048.i02

51. Kline RB. *Principles and Practice of Structural Equation Modeling.* The Guilford Press; 2005.

52. Hooper D, Coughlan J, Mullen M. Structural Equation Modelling: Guidelines for Determining Model Fit. *Electron*. 2008;6(1):53-60. doi:10.21427/D7CF7R

53. Selig JP, Preacher KJ. Mediation Models for Longitudinal Data in Developmental Research. *Res Hum Dev*. 2009;6(2-3):144-164. doi:10.1080/15427600902911247

54. MacKinnon DP. *Introduction to Statistical Mediation Analysis*. (Harlow L, ed.). Lawrence Erlbaum associates; 2008.

55. Byrne BM. Structural Equation Modeling: Perspectives on the Present and the Future. . *Int J Test*. 2001;1(3-4):327-334. doi:10.1080/15305058.2001.9669479

56. World Health Organization. *International Classification of Functioning, Disability and Health*.; 2001. Accessed 02/12/2024. https://iris.who.int/bitstream/handle/10665/42407/9241545429.pdf?sequence=1

57. Turan B, Smith W, Cohen MH, et al. Mechanisms for the Negative Effects of Internalized HIV-Related Stigma on Antiretroviral Therapy Adherence in Women: The Mediating Roles of Social Isolation and Depression. *J Acquir Immune Defic Synd*. 2016;72(2):198-205. doi:10.1097/QAI.0000000000000948.

58. Peplau LA, Perlman D. Perspectives on loneliness. In: *Loneliness: A Sourcebook of Current Theory, Research and Therapy*. Wiley; 1982:1-18.

59. Taylor HO, Taylor RJ. Intersectional approaches to equity in men's health and well-being interpersonal and structural social isolation among african american and black caribbean men. *International Journal of Men's Social and Community Health*. 2020;3(2):e1-e18. doi:10.22374/ijmsch.v3i2.33

60. Nguyen AW, Taylor HO, Taylor RJ, et al. The role of subjective, interpersonal, and structural social isolation in 12-month and lifetime anxiety disorders. *BMC Public Health*. 2024;24:760. doi:10.1186/s12889-024-18233-2

61. Xu Z, Müller M, Heekeren K, et al. Pathways between stigma and suicidal ideation among people at risk of psychosis. *Schizophr Res*. 2016;172(1-3):184-188. doi:10.1016/j.schres.2016.01.048

62. Drenkard C, Theis KA, Daugherty TT, et al. Depression, stigma and social isolation: the psychosocial trifecta of primary chronic cutaneous lupus erythematosus, a cross-sectional and path analysis. *Lupus Sci Med*. 2022;9:e000697. doi:10.1136/lupus-2022-000697

63. Prizeman K, Weinstein N, McCabe C. Effects of mental health stigma on loneliness, social isolation, and relationships in young people with depression symptoms. *BMC Psychiatry*. 2023;23:527. doi:10.1186/s12888-023-04991-7

64. Seth R, Kurmi SK, Kumari S, Pradhan D. Aging with Physical Disabilities: Experience Intersected by Stigma, Social Isolation and Finitude. *Escola Anna Nery*. 2018;22(4):e20180128. doi:10.1590/2177-9465-ean-2018-0128

65. Kesmen H, Cengiz AK, Bilgici A. Effects of disease activity, illness perception, social support and coping methods on quality of life in the patients with rheumatoid arthritis and fibromyalgia syndrome. *Ann Rheum dis*. 2019;78:679. doi:10.1136/annrheumdis-2019-eular.8039

66. Tander B, Cengiz K, Alayli G, Ilhanli I, Canbaz S, Canturk F. A comparative evaluation of health related quality of life and depression in patients with fibromyalgia syndrome and rheumatoid arthritis. *Rheumatol Int*. 2008;28(9):859-865. doi:10.1007/s00296-008-0551-6

67. Kool MB, van Middendorp H, Boeije HR, Geenen R. Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis Rheum*. 2009;61(12):1650-1656. doi:10.1002/art.24922

68. Bannon S, Greenberg J, Mace RA, Locascio JJ, Vranceanu AM. The role of social isolation in physical and emotional outcomes among patients with chronic pain. *Gen Hosp Psychiatry*. 2021;69:50-54. doi:10.1016/j.genhosppsych.2021.01.009

69. Karayannis N V., Baumann I, Sturgeon JA, Melloh M, Mackey SC. The Impact of Social Isolation on Pain Interference: A Longitudinal Study. *Annals of Behavioral Medicine*. 2019;53(1):65-74. doi:10.1093/abm/kay017

70. Oliveira VC, Ferreira ML, Morso L, Albert HB, Refshauge KM, Ferreira PH. Patients' perceived level of social isolation affects the prognosis of low back pain. *European Journal of Pain*. 2015;19(4):538-545. doi:10.1002/ejp.578

71. Gollwitzer M, Christ O, Lemmer G. Individual differences make a difference: On the use and the psychometric properties of difference scores in social psychology. *Eur J Soc Psychol*. 2014;44(7):673-682. doi:10.1002/ejsp.2042

72. Bernardes FS, Lima ML. Being less of a man or less of a woman: Perceptions of chronic pain patients' gender identities. *European Journal of Pain*. 2010;14(2):194-199. doi:10.1016/j.ejpain.2009.04.009

73. Bernardes FS, Keogh E, Lima ML. Bridging the gap between pain and gender research: A selective literature review. *European Journal of Pain*. 2008;12(4):427–440. doi:10.1016/j.ejpain.2007.08.007

74. Van Alboom M, Baert F, Bernardes SF, Bracke P, Goubert L. Public chronic pain stigma and the role of pain type and patient gender: An experimental vignette study Running title: public chronic pain stigma: role of pain type and gender. *Journal of Pain*. 2023;24(10):1798-1812. doi:10.1016/j.jpain.2023.05.007

Figure 1

Click here to access/download;Figure;Figure1final.pdf

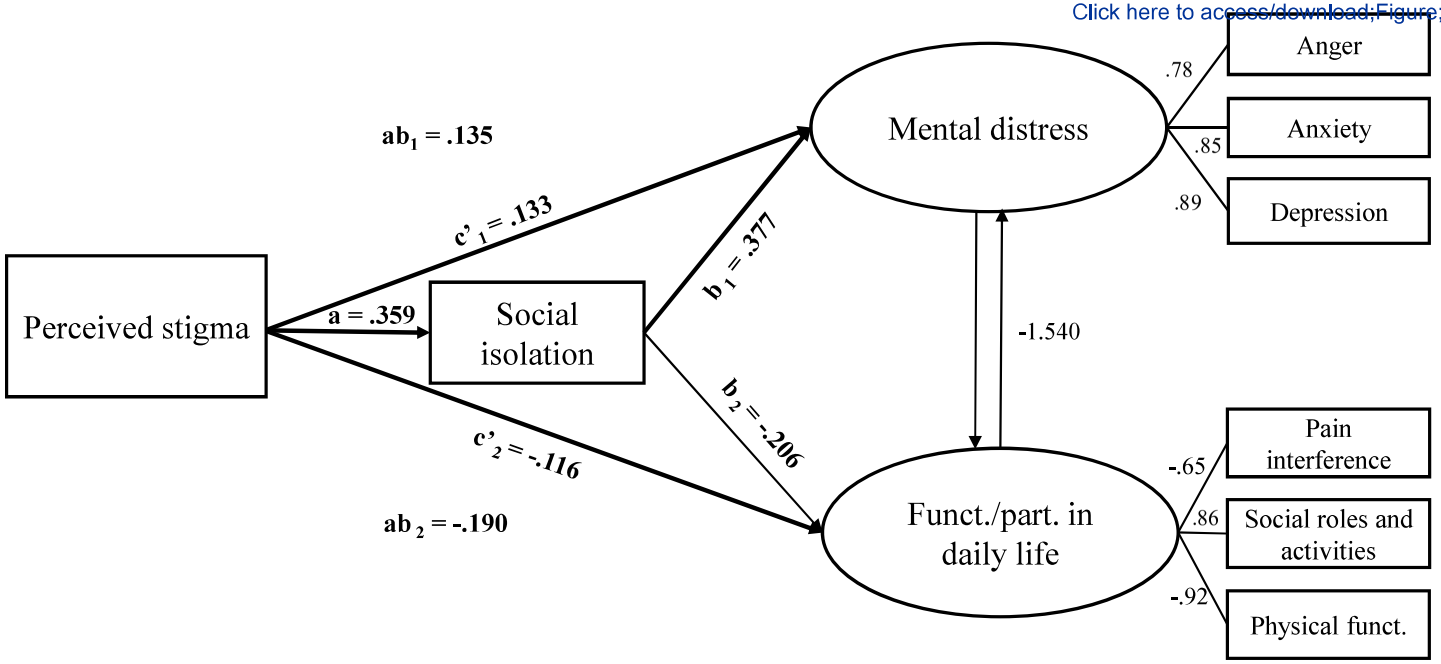


Figure 2

Click here to access/download;Figure;Figure2final.pdf

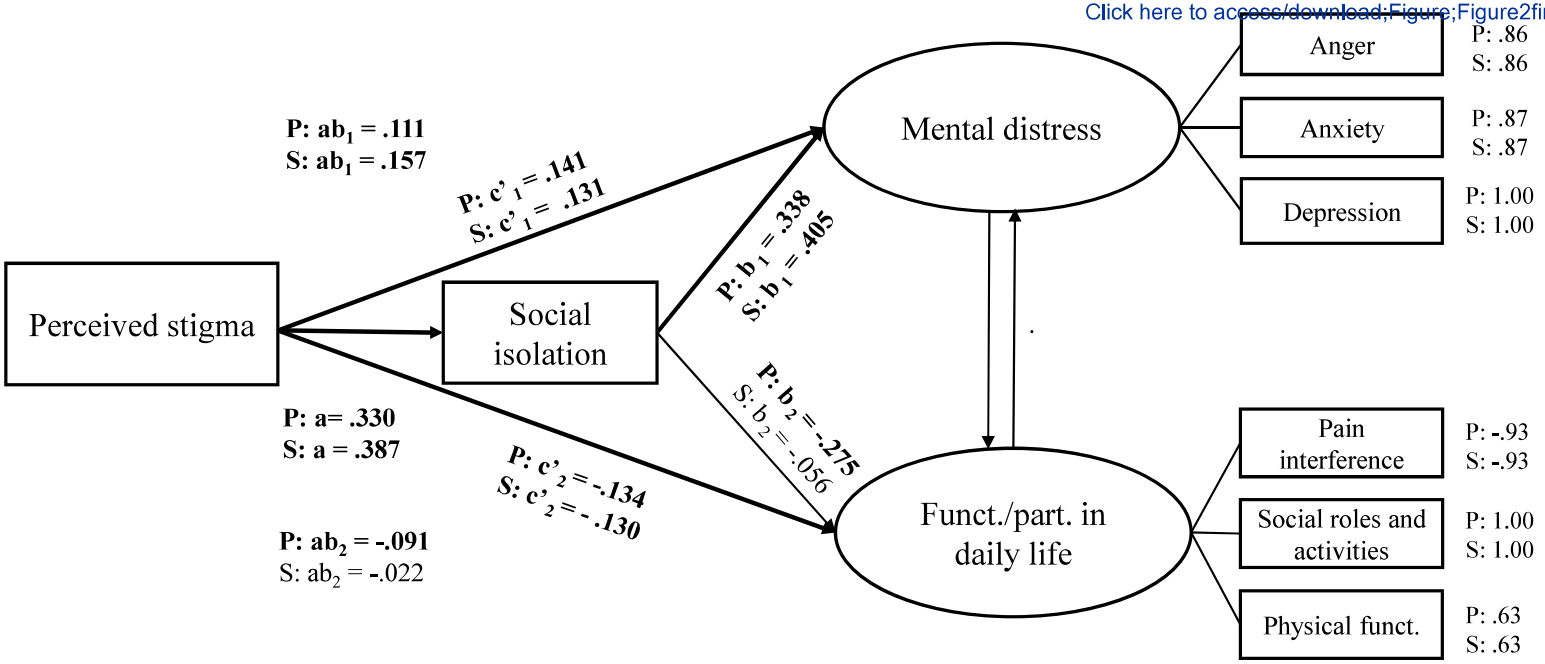
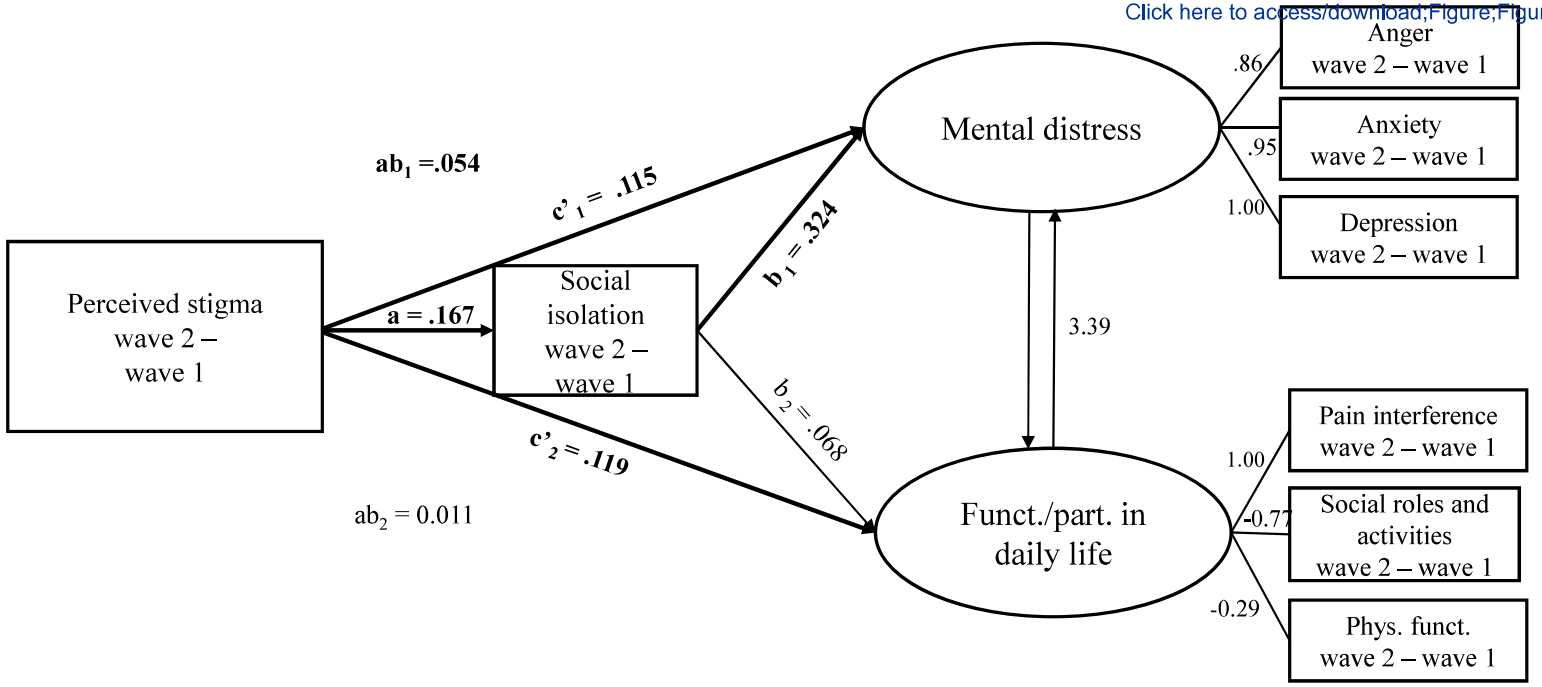


Figure 3

Click here to access/download;Figure;Figure3final.pdf



Tables
Click here to access/download;Tables;REVIEW_Tables_GENSI_STIGMA.d

Table 1. *Sociodemographic and pain characteristics*

	Primary CP (N=137)	**Secondary CP (N=131)**	**Unclear diagnosis (N=64)**
	M (SD) or N(%)	**M (SD) or N(%)**	**M (SD) or N(%)**
Gender			
Women	123 (89.8)	109 (83.2)	39 (60.9)
Men	14 (10.2)	22 (6.9)	25 (41.7)
Other gender identities	0	0	0
Age (years)	50 (12)	56 (12)	56 (11)
Nationality			
Belgium	131 (95.6)	123 (94.6)	59 (98.3)
Other	6 (4.4)	7 (5.4)	1 (1.7)
Marital status			
Married or cohabiting	95 (69.3)	95 (73.1)	36 (60)
In a relationship	10 (7.3)	3 (2.3)	6 (10)
Single	32 (23.4)	32 (24.6)	18 (30)
Work status			
Student	0	1 (0.8)	0
Working	23 (16.8)	33 (25.4)	8 (13.3)
Housewife/-man	4 (2.9)	4 (3.1)	0
Unemployed	6 (4.4)	2 (1.5)	3 (5.0)
Full or partial allowance	71 (51.8)	50 (38.5)	33 (55)
Retired	33 (24.1)	40 (30.8)	16 (26.7)
Education			
Primary school	1 (0.7)	0	1 (1.7)
Lower secondary 1st grade	11 (8.0)	8 (6.2)	7 (11.7)
Secondary 2nd and 3rd grade and short cycle higher education	76 (55.5)	58 (44.6)	28 (46.7)
Higher education – bachelor	43 (31.4)	46 (35.4)	19 (31.7)
Higher education – master	6 (4.4)	18 (13.9)	5 (8.3)
Pain duration (years)	18.5 (11.6)	17.5 (11.1)	18.4 (11.9)
Pain grades			
Pain grade I	3 (2.2)	17 (13.1)	3 (5.0)
Pain grade II	12 (8.8)	20 (15.4)	7 (11.7)
Pain grade III	27 (19.7)	35 (26.9)	11 (18.3)
Pain grade IV	95 (69.3)	58 (44.6)	39 (65.0)

N = number, M = mean, SD = Standard deviation. Grade 0 = no pain, Grade I = low intensity and low disability, Grade II = high intensity and low disability, Grade III = moderate disability, regardless of pain intensity, Grade IV = high disability, regardless of pain intensity.

Table 2. *Means of all variables in wave 1 and wave 2.*

Variable	Wave 1	Wave 2
Internalized + enacted stigma	32.04	30.68
Anticipated stigma	17.92	17.81
Social isolation	53.70	53.11
Depression	57.03	57.25
Anxiety	59.56	60.17
Anger	55.93	55.65
Physical functioning	34.78	35.33
Pain interference	65.55	64.44
Ability to participate in social roles and activities	38.14	39.26

Table 3. *Descriptive characteristics of individual difference scores related to research question 4.*

Variable	Min – Max	Mean	SD
Internalized + enacted stigma	47 to 39	-1.163	12.47
Anticipated stigma	-19 to 21	-0.034	5.79
Social isolation	-23 to 18	-0.423	5.55
Depression	-32 to 20	0.435	6.75
Anxiety	-34 to 25	0.645	7.14
Anger	-19 to 21	-0.357	7.41
Physical functioning	-10 to 10	0.333	2.62
Pain interference	-19 to 12	-0.977	4.24
Ability to participate in social roles and activities	-16 to 19	0.435	6.75

Table 1. Means, standard deviations and bivariate Pearson correlations for all variables.

		M (SD)	a	2	3	4	5	6	7	8	9	10	11
	Predictors												
1	Pain intensity	65.90 (15.37)	.82	.70**	.41**	.25**	.36**	.34**	.30**	.25**	.66**	-.53**	-.50**
2	Pain disability	63.23 (20.42)	.90	-									
3	Internalized + enacted stigma	20.85 (11.26)	.91		-	.70**	.74**	.59**	.53**	.49**	.59**	-.53**	-.31**
4	Anticipated stigma	17.92 (7.43)	.91			-	.63**	.45**	.41**	.42**	.43**	-.40**	-.17**
	Mediator												
5	Social isolation	53.70 (8.97)	.95				-	.61**	.55**	.51**	.55**	-.55**	-.33**
	Outcomes												
6	Depression	57.03 (8.93)	.95					-	.79**	.70**	.52**	-.37**	-.17**
7	Anxiety	59.56 (8.54)	.95						-	.70**	.41**	-.30**	-.10
8	Anger	55.93 (9.43)	.91							-	.41**	-.30**	-.07
9	Pain interference	65.55 (5.81)	.95								-	-.79**	-.60**
10	Social roles and activities	38.14 (6.61)	.95									-	.58**
11	Physical functioning	34.78 (5.89)	.92										-

*p< 0.05; ** p< 0.01; *** p< 0.001

Table 2. *Goodness-of-fit statistics for models testing MI of the SSCI-SF across CP type related to RQ1.*

Model	$\chi 2$	df	CFI	RMSEA	SRMR
1 baseline	30.530	12	0.985	0.076	0.036
2 primary CP	28.449	12	0.974	0.102	0.042
3 secondary CP	22.610	12	0.982	0.047	0.047
4 configural	51.059	24	0.978	0.040	0.040
5 metric	55.444	30	0.979	0.049	0.049
6 partial scalar	61.492	34	0.977	0.052	0.052

Table 3. *Goodness-of-fit statistics for models testing MI of the CIASS across CP type related to RQ1.*

Model	$\chi 2$	df	CFI	RMSEA	SRMR
1 baseline	39.218	19	0.989	0.063	0.031
2 primary CP	20.692	19	0.998	0.026	0.033
3 secondary CP	39.863	19	0.975	0.090	0.055
4 configural	60.555	38	0.987	0.067	0.040
5 metric	63.646	44	0.989	0.058	0.047
6 scalar	75.466	50	0.985	0.062	0.051
7 strict	96.181	58	0.978	0.070	0.058
8 more strict	96.181	58	0.978	0.070	0.058

Table 4. *Goodness-of-fit statistics for models testing MI across CP type related to RQ3*

Model	$\chi 2$	df	CFI	RMSEA	SRMR
1 baseline	123.539	71	0.959	0.074	0.057
2 primary CP	58.746	27	0.954	0.095	0.044
3 secondary CP	43.615	27	0.971	0.067	0.065
4 configural	123.539	71	0.959	0.074	0.057
5 metric	130.795	75	0.956	0.075	0.063
6 scalar	143.341	80	0.950	0.077	0.072
7 partial strict	149.949	86	0.950	0.074	0.075

Table 5. *Goodness-of-fit statistics for models testing MI of stigma measures across waves related to RQ4*

Model	$\chi 2$	df	CFI	RMSEA	SRMR
1 baseline	318.663	94	0.970	0.062	0.038
2 primary CP	213.75	94	0.970	0.062	0.043
3 secondary CP	180.611	94	0.976	0.056	0.041
4 configural	394.361	188	0.973	0.059	0.040
5 metric	406.282	200	0.973	0.057	0.043
6 scalar	418.014	212	0.973	0.056	0.043
7 strict	444.327	228	0.971	0.055	0.045
8 more strict	451.124	232	0.971	0.055	0.045

Table 6. *Goodness-of-fit statistics for models testing MI of outcome measures across waves related to RQ4*

Model	$\chi 2$	df	CFI	RMSEA	SRMR
1 baseline	3513.825	1293	0.934	0.052	0.050
2 primary CP	2500.878	1293	0.932	0.053	0.053
3 secondary CP	2520.917	1293	0.924	0.057	0.056
4 configural	5021.795	2586	0.928	0.055	0.053
5 metric	5058.191	2632	0.928	0.054	0.055
6 scalar	5149.607	2678	0.927	0.054	0.055
7 strict	5235.95	2731	0.926	0.054	0.056
8 more strict	5255.238	2742	0.926	0.054	0.056

Manuscript (revised, marked copy) Click here to view linked References

Two-wave study on intrapersonal stigma, social isolation, well-being, and functioning in individuals with chronic pain: A structural equation modeling approach

Van Alboom Maité*, Bernardes Sónia F.**, Baert Fleur*, Bracke Piet***, Goubert Liesbet*

*Ghent University, Faculty of Psychology and Educational Sciences, Department of Experimental-Clinical and Health Psychology

** ISCTE, Instituto Universitario de Lisboa, School of Social Sciences, Department of Social and Organizational Psychology

***Ghent University, Faculty of Political and Social Sciences, Department of Sociology

Corresponding author: Maité Van Alboom - Address: Ghent University, Faculty of Psychology and Educational Sciences. Henri Dunantlaan 2, 9000 Ghent, Belgium. - Email: maite.vanalboom@ugent.be – Tel: +32473353773

Running title: stigma, social isolation, and well-being/functioning in the context of chronic pain