

ORIGINAL REPORT

FACING INVALIDATION: A FURTHER CHALLENGE WHEN LIVING WITH CHRONIC WIDESPREAD PAIN

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Objective: The concept of “invalidation” refers to the patient’s perception that the social environment does not recognize their medical condition. This study explores and describes invalidation experiences among Swedish patients with chronic widespread pain with regard to sociodemographic and pain characteristics, impact of pain, self-reported health, and symptoms of anxiety and depressive.

Methods: A cross-sectional design using questionnaires, including sociodemographic and pain variables, the Illness Invalidation Inventory (Likert scale items regarding 5 sources), the Hospital Anxiety and Depression Scale, and the Short-Form General Health Survey. Descriptive and univariate analyses were applied.

Results: Of the 152 respondents, 91% were women. Swedish patients with chronic widespread pain experienced invalidation to a large extent from all sources. The highest scores for invalidation were reported from contacts with social services (68%), and the lowest from spouses (30%). Being younger ($p < 0.006$), having periodic pain ($p = 0.011$), and having had more frequent visits to a doctor in the previous year ($p = 0.007$) were characteristics associated with higher invalidation scores. Experiences of invalidation were associated with worse self-reported mental health scores ($r = -0.29$ to -0.46).
Conclusion: Since patients with chronic widespread pain frequently experience invalidation from the social environment, this further challenge in daily life must be taken into consideration in pain management within multimodal pain rehabilitation.

Key words: chronic widespread pain; invalidation; self-reported health; anxiety; depression.

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Chronic widespread pain (CWP) is a condition characterized by generalized persisting body

LAY ABSTRACT

Patient’s perception that the social environment does not recognize their medical condition may be defined as “invalidation”. This study explores invalidation experiences among Swedish patients with chronic widespread pain with regard to a range of sociodemographic and health factors. Questionnaires, including the Illness Invalidation Inventory, were sent by post to a sample of patients with chronic widespread pain. Most of the respondents were women. Swedish patients with widespread pain experienced invalidation to a large extent. The highest scores for invalidation were reported from contacts with social services, and the lowest from spouses. Being younger, having periodic pain, and having had more frequent visits to the doctor in the previous year were characteristics associated with higher invalidation scores. Experiences of invalidation were associated with worse mental health. Pain management within rehabilitation must thus take the patient’s experiences of invalidation from the social environment into consideration as an important aspect.

pain for at least 3 months (1, 2), with an estimated prevalence of approximately 10% (3). The unclear aetiology, combined with the characteristics of the invisible illness, may cause others to disbelieve the symptoms presented by the patient, with subsequent lack of understanding and discounting by them. The term “invalidation” has been used to illustrate the phenomenon that occurs when patients perceive that the social environment does not recognize their illness. This phenomenon depends on the interaction between intentional or unintentional invalidation from persons in the environment, and the patient’s personal interpretation of the provided response (4). Invalidation includes 2 dimensions, discounting (denying and patronising) and lack of understanding (lack of support and acknowledgment), based on suspicion that the illness could be exaggerated or solely psychological (4). This entails that the overall burden of having a chronic illness and defending this unwanted new identity from invalidation (5) may increase the risk of experiences of reduced physical and psychological health (6, 7). The Illness Invalidation Inventory was developed by Kool

et al. with Likert scale scorings regarding frequency, from seldom/rarely to often/very often (8).

Several studies (8–10) have shown that invalidation may arise from different sources, including spouses, other family members, colleagues, medical professionals and social services. It is believed that invalidation experienced by patients with rheumatic diseases, especially in the case of discounting from closer relations (e.g. a spouse or partner), may have negative impact on pain and mental well-being (8–10). Similarly, discounting from family members has been found to be a significant predictor of depressive disorders in diabetic patients (11). Qualitative studies also show that family life as a whole may be influenced and limited when patients with pain encounter invalidation (12). Invalidation from medical professionals may interfere with decision-making and may complicate pain management in patients with fibromyalgia (13). A significant proportion of patients with fibromyalgia, a large subcategory of CWP, were found to have frequently experienced invalidation from social services (8).

A biopsychosocial approach is applied in modern pain management of CWP. Thus, healthcare including rehabilitation is based on a model covering biological, psychological and social factors (14, 15). The biopsychosocial approach in pain management strategies is widely accepted, even though the social domain seems to have received less attention than the other components of the model. Furthermore, the associations between invalidation and different health outcomes have not been extensively examined. Since CWP is a common health condition, more knowledge is needed concerning the experience of invalidation, as well as to what extent patients with CWP experience invalidation and from which sources. Such findings may be used to guide the actions to be taken in clinical management. Hence, the aim of this study was to explore and describe invalidation experiences among Swedish patients with CWP. A further aim was to analyse the association between experiences of invalidation and sociodemographic and pain characteristics, impact of pain, self-reported health, and symptoms of anxiety and depression.

MATERIALS AND METHODS

Design

The study had a cross-sectional design including postal questionnaires.

Participants

During January 2011 to June 2013, patients were consecutively recruited from the Pain and Rehabilitation Centre at Linköping university hospital, Sweden. The

inclusion criteria were: at least 18 years of age, able to understand Swedish, and having CWP according to the Manchester definition (1), as found in reviewed pain drawings. CWP according to the Manchester definition requires spreading of pain to be present in the axial skeleton above and below the waist, in at least 2 sections of a limb in 2 contra-lateral limbs (1). According to power analysis, 128 respondents would be sufficient for statistical analyses (to describe invalidation experiences with regard to the different sources and the 2 dimensions). The numbers of patients with CWP reporting data in all questionnaires are shown in Tables I–III. For patients whose pain drawing met the definition criteria, their medical records were reviewed; 330 patients with CWP met the basic inclusion criteria.

Procedure

First, the patients received an information letter about the study and, after 1 week, questionnaires with a more detailed letter informing about the purpose of the study were sent to the patients by post.

Self-report measures

Sociodemographic and pain characteristics. Sociodemographic and pain characteristics were self-reported

Table I. Sociodemographic and clinical characteristics of patients with chronic widespread pain (CWP) ($n = 152$)

Characteristics	
Sex, n (%)	
Women	138 (91)
Age (years), n (%)	
18–46	80 (53)
Mean (SD)	46.3 (14)
Median (range)	46 (19–80)
Family situation, n (%)	
Cohabiting with adult	108 (71)
Education, n (%)	
Low up to upper secondary	129 (85)
Work status, n (%)	
Working/studying	48 (31)
Pain characteristics	
Spread of pain according to Manchester definition, n (%)	114 (75)
Pain duration (years), n (%)	
0–16	89 (62)
Mean (SD)	16 (11)
Median (range)	13 (2–49)
Form of pain, n (%)	
Periodic pain	18 (13)
Persisting pain	125 (87)
Pain severity by BP Bodily Pain of SF36 ^a ($n = 151$), mean (SD)	24 (15)
Anxiety and depression ^b	
HADS Anxiety symptoms ($n = 149$), n (%)	
Cases*	49 (33)
HADS Depressive symptoms ($n = 148$), n (%)	
Cases*	48 (32)
Visits to physician in previous 12 months, n (%)	
≥ 4 visits	97 (64)

^aBP (Bodily Pain) is a dimension of SF36 The Short-Form General Health Survey

^bNote: the data concerning pain severity and anxiety and depression have been published elsewhere by Järemo et al. in 2017 (28).

HADS: Hospital Anxiety and Depression Scale; SD: standard deviation.

*Cases = HADS cut-off point 11.

Table II. Invalidation^a experiences of patients with chronic widespread pain (CWP) ($n = 152$)

Dimensions of invalidation	Source of invalidation	<i>n</i>	Mean (SD)	Median (range)
Discounting	Spouse	112	2.1 (0.9)	1.8 (1–5)
	Family	145	2.2 (1.0)	2.0 (1–5)
	Medical professionals	143	2.4 (1.1)	2.2 (1–5)
	Work environment ^b	70	2.5 (1.0)	2.4 (1–5)
	Social services ^b	95	3.1 (1.1)	3.0 (1–5)
Lack of understanding	Spouse	114	2.2 (1.0)	2.0 (1–5)
	Family	145	2.4 (1.0)	2.3 (1–5)
	Medical professionals	142	2.6 (1.0)	2.7 (1–5)
	Work environment ^b	70	3.0 (0.9)	3.0 (1–5)
	Social services ^b	97	3.3 (1.0)	3.3 (1–5)

^aIllness Invalidation Inventory (3*I): 5-point Likert scale (1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = very often).

^bSections that were omitted by those not working/not having contact with social services.

background data, and included sex, age, family situation, education (low to upper secondary/post-secondary level and higher), work status, form of pain (periodic/persisting), pain duration, level of and impact of pain indicated by BP (Bodily Pain, Short-Form 36 (SF-36)), number of visits to physicians in the previous year ($<4/\geq 4$) and spread of pain. To confirm the presence of widespread pain, the spread of pain was indicated, using a table with 18 boxes each for the left and right sides of the body. The pain table was subsequently evaluated according to the Manchester definition, (CWP yes/no). Variables that were dichotomized were sex (female/male), age ($\leq 46/>46$ years), education (low/high), cohabiting (yes/no), working or studying (yes/no), pain duration ($\leq 16/>16$ years), form of pain (periodic/persisting), spread of pain according to the Manchester definition (1) (yes/no) and number of visits to a physician in the previous year ($<4/\geq 4$).

Invalidation. The Illness Invalidation Inventory (3*I) (8) Swedish version (16) was used to measure the occurrence of invalidation from 5 different sources (spouse, family, medical professionals, work environment, and social services). The 8 items, repeated for each source,

cover the dimensions *discounting* (5 items) and *lack of understanding* (3 items). Participants indicate on a 5-point Likert scale (1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = very often) how often people in each source reacted to them in the described way during the past year. Non-applicable sections could be omitted (e.g. if the patient was not working). The questionnaire is generated for patients with rheumatic diseases and is reported to have good psychometric properties (8). Levels of invalidation, discounting and lack of understanding, were calculated with mean and standard deviation (SD) for the 5 sources, respectively. To show the frequency of invalidation, the proportions of patients were classified into 3 groups; “often/very often”, “sometimes”, and “never/rarely” (8).

Symptoms of anxiety and depression. The Hospital Anxiety and Depression Scale (HADS) (17, 18) is a self-report rating scale for assessing the presence and severity of anxiety and depression in non-psychiatric settings. Two subscales, each containing 7 items on a 4-point Likert scale (ranging from 0 to 3), are summed separately to yield scores for anxiety and depression. Each subscale ranges from 0 to 21; higher scores

Table III. Correlations^a (correlation coefficient *r*) together with number of respondents (*n*) between dimensions of invalidation^b and SF-36^c (MCS, PCS, BP) in patients with CWP ($n = 152$)

Dimensions of invalidation	Source of invalidation	MCS <i>r</i>	MCS <i>n</i>	PCS <i>r</i>	BP ^d <i>r</i>	PCS & BP <i>n</i>
Discounting	Spouse	-0.40*	110	-0.11	-0.18	112
	Family	-0.29*	141	-0.03	-0.17	144
	Medical professionals	-0.05	139	-0.04	-0.02	142
	Work environment	-0.46*	68 ^e	0.08	-0.16	70 ^e
	Social services	-0.12	93 ^e	-0.03	-0.03	94 ^e
Lack of understanding	Spouse	-0.31*	112	-0.08	-0.07	114
	Family	-0.14	141	0.06	0.05	144
	Medical professionals	0.03	138	-0.04	0.06	141
	Work environment	-0.42*	68 ^e	0.07	-0.12	70 ^e
	Social services	-0.06	95 ^e	-0.01	0.01	96 ^e

A negative correlation indicates that more discounting and lack of understanding are associated with worse mental and physical health and more severe pain.

^aSpearman's correlation.

*Significant correlation.

^b3*I: Illness Invalidation Inventory.

^cSF-36: Mental Component Summary (MCS), Physical Component Summary (PCS).

^dBP (Bodily Pain) is a dimension of PCS.

^eSections that could be omitted by those not working/not having contact with social services.

indicating greater anxiety/depression. A cut-off point of 11 was chosen to indicate a definite case.

Self-reported health status. The Short-Form General Health Survey (SF-36) Swedish version (19, 20) was used to measure patients' self-reported health status. SF-36 is a self-report rating scale that includes 36 items covering 8 domains (physical functioning, role of limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role of limitations due to emotional problems and mental health), which are summarized into separate physical component scale (PCS) and mental component scale (MCS) summaries. The domains are reported using a standardized scale from 0 to 100. The SF-36 scores were computed according to the procedure proposed by Ware et al. (20), and higher scores represent less affected health status.

Statistical analyses

Analyses were performed with SPSS 24.0. The significance level was set at $p \leq 0.01$ in all analyses. Analyses of associations were performed using the Mann–Whitney *U* test (21) with invalidation scores and dichotomized sociodemographic characteristics, pain characteristics and anxiety and depressive symptoms. The Spearman correlation test (21) was used to examine correlations between dimensions of invalidation, self-reported health status including PCS, MCS and BP. To label the strength of the rank correlations, 0.1 was regarded as small, 0.3 as moderate and 0.5 as large (22).

Ethical considerations

The Regional Ethics Review Board in Stockholm (2011/1384-31/3) and the management of the Pain and Rehabilitation Centre, Linköping University Hospital, Linköping approved the study. The patients received information letters prior to the study and they consented to participation in the study by returning the questionnaires.

RESULTS

Sociodemographic and clinical characteristics

The sociodemographic and clinical characteristics of the patients with CWP are shown in Table I. Some 152 (46%) patients with CWP responded, of whom 91% were women, the mean age was 46.3 years, and 31% were working or studying. CWP, according to the Manchester definition, when answering the questionnaire, was reported by 75% of the patients and 87% reported having persisting pain. Some 72% reported having severe or very severe pain in the

previous 4 weeks, and approximately a third of the patients with CWP reported symptoms of depression (32%) and anxiety (33%). Over half of the sample (64%) had visited physicians more than 4 times in the previous year (Table I).

Invalidation experiences and associations with sociodemographic and pain characteristics

Highest scores of invalidation were reported from contacts with social services for discounting (mean \pm SD) (3.0 ± 1.1) and lack of understanding (mean \pm SD) (3.3 ± 1.0), respectively (Table II). More than half of the patients with CWP were experiencing discounting (sometimes or often/very often) from social services (68%) and lack of understanding from medical professionals (55%), work (66%) and social services (72%). The least discounting and lack of understanding were experienced from the spouse (30% and 36%) (Fig. 1).

Patients with CWP under the age of 46 years (median age of the group) reported significantly higher discounting scores than those above the median age regarding the sources family ($p=0.006$), medical professionals ($p<0.001$), and social services ($p=0.006$). Patients with CWP who had had 4 or more visits to a physician in the previous 12 months reported significantly higher discounting scores from the source work ($p=0.007$). Those patients with periodic pain reported significantly higher discounting scores from the source medical professionals than patients with persistent pain ($p=0.011$).

Associations between invalidation and health status, pain, anxiety, and depressive symptoms

Ratings of MCS correlated significantly and negatively with discounting from spouse ($r=-0.4$), family ($r=-0.29$) and work environment ($r=-0.46$) (Table III). Furthermore, ratings of MCS significantly and negatively correlated with lack of understanding from spouse ($r=-0.31$) and work environment ($r=-0.42$). Impact of pain (BP) was weakly correlated with discounting from family ($r=0.17$). No correlations were found between dimensions of invalidation and PCS (Table III).

The presence of anxiety symptoms was significantly associated with experiencing more discounting from work ($p=0.010$) and social services ($p=0.009$). The presence of depressive symptoms was significantly associated with experiencing discounting from spouse ($p<0.001$) and family ($p=0.010$).

DISCUSSION

The results of the current study showed that large proportions of Swedish patients with CWP experienced invalidation from all sources studied, according to

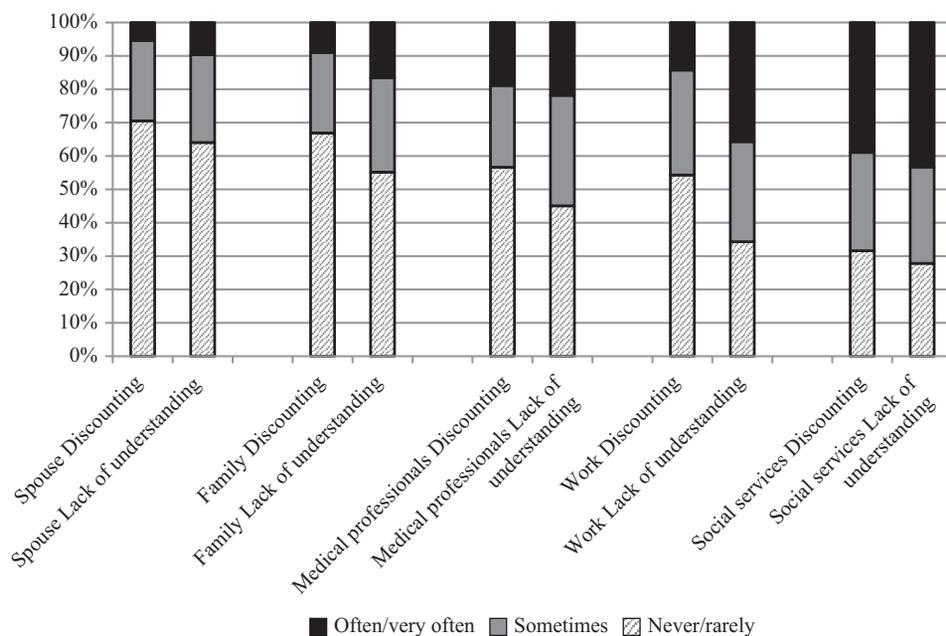


Fig. 1. Percentage (%) of patients who experienced discounting and lack of understanding from the 5 sources "never/rarely", "sometimes" and "often/very often" according to the Illness Invalidation Inventory (3*1).

the self-report measure 3*1. The highest scores of invalidation were reported from contacts with social services and the lowest scores from spouses, both regarding discounting and lack of understanding. Of the sociodemographic characteristics studied, several significant associations were found between age and various sources, showing that younger patients more often experienced discounting from family, medical professionals, and social services. Furthermore, having had more frequent visits to a doctor in the previous year were characteristics associated with higher invalidation scores. Experiences of invalidation from several sources were associated with worse self-reported mental health and the presence of anxiety and depressive symptoms.

Like qualitative studies (12, 23, 24), this quantitative study confirms that Swedish patients with chronic pain experience invalidation. In general, lack of understanding from all sources was more frequent than discounting, which is consistent with studies of patients with fibromyalgia (7), chronic low back pain (10), and rheumatic diseases (7). The extent of invalidation varied depending on the sources, as found in previous studies (7–10). Previous research on CWP has focused on the biological and psychological aspects, while the social context has been less explored. However, knowledge of invalidation is scant and may be needed in other chronic pain patient groups/diagnoses since the presence of invalidation in them is mainly unknown.

The highest scores for invalidation were reported from contacts with social services, both regarding discounting and lack of understanding, which is similar to results in studies of patients with rheumatic diseases (8). The patients' negative experiences from contacts/inte-

ractions with staff from social services (e.g. staff at the government agency that administers social insurance) seem to have consequences for the patients' self-perceived ability to return to work (25). Hence, there is a need to become aware of how interactions are perceived in this negative way; for example by performing qualitative research. In Sweden, there is a general health insurance, but its applications vary, e.g. with political decisions. Patients who are in the border zone of work ability, such as the patients in the present study, may be disadvantaged. Studies reporting scores of invalidation from social services are scant and difficult to compare due to differences in the respective countries' systems of organizing their social services.

In contrast to previous studies, the patients in the current study reported high scores of invalidation from medical professionals (8–10). Considering that 64% of the patients had visited a physician more than 4 times in the previous year, and that similar proportions also experienced invalidation from medical professionals, the patients might not have received the assessment and care they needed. The results from this study indicated that invalidating encounters with medical professionals may create feelings of suffering, even though the obvious aim for all personnel is to do their best to enhance the patients' health. Hence, this phenomenon requires further research. Patients experiencing invalidation seem to expend effort and energy on being seen and taken seriously, instead of adjusting to their illness, and might therefore withdraw from traditional care (23). Patients not experiencing invalidation, apart from having higher satisfaction with care, seem to report better quality of life (13) and report feeling less pain (26).

Medical professionals can be powerful elements of the care for patients with CWP by facilitating dialogue to understand what matters most, acknowledging patients' individual beliefs (27, 28), difficulties and social contexts (29), involving patients in their own care and supporting their own resources (24, 27).

The lowest scores for invalidation were reported from spouses, both regarding discounting and lack of understanding, indicating that the spouse and family are perceived as relatively understanding by the patients, which is consistent with studies of rheumatic diseases (8, 30). A review study found that spouses' responses in relationships where chronic pain was present highly influenced adjustment to the condition, in both a positive and a negative way (31). One aspect of the case is described by Söderberg et al. (32) who concluded that as if working through problems together strengthened the relationship despite the chronic illness. On the other hand, several studies show higher levels of invalidation from spouses (9, 10) and family (6, 9) than from other sources, compared with the current study. Furthermore, studies show that invalidation from spouses was correlated with more disability (10), was a predictor of depressive disorders, and increased the severity of symptoms (11, 33). Patients can experience deterioration of relationships due to their chronic illness as living with a double burden (24). Since illness is a family affair, the people one has the closest relationships with and spends most time with might affect one's health most (27). However, spouses and family should not be too empathetic, since this may reinforce pain behaviour (31, 34). Thus, the social aspect should be considered in pain management, including multimodal rehabilitation, by involving and making the spouse and family aware of the potential impact of invalidation and the social aspect of living with CWP. It has been suggested that patients, family and medical professionals would benefit from increased awareness about situations that convey invalidation, and improved communication skills, in order to avoid feelings of invalidation (6).

Consistent with previous research (8), no associations were found between invalidation and ratings of the physical component of self-reported health. Discounting correlated more closely with self-reported health than did lack of understanding, as in previous studies (8). Even though patients experienced high levels of invalidation from social services, it did not seem to affect their self-reported mental health, in contrast to our previous qualitative study, in which invalidation from social services appeared to cause much suffering (24). This may be due to the scope of the measure SF-36 not including suffering. The results from the current study are consistent with

several other studies on patients with chronic pain (6–8, 35) in that the presence of symptoms of anxiety and depression were associated with worse self-reported mental health.

More than 6 out of 10 patients with CWP were experiencing lack of understanding at work. This source of invalidation was associated with worse self-reported mental health. The importance of being part of the social context of work is thus worth acknowledging, since there may be 2 sides to this according to previous research (36, 37). A qualitative study of patients with back pain showed that belonging to a group, and maintaining relationships and interactions with workmates was essential for their well-being (36). In addition, positive encounters with medical professionals and staff from social services who believed in their work ability and were supportive and encouraging, may have promoted return to work (37). Interventions aiming at supporting patients in returning to work and increasing understanding of their CWP at their workplaces may thus be an important part of multimodal rehabilitation. Both pharmacological and non-pharmacological interventions in multimodal rehabilitation may alleviate pain and enhance self-reported health (38).

This study is unique in using the 3*I (i.e. Illness Invalidation Inventory) to measure invalidation experienced by Swedish patients with CWP. However, there are several limitations that should be considered; namely the cross-sectional design meaning that interpretation of causal relationships is not possible, and the response-rate of 46%. This relatively low response-rate could have affected the representativeness of the sample of patients with CWP cared for at a specialist pain and rehabilitation centre. Some 75% of patients reported spread of pain according to the Manchester definition at the time of answering the questionnaires, indicating fluctuation of pain and fulfilment of this diagnosis criteria. Furthermore, the number of analyses needed for studying associations was relatively high, and a $p \leq 0.01$ was therefore decided to avoid type I error (multiple statistical testing). The results of the study should therefore be interpreted with these limitations in mind.

In conclusion, large proportions of Swedish patients with CWP experience invalidation from various sources, especially from social services. Experiences of lack of understanding were more frequent than those of discounting, which applied to all sources. Being younger and having had more frequent visits to a doctor in the previous year were characteristics associated with higher scores of invalidation. Experiences of invalidation from spouse, family and work were associated with worse

self-rated mental health, including the presence of symptoms of anxiety and depression. Considering this self-reported psychological impact, invalidation seems to be a further challenge when living with CWP. Research-based interventions are warranted, aiming to increase understanding of the patient's perspective of living with CWP in the social environment (relatives, medical professionals, society, social services) and based on integration of knowledge from several of these fields. Furthermore, the patients' experiences of invalidation from the social environment should be taken into consideration in pain management, including multimodal pain rehabilitation.

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Ethical considerations

The regional ethics committee in Stockholm approved the study (2011/1384-31/3) and approval was also obtained from the management of the pain and rehabilitation centre. The participants consented to participation in the study by returning the self-report measures.

Availability of data and materials

The data collected in the present study is, according to Swedish laws and regulations, considered sensitive, although data from specific individuals cannot be identified. The ethical approval only included permission to publish results on group levels.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

PJ: design, planning, conducting, data collection, performing analyses, reporting by writing the first draft of the manuscript. MA: design, planning, valuable comments on the manuscript and interpretation of results. BG: design, planning, analyses of SF-36 data, management of disease-related information about persons with CWP, valuable comments on the manuscript and interpretation of results. KG: design, planning,

conducting; performing analyses, valuable comments on the manuscript and interpretation of results.

In addition, all authors discussed the results and revised the manuscript critically. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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