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**Patients are socially excluded
when their pain has no medical explanation**

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Abstract

This study investigated whether observers socially exclude patients who experience pain that is not medically explained by means of an experimental design. Fifty-nine participants (individuals from the general population) viewed videos of 4 patients, each accompanied by a vignette describing the presence or absence of a medical explanation for their pain. Participants estimated patient's pain, and rated the sympathy felt for and the inclination to help the patient. In order to measure social exclusion, participants indicated their willingness to interact with the patients in several situations (Social Distance Scale). Furthermore, the participants were invited to select two of the four patients as confederates to play a game against another duo. When no medical explanation for the pain was provided, participants attributed less pain, reported feeling less sympathy and were less inclined to help the patients with daily activities. Of particular importance to this study, participants were less willing to interact with patients with medically unexplained pain and selected less often patients with 'medically unexplained' pain than patients with 'medically explained' pain as confederates in the social game. These results are indicative of social exclusion of patients with pain for which there is no clear medical explanation.

Perspective: Observers socially exclude patients with pain for which there is no clear medical explanation. These findings have important clinical implications. In particular, social exclusion might have detrimental effects on both the mental and physical wellbeing of patients with pain.

Keywords: social exclusion, observers, medical unexplained pain

Introduction

Chronic pain is a major health problem.^{15,26} Pain, and especially chronic pain, involves a significant burden on an individual level (e.g., relational problems and depressive symptoms⁴³) and societal level (e.g., healthcare costs¹⁶). Even more, patients frequently report dissatisfaction with the provided care^{41,53} and abundant research indicates that individuals with chronic pain might be prone to stigmatization by others.^{17–20,30,32}

Stigmatizing responses have been defined as ‘devaluing and discrediting responses of observers towards individuals who possess a particular characteristic that deviates from societal norms’¹⁴. In the context of chronic pain, many individuals suffer from pain that is not clearly medically understood^{29,34}. Such absence of medical evidence can be considered as a deviation from the biomedical model, which is still widely endorsed in Western societies.²³ Accordingly, the absence of medical evidence has been related to lower pain estimates by observers,^{7,8,18–20,46,47} higher beliefs of deception,¹⁸ and less sympathy and inclination to help.^{18–20} As yet, there is no evidence that observers also socially exclude patients with medically unexplained pain. Social exclusion is one of the core features of stigmatizing behavior, is related to lower psychological wellbeing,³⁸ and has been identified in many health conditions, such as mental health illnesses,⁹ chronic infectious diseases,⁶ and eating and weight disorders.⁴²

Using a vignette paradigm with videos of low back pain patients performing back straining activities, the present study had three aims. The primary aim was to investigate the effects of presence versus absence of medical evidence on the degree to which observers socially exclude patients. Social exclusion was measured in two ways. Using the social distance scale,³⁵ observers rated their willingness to interact with patients in several interpersonal situations. We expected more social distance towards patients with medically unexplained pain than towards patients with medically explained pain. We also measured social exclusion in a fictitious game. More specifically, we expected that observers would select patients with

‘medically unexplained’ pain less often than patients with ‘medically explained pain’ as confederates in the game. A second aim was to investigate the effects of absence versus presence of medical evidence upon observer pain estimates, felt sympathy for and inclination to help the patients. By doing so, we tested the replicability and robustness of previous findings of De Ruddere and colleagues.^{18–20} We hypothesized that observers would attribute less pain, report feeling less sympathy and being less inclined to help patients when there is no medical evidence for the pain compared to when there is medical evidence for the pain. A third aim relates to the moderating role of patient’s pain behavior in the impact of presence versus absence of medical evidence upon observer responses (pain, sympathy and inclination to help). Given that a patient’s pain behavior has an impact upon others’ reactions towards pain (see Social Communication Model of Pain^{13,27,55}) we exploratory investigated its moderating role in the impact of presence/absence of medical evidence upon social exclusion and estimates of pain, sympathy and inclination to help.

Methods

Participants

We aimed to have at least 40 participants in our study. This sample size is based upon our previous work²⁰ using a similar study design. In total, sixty participants from the community in Ghent contacted us in response to advertisements in a local newspaper. Exclusion criteria were being younger than 18 years ($N=0$), not speaking fluently Dutch ($N=0$) and not having basic computer skills (i.e., knowing how to manage the computer mouse; $N=1$). The final sample of 59 Dutch-speaking participants ($M_{\text{age}} = 42$ years, $SD_{\text{age}}=15.68$; range = 18-74 years) included 23 men ($M_{\text{age}} = 39$ years, $SD_{\text{age}}=15.10$; range = 18-65 years) and 36 women ($M_{\text{age}} = 44$ years, $SD_{\text{age}}= 16.00$; range = 19-74 years). About one third of the participants were single (37%) and half of the participants were employed (48%). Half of the participants (46%) reported having had no pain in the past six months, 32% reported having had non-persistent pain in the past six

months (i.e., pain for no longer than 89 days), and 22% reported having had persistent pain (i.e., pain for 89 days or longer in the last 6 months). The male participants did not differ from the female participants in age ($t(57) = 1.13$; $p = .265$), marital status ($\chi^2(3) = .18$, $p = .981$), employment ($\chi^2(9) = 8.78$, $p = .457$), pain in the last six months ($\chi^2(1) = .62$, $p = .429$) or pain persistency ($\chi^2(1) = .16$, $p = .687$). This study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of Ghent University.

Design

Pictures of 4 different patients with chronic low back pain were shown to the participants and were presented with vignettes. These vignettes described the presence versus absence of a medical explanation for the pain. Immediately after showing the picture and the vignette, a video was shown in which the patient performed a pain inducing activity. Subsequently, participants were asked to estimate the patient's pain, their sympathy felt for the patient and their inclination to help the patient with daily activities. Next, participants were presented a picture of each patient and rated their willingness to interact with the patient in different interpersonal situations. Finally, participants were asked to select two patients as confederates in a subsequent (fictitious) social game.

Stimuli

Videos and pictures

During the experiment, pictures and videos of 4 actual patients (not actors) from the *Ghent Pain Videos of Daily Activities* were presented to participants (De Ruddere and colleagues¹⁹). All patients reported chronic low back pain and were in outpatient treatment for their pain at the Ghent University Hospital. All patients started the movement in upright position with their face directed to the camera. The pain behaviors (active full body pain behavior and facial expression) of the patients have been coded prior to this study (De Ruddere and colleagues¹⁹ for the description of the coding procedure).

For the present experimental design, videos of two male patients and two female patients were selected (all 4 patients were Caucasian; $M_{\text{age}} = 57.3$; range = 55–59 years). Two patients had a low level of pain expression and two patients showed high levels of pain. Scores on facial pain expression could range from 0 to 2; the score of active pain behavior was the number of seconds during which the patient displayed active pain behavior of the full body (i.e., active head, torso, or limb pain behavior such as guarding, holding, or rubbing). In the present study, each participant observed all four patients, i.e., one male and one female patient showing a low level of pain and one male and one female patient showing a high level of pain. Each patient was presented twice to participants, performing two back straining movements: (1) sitting down on a chair and standing up, and (2) lying down on a bed and standing up again. The length of the video sequences was dependent upon the duration of the movement, and varied between 9 and 33 seconds (see Table 1 for an overview of the duration of the videos and the scores on facial pain expression and active pain behavior of the patients averaged across the videos). Videos were displayed by Inquisit Millisecond software (version 3.0.6., 2012) on a Dell laptop with a 17 inch color monitor.

--INSERT TABLE 1--

Vignettes

The presence (arthritis or a compressed nerve in the back) versus absence of medical evidence for the pain was manipulated in the vignettes (see also De Ruddere and colleagues¹⁹). Each vignette also contained information on patient's name, age, profession, and number of children in order to make the pictures and video sequences of the patients more vivid/realistic for the participants. This background information was counterbalanced across the vignettes to ensure that our results could not be confounded by this background information (see Table 2 for examples of vignettes). Further, the information about the presence versus absence of medical evidence for the pain was counterbalanced across the level of pain expressed by the patient and across patient gender.

--INSERT TABLE 2--

Measures

Rating scales

Participants used a visual analog scale (VAS; 0 to 100mm) to estimate the patient's pain, their sympathy felt for the patient, and their inclination to help the patient with daily activities. Zero indicated "no pain at all", "no sympathy at all", and "totally unwilling", respectively; 100 indicated "pain as bad as could be", "a lot of sympathy", and "totally willing", respectively. All rating scales were presented on the computer screen.

Social Distance Scale (SDS)

The Social Distance Scale (SDS) contains seven items to measure observers' willingness to interact with another person in different social situations.^{35,36} In the current experiment one item was omitted from the original scale because it did not adequately fit the vignettes. The item "How would you feel if one of your children would marry this person?" was considered not highly relevant because the age of the patients described in our vignettes varied between 55 and 59 years. Participants were asked to answer the questions on a VAS ranging from 0 ("not at

all”) to 100 (“absolutely”). The inter-item reliability (Cronbach’s alpha) of the SDS in our study was 0.92 (see Table 3 for the SDS items).

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Procedure

In the experiment room, the participant was seated in front of a computer at a distance of about 60 cm from the screen. Participants were told that the study examined people’s ‘impression formation’ of individuals with pain. They provided a written informed consent. The experiment consisted of three parts. In the first part, a picture of one of the four patients was presented together with a vignette describing the absence or presence of medical evidence for the pain of the patient. Next, a video with the patient performing a pain-inducing activity was presented, and participants rated the pain, the sympathy felt for the patients and the inclination to help the patient. This sequence was repeated with the other three patients; each patient was presented twice (each patient performed two different movements) and the videos were presented in a random order. In the second part of the experiment, a picture of each patient was shown and participants were requested to complete the social distance scale. Finally, in the third part, the participants were asked to take part in a subsequent social game experiment. The experimenter told the participants that the 4 patients presented in the videos were present in the university building and asked the participants to select 2 of the 4 patients as confederates in the social game. After the selection, the participants were debriefed about the purpose of the study.

Statistical analyses

A 2 (medical evidence: present versus absent) x 2 (pain expression: high versus low) repeated measures MANOVA was used to test the effect of presence versus absence of medical evidence on estimated pain, sympathy felt for the patient, and inclination to help the patient with daily activities. Furthermore, the medical evidence x pain expression interaction effect was tested. Next, a 2 (medical evidence: present versus absent) x 2 (pain expression: high versus low)

repeated measures ANOVA was used to test the effect of presence versus absence of medical evidence on social distance ratings (mean score on the six SDS ratings). In these analyses, the medical evidence x pain expression interaction was also tested. To be able to use the norms of Cohen's d ($0.20 =$ small effect, $0.50 =$ medium effect, and $0.80 =$ large effect), effect sizes were measured using the formula of Dunlap and colleagues.^{4,22} Data of 59 participants were included in the above mentioned analyses. Further, a Non Parametric Chi Square Test measured the effect of the presence versus absence of medical evidence on the number of patients with medically unexplained pain who were 'excluded' (i.e., not selected). In particular, given that the selection of patients with 'medically unexplained pain' was dependent on the selection of patients with 'medically explained pain', a classical T-test was inappropriate. By means of the Chi Square Test, we tested whether each of the six selection possibilities occurred with equal frequency. In particular, the probability that participants selected two patients with 'medically explained pain' was 1 out of 6 (15%); the probability that participants selected two patients with 'medically unexplained pain' was 1 out of 6 (15%), and the probability that participants selected one patient with medical evidence and one patient without medical evidence was 4 out of 6 (67%). Data of one participant was missing in this part of the experiment due to the fact that this participant did not want to participate in the (fictitious) social game. Therefore, data of 58 participants were included in the analyses regarding the selection of patients to play the game.

Results

3.1. Impact of medical evidence and pain expression on estimated pain, sympathy and inclination to help

Results showed a significant multivariate main effect for both medical evidence [$F(3,56) = 5.22, p = .003$] and pain expression [$F(3,56) = 94.6, p < .001$] on the outcome variables (pain, sympathy and help). Participants estimated lower pain [$F(1,58) = 15.31, p < .001$], reported less sympathy [$F(1,58) = 7.49, p = .008$], and less inclination to help [$F(1,58) = 12.68, p = .001$]

when medical evidence for the pain was absent compared to when medical evidence was present. Means and standard deviations of the ratings, as well as effect sizes are provided in Table 4. Furthermore, participants reported higher pain ratings [$F(1,58) = 287.34, p < .001; d = 3.13, 95\% \text{ CI} = 2.60:3.67$], more sympathy [$F(1,58) = 40.07, p < .001; d = 1.17, 95\% \text{ CI} = 0.78:1.56$], and a higher inclination to help [$F(1,58) = 105.67, p < .001; d = 1.90, 95\% \text{ CI} = 1.46:2.33$] when pain expression was high versus low. There was no medical evidence x pain expression interaction [$F(3,56) = 2.04, p = .12$].

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3.2. Impact of medical evidence and pain expression on social distance

The analyses revealed a main effect of medical evidence [$F(1,58) = 6.75, p = .012; d = 0.48, 95\% \text{ CI} = 0.11:0.84$], indicating that participants were less willing to interact with the patient in interpersonal situations when medical evidence was absent ($M_{\text{nomedical evidence}} = 54.97; SD = 19.34$) compared to when medical evidence was present ($M_{\text{medical evidence}} = 59.36; SD = 18.92$). Further, there was no significant effect of pain expression on social distance [$F(1,58) = 3.26, p = .076$], neither a medical evidence x pain expression interaction [$F(1,58) = 1.13, p = .29$].

3.3. Impact of medical evidence and pain expression on social exclusion behavior

Results indicated that the six possibilities did not occur with equal frequencies ($\chi^2(5) = 12.14, p = .033$). In particular, participants selected less often two patients with medically unexplained pain (Observed $N = 6$; Expected $N = 9.7$) than two patients with medically explained pain (Observed $N = 19$; Expected $N = 9.7$). This means that participants selected less patients with medically unexplained pain as confederates than patients with medically explained pain. See Table 5 for the six possible patient combinations that the participants could select and the observed and expected number of participants who selected each of the combinations. There was no effect of pain expression on social exclusion behavior.

In general, participants' gender did not moderate the impact of medical evidence and pain expression on the ratings of pain, sympathy and inclination to help (gender x medical evidence: $F(3,55) = .198, p = .897$; gender x pain expression: $F(3,55) = .155, p = .213$) or social distance ratings (gender x medical evidence: $F(1,57) = .132, p = .718$; gender x pain expression: $F(1,57) = 2.60, p = .112$). Furthermore, participants' gender did not influence the selection of the patients ($\chi^2(5) = 6.18, p = .289$).

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Conclusions

The primary aim of this study was to investigate the effects of presence versus absence of medical evidence for pain on social exclusion by observers. The results indicated that observers were less willing to interact with patients whose pain is not medically explained. Furthermore, observers selected less often patients with unexplained than with explained pain as confederates in a social game of a fictitious additional experiment.

Research on the effects of medical evidence on social exclusion behavior is scarce. Nevertheless, there is abundant research suggesting that individuals with 'medically unexplained pain' are more prone to stigmatization. In line with the results of our study, individuals from the general population as well as healthcare professionals attribute lower pain to patients with unexplained pain,^{7,8,18-20,46,47} feel less sympathy for these patients and are less inclined to help them.¹⁸⁻²⁰ Patients also report to experience stigmatizing responses. In the study of Kool and colleagues,³³ individuals with fibromyalgia (i.e., an illness that is characterized by widespread pain that is not medically understood) experienced more discounting responses by others than individuals with rheumatoid arthritis (i.e., an illness that is characterized by widespread pain that is well understood medically). Also, considerable qualitative research highlights the ubiquity of stigma in the life of individuals with chronic non-malignant pain.^{21,25,30,40,48,49,54}

Several explanations may apply for our findings. First, the presence of medical evidence may have served to validate the pain symptoms of the patients. In line with this reasoning are the findings De Ruddere and colleagues¹⁸⁻²⁰ indicating that observers ascribe more pain to patients with medically explained pain than to patients with medically unexplained pain. Furthermore, Kool and colleagues found that patients indeed report more validating responses (i.e., more understanding and less discounting) when their pain is medically understood³². Observers might even have considered the absence of a medical explanation for the pain as a cue towards social cheating. Specifically, the absence of a clear medical explanation for the pain does not fit within a biomedical perspective that is still often taken for granted within Western society. Accordingly, it may lead to suspiciousness about the genuineness of the pain complaints.^{11,12,18} In general, individuals are particularly sensitive to cues towards social cheating¹⁰ given that this sensitivity may protect them from being exploited by significant others who might take benefits without earning it.³¹ It is reasonable to assume that the greater the observer's suspiciousness about the realness of the pain symptoms, the more cautious he or she will be in interacting with the persons in pain. This line of reasoning is congruent with the biocultural framework on stigmatization formulated by Neuberg and colleagues.³⁹ According to this framework, individuals stigmatize when they perceive that their ability to derive benefits from living in a social group is threatened. One core aspect here is the norm of reciprocity, i.e., that the efforts of the givers are repaid by the efforts of the recipients. For example, it might be that observers were less willing to have the individual with 'medically unexplained' pain as a neighbor because they would not expect to get help from them when needed. A second potential explanation relates to the concept of uncertainty. In particular, we may assume that the observers in our study were rather unfamiliar with 'medically unexplained' pain and therefore might have felt uncertain regarding appropriate behaviors towards the patients. For example, the observers in our study might have been afraid that participation in the social game would

increase the patients' pain. Increased uncertainty and a lack of familiarity with 'stigmatized' individuals may indeed come at the cost of appropriate social interactions.³ Although less common, a third potential explanation might be that the observers in our study were afraid to catch some contagious disease from the patients whose pain was not medically understood. Although we know that these fears are characteristic of people's stigmatizing behaviors towards others with infectious diseases⁶, little is known about their influence in the context of stigma related to unexplained pain.

The finding that patient's pain behavior was related to higher pain estimates, more sympathy and more inclination to help on the side of the observer is consistent with research showing that patient's pain expression influences others' reactions towards patient pain,⁵⁵ such as pain estimates,^{18-20,27} empathic and solicitous partner responses⁵⁶ and pain attending parental responses.⁵ However, we did not find any effect of the patient's pain behavior on social exclusion measures. One potential explanation is that the level of pain expression, in contrast with the information about the absence versus presence of medical evidence, did not serve as a cue for the participants towards social cheating and as such, was not considered relevant in making a decision about a social interaction with the patient. Furthermore, social exclusion measures were administered after presentation of a picture of the patient showing a neutral facial expression, which might also be a potential explanation for the lack of effect of pain expression on social exclusion outcomes.

Our results have some implications. In particular, according to a social pain account of rejection,³⁷ social exclusion is a powerful social process that typically relates to 'social pain' -- 'a distressing experience arising from the perception of actual or potential psychological distance from close others or a social group'.²⁴ Experimental research has shown that social exclusion is related to lower psychological wellbeing, characterized by lower self-esteem, more depressive symptoms, and higher negative affect among those excluded.^{28,38} Although research

about the relationship between social exclusion and psychological wellbeing is lacking in a population of individuals with pain, we might expect that social exclusion, besides other stress factors (e.g., prolonged discomfort, the loss of functional ability and sleep disturbance⁴⁴), will have an adverse impact on their wellbeing. Social exclusion might be considered a potential cause of the frequently observed lower psychological wellbeing (more mood and anxiety disorders^{2,52}) of individuals with medically unexplained pain. Furthermore, social exclusion might even be related to a decrease in prosocial behavior⁵⁰ and to an increase in aggressive behavior,⁵¹ which may, in turn, heighten the stigmatizing responses of others. For example, professional healthcare providers might ‘socially exclude’ patients by distancing themselves or by making a referral. This, in turn, might lead to defensive behaviors and hostility in both patient and healthcare providers.⁴⁵ Finally, social exclusion might also impact on the physical condition of the individual with pain, for example, through restricted access to health care, housing, and sport facilities. Given the potential adverse impact of social exclusion upon the overall wellbeing and behavior of individuals with chronic pain, it is important to address social exclusion and stigma in therapeutic pain programs. Despite the ubiquity of stigma in the lives of individuals with chronic pain,³⁰ programs aimed at teaching individuals with pain how to deal with others’ stigmatizing reactions is to our knowledge scarce.

Some limitations, each of which point to directions for future research, need attention. First, the results may not be generalized towards relatives, friends or professional healthcare providers. We might expect that our effects would be less pronounced when observers have a good relationship with the individual in pain. In particular, according to the Intergroup Contact Theory,¹ positive contact between in – and outgroup members is a buffer against negative relations among them. Future research might focus on the moderating effect of a positive relationship between the observer and the individual in pain. Furthermore, all participants in our study were Caucasian, which may limit the generalizability of the results towards non-

Caucasian individuals. Second, twenty-two percent ($N=13$) of the observers in our study reported to have had persistent pain during the last six months. One might expect that the effect of the absence of medical evidence on social exclusion would be less pronounced in observers with (medically unexplained) pain themselves. We were not able to test this hypothesis because of the small number of participants reporting pain. Future research should investigate whether observers with ‘medically unexplained’ pain react in a different way to patients with ‘medically unexplained’ pain than observers with no pain or with medically explained pain. Third, observers’ willingness to interact with patients in interpersonal situations was measured by means of self-reports and by means of one behavioral measure, i.e., the exclusion of patients from participation in a social game. These results may not be generalized towards other social exclusion behaviors such as the exclusion of patients from participation in other social activities, sports, etc. Therefore, future studies that focus upon different behavioral responses of observers towards individuals with pain are needed to further investigate the impact of presence versus absence of medical evidence on observers’ stigmatizing responses towards individuals with pain. Fourth, except for the participants’ gender, our study did not investigate observer variables that could moderate the effects of the absence versus presence of medical evidence on observer responses. Future research might benefit from a focus on potential observer and patient characteristics influencing the impact of contextual information on observers’ responses. To conclude, our results indicate that individuals with pain that is not clearly medically understood are prone to social exclusion behavior of observers.

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