

RESEARCH ARTICLE

Struggling to be seen and understood as a person – Chronic back pain patients' experiences of encounters in health care: An interview study

Renée Allvin^{1,2}  | Erika Fjordkvist³ | Karin Blomberg² ¹Clinical Skills Center, Örebro University Hospital, Örebro, Sweden²Faculty of Medicine and Health, School of Health Sciences, Örebro University, Örebro, Sweden³Departments of Orthopedics, Örebro University Hospital, Örebro, Sweden**Correspondence**Renée Allvin, Faculty of Medicine and Health, Örebro University Hospital, School of Health Sciences, Örebro University, S-702 81 Örebro, Sweden.
Email: rene.allvin@regionorebrolan.se**Abstract****Aim:** The aim of this study was to describe how patients with chronic back pain experience encounters with health care. Persons with chronic back pain are a stigmatized group often treated based on stereotypes, which may lead to misunderstandings and create frustrated patients and healthcare personnel. Few studies have examined the generic aspects of quality of care in this context.**Design:** A descriptive design with a qualitative approach was used.**Methods:** Nine individual interviews were conducted with chronic back pain patients after admission to an orthopaedic hospital ward. Data were analysed using content analysis.**Results:** The patients' experiences of healthcare encounters can be described by the theme "Struggling to be seen and understood as a person," comprising the categories "Lack of access and trust to care," "A desire to be taken care of and listened to" and "Own strength to handle healthcare situations."**KEYWORDS**

chronic back pain, experiences, patient-provider relationship, person-centred care

1 | INTRODUCTION

Chronic back pain (CBP) is a major health problem and a leading cause of disability in industrialized countries. Worldwide the prevalence ranges between 4.2%–25.4% and in Sweden 16.4% (Meucci, Fassa, & Faria, 2015). CBP is defined as "persistent or recurrent pain that arises as a part of a disease process directly affecting musculoskeletal issues" lasting over three months (Treede et al., 2015). No single treatment is generally effective, so patients and healthcare personnel must identify the optimum treatment for each individual. Aside from personal suffering, back pain can also be regarded as a social burden; approximately 50% of people suffering from CBP still cannot work six months after pain onset, and the chance of returning to work after being on sick leave more than two months is

small (Tymecka-Woszczerowicz, Wrona, Kowalski, & Hermanowski, 2015).

2 | BACKGROUND

Persons with CBP have been described as a stigmatized group often treated based on a stereotypical image in both society and health care (Slade, Molloy, & Keating, 2009). They experience both subtle and overt stigmatization, especially when no specific pathology validates their pain experience. A need for legitimation when there are no external signs of disease is often described (Hopayian & Notley, 2014). The absence of physiological explanations may lead to the underassessment of patients' pain intensity by both healthcare

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2019 The Authors. *Nursing Open* published by John Wiley & Sons Ltd.

personnel and laypersons (De Ruddere et al., 2014). Healthcare personnel have described emotional frustration in dealing with patients without physiological explanations of their pain (Matthias et al., 2010). It has been found that healthcare personnel take the pain of patients they have a poor relationship with less seriously than the pain of patients they like (De Ruddere et al., 2011).

Persons with CBP sometimes feel obliged to adapt their behaviour to others' expectations, resulting in withdrawal from social contacts (Osborn & Smith, 2015) and sometimes in reluctance to seek care for their pain (Matthias et al., 2010).

Considerable medical research activity has targeted CBP. Previous qualitative research in the area has investigated expectations and beliefs underlying diagnostic tests and treatment (Dima et al., 2013; Georgy, Carr, & Breen, 2009; Verbeek, Sengers, Riemens, & Haafkens, 2004), lived experiences (Hopayian & Notley, 2014; Osborn & Smith, 2006; Walker, Sofaer, & Holloway, 2006) and access to treatment services (Slade et al., 2009). Other studies have focused on developing instruments to measure back pain-specific expectations regarding consultant outcome (Georgy, Carr, & Breen, 2013). Few studies have examined the generic aspects of adequate care (for example a person-centred care and appropriate treatment) in this context. The relationship between healthcare personnel and patients is essential. Persons with CBP might experience difficulties in encounters with health care due to stigma. Improved knowledge and understanding of patient experiences may lead to changed healthcare personnel behaviour, which in turn could generate changed patient responses, contributing to better and safer care. The aim of this study was therefore to describe how patients with CBP experience encounters with health care.

3 | METHODS

The study has a qualitative descriptive design (Polit & Beck, 2016) where individual interviews were conducted with CBP patients.

3.1 | Participants and setting

Participants who were included in the study were persons who experience CBP and contact the health care to get help with their pain. They are admitted to the hospital by a referral from primary care doctors or through the emergency department. In Sweden, the health care is managed and run either by the county council, local authority or municipality. This study was carried out at an orthopaedic department at a University hospital in the middle of Sweden. The department included two inpatient wards divided into different sections of which one cared for patients with back disorders. Other sections cared for patients after a variety of surgical procedures, for example hip replacement and knee replacement, trauma and reconstructive surgery and ligament reconstructions. Registered nurses on the ward were responsible for the overall care of patients.

Patients who sought acute hospital care for CBP were identified on the departments' inpatient lists and consecutively invited

according to the inclusion criteria to participate in the study the day after admission to the ward. The inclusion criteria were having back pain for a period of three months or more and previous contact with health care due to back pain. Patients undergoing back surgery or nerve blocks at the time of study or suffering from dementia or other cognitive impairments were excluded. The first ten patients were invited by one of the authors (EF) to participate in the study. One person was excluded after the request due to newly diagnosed acute cognitive failure. In total, nine persons, five women and four men 39–74 years old (median, 66 years) participated in the interviews. They had been suffering from back pain for between 1–57 years (median, 23 years). Everyone was of Nordic origin and lived with a partner; one had children living at home. Four persons worked, one had retired early, one was unemployed (due to back pain), and three were retirement pensioners.

3.2 | Data collection

Individual semi-structured interviews (Kvale & Brinkmann, 2009) were conducted between April to May–September to November 2014 by one of the authors (EF) using an interview guide designed according to the aim of the study (Appendix). The interviews started with an open-ended question: "Please, tell me about your back pain." If patients did not know what to say, they were asked to start from the time their pain began. Afterwards more specific questions were asked, such as "How have you experienced yourself being treated by healthcare personnel in relation to your back pain?"; "Can you tell me how you handle your pain?"; and "How do you behave so that healthcare personnel understand your pain?" To reach a deeper understanding, probing questions were asked, such as "Could you describe that in more detail?"

A pilot interview was conducted to improve the interview guide. This resulted in an emphasis on creating a relaxed atmosphere, so the interviews started with the more general invitation to talk about experiences of back pain, before proceeding to more sensitive issues, such as experiences of treatment by healthcare personnel. The pilot interview was not included in the data analysis. Demographic data were verbally collected at the beginning of each interview. The interviews were conducted at a time during the daytime that suited the patients, in a room in an orthopaedic hospital ward, free of disturbances. The patients chose whether they preferred to sit on a chair or lie on a bed brought into the room, depending on their back pain. All the interviews were audio-recorded and lasted 35–95 min. At the end of each interview, the interviewer summarized the content of the interview to ensure that all were understood and if the participant would add or revise something. All interviews were transcribed verbatim by one of the authors (EF).

3.3 | Data analysis

Demographic data were managed using Excel. The interview data were analysed using qualitative content analysis (Graneheim & Lundman, 2004). As a first step, the transcribed interviews were read

several times in their entirety to gain an overview of the content and to identify meaning units corresponding to the aim of the study. The meaning units were then condensed to produce more manageable material without losing the essence of the text. From the condensed units, codes were extracted, consisting of words, phrases or short sentences. For example, codes might capture specific experiences of encounters with healthcare personnel when seeking care for CBP that patients described in the interviews. During the analysis, we attempted to create codes that were close to the original text, although more concise as well as abstracted to a higher conceptual level. Special attention was paid to the context of the meaning units. The codes were sorted into subcategories based on similarities and differences in the patients' experiences. From the subcategories, three categories were abstracted describing patients' experiences of encounters with healthcare personnel. Finally, the underlying meaning was formulated into a theme (i.e., the latent content). During the analysis process, the coding and categorization were reflected and discussed by the researchers to increase trustworthiness. All nine interviews yielded rich and deep descriptions of the patients' experiences, which we considered as data saturation. During the process of analysis, the researcher's pre-understandings and aspects that might have influenced the interpretation of data were considered by dialogues between the researchers.

3.4 | Ethical approval

The study was ethically approved by the Regional Ethics Board in Uppsala (reg. no. 2014/064). The participants were informed, verbally and in writing, that their participation was voluntary and that they had the right to withdraw from the study at any time without giving any reason. Written informed consent was obtained before the interviews.

4 | RESULTS

The results indicate that the participants struggled to be seen and understood as persons. This theme was based on three categories identified in the data (Table 1). Quotations are used in the following text to illustrate the findings (the names in brackets are pseudonyms to ensure participant anonymity) and ensure trustworthiness.

TABLE 1 Subcategories, categories and an overall theme

Subcategories	Categories	Theme
Being disbelieved	Lack of access and trust to care	Struggling to be seen and understood as a person
Lacking confidence in health care		
Being isolated in a system		
Wanting to be cared for	A desire to be taken care of and listened to	
Being listened to		
Not being understood		
Adapting to conditions of health care	Own strength to handle healthcare situations	
Finding inner strength		

4.1 | Struggling to be seen and understood as a person

The patients with CBP felt vulnerable in their encounters with health care. They experienced powerlessness, often expressed as frustration. Although they tried to explain how they felt and what they needed, they sensed an obligation to adapt to the demands and preconditions of care. Ambivalent feelings arose when they felt cared for individual persons, simultaneously with feeling not understood. They felt disappointed and not taken seriously, so inner strength was seen as essential to be able to handle everyday healthcare situations. The patients expressed a desire for support and confirmation when meeting with health care, but often experienced the reverse, which reinforced the feeling of vulnerability. Although they did experience positive responses from healthcare personnel, the feeling of not being able to influence their own situation remained.

4.2 | Lack of access and trust to care

The patients described having insufficient access to health care when they needed consultations for back pain. They were often refused visits to primary care centres or refused hospitalization. They could be denied medical examinations as healthcare personnel considered they would not lead to any new results. The experience of being disbelieved was not based only on verbal communication, but could also be seen in the expressions and body language of healthcare personnel. The patients experienced a feeling of being dependent of others without getting any help from health care. Their problems were sometimes downplayed or ignored, or even joked about, which is why they felt discredited:

It didn't feel good. I think he [i.e., the doctor] was joking, but I got angry since I had been in pain for so long. It was not proper treatment. [John, male 39 years]

Some patients described being taken more seriously as they got older. Coming down with a serious illness in addition to the back pain also made healthcare personnel more receptive. Mainly, the female patients reflected about their appearance in relation to visiting healthcare facilities and they felt their problems were taken less seriously if they dressed nicely or used makeup. Usually,

patients trusted the doctor's knowledge. Sometimes, however, they experienced that the doctor from the outset already had the attitude that nothing more could be done for them, which engendered a sense of powerlessness:

The feeling I get is that "back problems" are very complicated ... and I mean, the physiotherapist ... and the doctors ... it feels like they do not want to pay any attention. [Leif, male 60 years]

Negative experiences of healthcare encounters caused a lack of trust. Several patients stated that medical treatment and care were often performed based on the premises of the healthcare personnel. For example, one patient described being forced to stay in extremely painful positions during X-rays, even though she was screaming and crying. They believed that healthcare personnel were probably following guidelines and routines instead of listening to the patients' wishes. However, healthcare personnel could change if proved wrong:

I cannot forgive them - there must be other ways. They got no [x-ray] images using their way of doing it. When they realized it, they changed and said that I would be x-rayed in a standing position - THEN it worked! [Anne-Catrine, female 69 years]

Realising that healthcare personnel did not understand their problems resulted in frustration and resignation:

I feel resigned because I know I cannot do anything about it. I can only accept that they do not do anything. I cannot change that. [Fredrik, male 55 years]

The patients also described huge differences between different healthcare providers, which resulted in a lack of confidence:

When I've been taken care of at other hospital wards, they've given me hot rice bags and hot water gloves. If I've been crying, they've stayed by my side. Sort of taking me away from the pain and giving me positive thoughts. In this hospital ward, no one has done that. It might differ a lot from ward to ward, one almost gets scared. [Ulrika, female 42 years]

The patients often experienced being shuttled between healthcare providers, with no one being able or willing to answer for the whole picture. Each specialist saw only a minor part of a complex problem:

Our specialists are skilled, but sometimes they are blinkered regarding the whole. [Ulla, female 74 years]

Coordination and cooperation between different specialties reduced the sense of hopelessness. However, the patients could even feel abandoned within a single specialty if they had to meet different

doctors all the time. The lack of continuity and a holistic perspective was particularly prominent among patients with complex medical histories. Even the healthcare system itself, which is governed by laws and regulations, could create a sense of loneliness:

But I feel they don't care because it's beyond their reach. They must follow the standards of social welfare and not act on their own resolve and will. [Fredrik, male 55 years]

The feeling of being isolated in a system also occurred when the patients perceived that healthcare personnel did not want them to stay in the ward. They often felt as if they were in the way, in the wrong place.

4.3 | A desire to be taken care of and listened to

The patients expressed a desire to be cared for in their encounters with healthcare. They appreciated when healthcare personnel took time, even though they were under pressure and when they offered care without being asked. Healthcare personnel were often described as friendly and kind, which were considered essential qualities. The patients also highlighted the importance of humour and despite being in a serious situation, they needed that type of response.

It was considered important to know that pain medication and even hospitalization were options if needed and that healthcare personnel would evaluate the effects of administered treatments:

I know that I never will be completely pain free, I've never been. He [i.e., the doctor] sort of helped me ... titrated the dose needed, didn't just give "30 morphine", for example, but took one step at a time and finally found the right level. [Ulrika, female 42 years]

A feeling of being listened to arose when healthcare personnel clearly demonstrated that they understood the patient's problems:

They show empathy, they care, particularly the nurses. Of course, they work in this profession because they care about people. As do the doctors, when you are really in pain... [Fredrik, male 55 years]

This feeling could also be achieved when personnel apologized for bad behaviour and explained that it was due to heavy workload or stress. The value of being confirmed in their right to seek care was emphasized:

She [i.e., the doctor] never thought I was one of those who want to consult the doctor all the time, if they even exist ... I have a hard time believing it. [Britta, female 70 years]

The patients also felt cared for when they perceived different healthcare providers and organizations coming together to provide them with care based on a holistic perspective and they were seen as individual persons instead of simply diagnoses. In contrary, a sense of not being accurately cared for triggered negative feelings. The patients often felt that nobody took the time to answer questions. Although they often understood the underlying reasons for it, the patients still did not like unpleasant treatment. They had experienced doctors who did not fully agree on their diagnoses, problems and requests for treatment. One patient explained that she had been prescribed psychotropic drugs, even though she herself thought her sadness was due to her back pain:

I'd probably said something silly, when I didn't get a response ... Then I asked the doctor if the next step was to die. That was when she prescribed antidepressants. [Ulla, female 74 years]

When the patients experienced nobody listening to what they considered a problem, they got the impression that no one really cared.

The patients said that healthcare personnel sometimes did not seem to understand their situation. For example, it was a negative experience when personnel asked a lot of questions, even though the patient was in severe pain:

It felt too bad that the doctor did not understand that I was in pain – he should understand. He could have returned when the pain was less intense, but he kept asking me questions ... Those times you get frustrated. [John, male 39 years]

Patients also felt misunderstood when they felt blamed for their own problems. One patient had experienced back pain her whole life, even when she was younger and weighed less. She perceived that the healthcare personnel linked her back problems to her weight, suggesting that they understood neither her nor her entire life situation. The patients wanted explanations of why they were suffering from back pain. They wanted themselves and the healthcare personnel to aim for the same goal. They wanted personnel to listen and to give honest answers and information:

I can understand the doctors when they do not know what to do. But often they could be more forthcoming, or explain why. They have difficulty saying "I do not know" ... I would feel better if they explained more. [Britta, female 70 years]

4.4 | Own strength to handle healthcare situations

The patients described extended previous experience with multiple healthcare contacts. They had learned to observe the work situation of healthcare personnel and chose to accept and adapt to it. Several

patients said that they knew their body and how it functioned and that they had their own purpose for the future, which gave them inner strength. Some of the patients experienced frustration when healthcare personnel did not understand or listen, but through their inner strength they had the power to be stubborn and go on explaining until they perceived that the personnel understood. Several patients also had a strong self-image, which gave them the strength to question therapy proposals that they did not feel comfortable with. Sometimes this strength could be an obstacle, as they did not want to show weakness and therefore made greater efforts than they could handle:

I don't want people to feel sorry for me and that makes it difficult for me. If someone says, "Sit down and relax because you're in pain", then I instead do more to show that I'm not disabled.

[John, male 39 years]

5 | DISCUSSION

This study describes CBP patients' experiences of everyday healthcare encounters. The findings reveal that these patients' struggle to be seen and understood as the unique persons they are. They want to be acknowledged as individuals with goals and responsibilities beyond their pain. Instead, they subject themselves to the healthcare personnel's decisions and assessments regarding their condition and do not always experience understanding of their unique situation. This is in contrast to the framework of person-centred care, which requires knowledge of the person's own view of his or her health and resources (Morgan & Yoder, 2012). Increased awareness of what CBP patients confront could result in an understanding of situations they experience as problematic, thereby preventing the reinforcement of stereotypical images. Previous research has shown that legitimizing the pain experience through person-centred care can encourage people with CBP to regain control of their life situation (Howarth, Warne, & Haigh, 2014). Showing confidence in the patient and his or her pain experience is crucial for building a trusting partnership. It has been claimed that persons with different chronic pain conditions (Howarth et al., 2014; Upshur, Bacigalupe, & Luckmann, 2010) and long-term illness (Fox & Chesla, 2008; Jangland, Larsson, & Gunningberg, 2011) wish to interact and reach consensus with healthcare personnel to achieve comfort. In line with this reasoning, the participants in the present study expressed frustration when they lacked dialogue with nurses and doctors. They sometimes felt that guidelines and routines based on laws and regulations were regarded as more important than them as individuals. This frustration might be reduced by a different approach to dealing with CBP patients. Honest and open dialogue taking both patients' hopes and medical/healthcare limitations into account, with a clearer focus on the patient experience (e.g., through a more comprehensive nursing investigation), may be part of an effort to minimize this frustration.

The overall healthcare system is facing major challenges when it comes to creating organizations that promote a person-centred approach to dealing with CBP patients. The participants in this study argued that the high level of specialization meant that the doctors, nurses and physiotherapists they met saw only minor parts of a complex problem. Their experience was that no one had a holistic perspective. There is a need for balance between fixed structures for care and treatment, on the one hand and individual wishes and needs, on the other. Both perspectives are in various ways prerequisites for safe and quality care. The healthcare professions can be expected to find this balance. Persons with CBP often seek care repeatedly and from multiple healthcare providers, so it may be beneficial to have a contact person who helps the person maintain continuity in care. A review of qualitative studies of patient experiences with care showed that having a trusted clinician who helps the patient navigate the healthcare system and sees the patient as a partner strengthens continuity (Haggerty, Roberge, Freeman, & Beaulieu, 2013). Introducing contact nurses for people with CBP and evaluating the treatment outcomes could be interesting from the patient and healthcare personnel perspectives. Furthermore, prioritizing reflection in the team around the patient could be enlightening, helping develop healthcare personnel working with people with CBP.

The participants in this study described contradictions in their encounters with health care. They described feeling alone in the healthcare system, forced to adapt to care and its conditions, at the same time as they said that the healthcare personnel were fantastic and treated them properly. It has been said to be of secondary importance that a person-centred approach be used at the individual level between patients and healthcare personnel, if the healthcare organization is not structured in a person-centred way (Morgan & Yoder, 2012). A misalignment between the organizational structure and the attitude of individual healthcare personnel might explain the contradictory feelings of being well cared for and simultaneously alone in the system. To break a negative pattern, it is important for healthcare personnel to understand patient dissatisfaction with the relationship to the healthcare organization and use this insight to bring about improvements (Jangland et al., 2011).

It could be debated whether the description of being disbelieved in the present study can be linked to distrust. The participants said that they longed for explanations of why they were suffering from back pain. The fact that healthcare personnel did not propose further investigations could have reinforced a feeling of distrust, as the patients did not have diagnoses that identified the source of their pain. Earlier studies confirm that patients with CBP experience their pain as legitimate when there is physiological evidence for it (Slade et al., 2009). A possible explanation of the negative communication pattern is the stigmatized view of the patient's discomfort, which creates a barrier to communication that complicates person-centred care. Dinc and Gastmans [22] characterized trust as "an attitude of relying with confidence on someone." To recognize patient vulnerability, nurses must be aware of the unequal power relationships between them and patients (Dinc & Gastmans, 2012). Previous

research has described how healthcare personnel sometimes experience frustration and a sense of guilt in meeting patients with CBP (Matthias et al., 2010). The patients may discern this frustration and make incorrect interpretations, which could explain why the patients in this study described what they perceived as bad behaviour by healthcare personnel. Having a common approach to back pain and a structured plan for treatment and care created through cooperation between healthcare personnel and patients might well improve the care relationship, benefitting both patients and personnel.

6 | METHODOLOGICAL LIMITATIONS

In responding to the study's aim, the choice of a qualitative descriptive design allowed the participants to express their own experiences and that is a strength of this study. This is particularly important in the light of the few studies in this research area. One limitation is the convenience sample of patients, which might have selectively included patients who were "healthier," as they had sufficient energy and ability to attend an interview. It might also be that patients who had negative experiences of health care responded to the study to a greater extent. These limitations must be taken into consideration when interpreting the results. Another limitation of the study is the few participants included and conclusions should therefore be made with cautions. However, all the interviews yielded rich and deep descriptions of the phenomena of interest. Several illustrative examples were cited throughout the interviews. The sample also included participants of both genders and various ages. The credibility of the study was strengthened by striving for a comprehensive methodology where the different stages of the analysis phase are presented. In the analysis process, consensus about the meaning of the data was reached after reflections and several discussions between the researchers to ensure confirmability.

7 | CONCLUSIONS

The present findings provide insight and understandings of CBP patients' encounters with health care. They described that they experience vulnerability based on not having the opportunity to influence their own situation in healthcare organizations that lack flexibility. Instead of feeling seen and understood as individual persons, they often leave encounters with health care with a sense of disappointment, powerlessness and impaired self-confidence. All healthcare professionals who meet CBP patients must understand that their own approach in these meetings can be decisive for how the patients handle their life situation. It is a major challenge to create an organization that promotes a person-centred approach in meeting patients with CBP. Creating and implementing structured plans for treatment and care, taking both patients' hopes and medical/healthcare limitations into account, are crucial for creating the basis of a trusting relationship. Prioritizing reflection in the team around the patient and introducing contact nurses (i.e. a special nurse for every patient, who

have all the contacts with the same patient during the care) for CBP patients could be enlightening, promoting development for patients, healthcare personnel and healthcare organizations.

ACKNOWLEDGEMENTS

The authors acknowledge the contribution of the patients/persons who participated in the study.

CONFLICT OF INTERESTS

None.

AUTHOR CONTRIBUTIONS

RA, EF and KB: Study conceptualization. EF: Data collection. EF, RA and KB: Data analysis. RA and KB: Manuscript drafting. RA, EF and KB: Critical review of manuscript. All authors have agreed on the final version and meet the following criteria (recommended by the International Committee of Medical Journal Editors [http://www.icmje.org/recommendations/]):

Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

Drafting the article or revising it critically for important intellectual content.

ORCID

Renée Allvin  <https://orcid.org/0000-0003-2470-4902>

Karin Blomberg  <https://orcid.org/0000-0002-9209-5179>

REFERENCES

- De Ruddere, L., Goubert, L., Prkachin, K. M., Stevens, M. A., Van Ryckeghem, D. M., & Crombez, G. (2011). When you dislike patients, pain is taken less seriously. *Pain*, *152*, 2342–2347. <https://doi.org/10.1016/j.pain.2011.06.028>
- De Ruddere, L., Goubert, L., Stevens, M. A., Deveugele, M., Craig, K. D., & Crombez, G. (2014). Health care professionals' reactions to patient pain: Impact of knowledge about medical evidence and psychosocial influences. *The Journal of Pain*, *15*, 262–270. <https://doi.org/10.1016/j.jpain.2013.11.002>
- Dima, A., Lewith, G. T., Little, P., Moss-Morris, R., Foster, N. E., & Bishop, F. L. (2013). Identifying patients' beliefs about treatments for chronic low back pain in primary care: A focus group study. *British Journal of General Practice*, *63*, e490–498. <https://doi.org/10.3399/bjgp13X669211>
- Dinc, L., & Gastmans, C. (2012). Trust and trustworthiness in nursing: An argument-based literature review. *Nursing Inquiry*, *19*, 223–237. <https://doi.org/10.1111/j.1440-1800.2011.00582.x>
- Fox, S., & Chesla, C. (2008). Living with chronic illness: A phenomenological study of the health effects of the patient-provider relationship. *Journal of the American Academy of Nurse Practitioners*, *20*, 109–117. <https://doi.org/10.1111/j.1745-7599.2007.00295.x>
- Georgy, E. E., Carr, E. C., & Breen, A. C. (2009). Back pain management in primary care: Patients' and doctors' expectations. *Quality in Primary Care*, *17*, 405–413.
- Georgy, E. E., Carr, E. C., & Breen, A. C. (2013). Back pain management in primary care: Development and validity of the Patients' and Doctors' Expectations Questionnaire. *Quality in Primary Care*, *21*, 113–122.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*, 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2013). Experienced continuity of care when patients see multiple clinicians: A qualitative metasummary. *The Annals of Family Medicine*, *11*, 262–271. <https://doi.org/10.1370/afm.1499>
- Hopyayan, K., & Notley, C. (2014). A systematic review of low back pain and sciatica patients' expectations and experiences of health care. *The Spine Journal*, *14*, 1769–1780. <https://doi.org/10.1016/j.spinee.2014.02.029>
- Howarth, M., Warne, T., & Haigh, C. (2014). Pain from the inside: Understanding the theoretical underpinning of person-centered care delivered by pain teams. *Pain Management Nursing*, *15*, 340–348. <https://doi.org/10.1016/j.pmn.2012.12.008>
- Jangland, E., Larsson, J., & Gunningberg, L. (2011). Surgical nurses' different understandings of their interactions with patients: A phenomenographic study. *Scandinavian Journal of Caring Sciences*, *25*, 533–541. <https://doi.org/10.1111/j.1471-6712.2010.00860.x>
- Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing*. Los Angeles, CA: Sage Publications.
- Matthias, M. S., Parpart, A. L., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Sargent, C., & Bair, M. J. (2010). The patient-provider relationship in chronic pain care: Providers' perspectives. *Pain Medicine*, *11*, 1688–1697. <https://doi.org/10.1111/j.1526-4637.2010.00980.x>
- Meucci, R. D., Fassa, A. G., & Faria, N. M. (2015). Prevalence of chronic low back pain: Systematic review. *Revista De Saude Publica*, *49*, <https://doi.org/10.1590/s0034-8910.2015049005874>
- Morgan, S., & Yoder, L. H. (2012). A concept analysis of person-centered care. *Journal of Holistic Nursing*, *30*, 6–15. <https://doi.org/10.1177/0898010111412189>
- Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. The experience of the body in chronic benign low back pain: An interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences*, *20*, 216–222. <https://doi.org/10.1111/j.1471-6712.2006.00399.x>
- Osborn, M., & Smith, J. A. (2015). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Pain*, *9*, 65–83. <https://doi.org/10.1111/j.1471-6712.2006.00399.x>
- Polit, D. F., & Beck, C. T. (2016 [2017]). *Nursing research: Generating and assessing evidence for nursing practice*, (10th ed.) Philadelphia, PA: Wolters Kluwer.
- Slade, S. C., Molloy, E., & Keating, J. L. (2009). Stigma experienced by people with nonspecific chronic low back pain: A qualitative study. *Pain Medicine*, *10*, 143–154. <https://doi.org/10.1111/j.1526-4637.2008.00540.x>
- Treede, R.-D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., ... Wang, S.-J. (2015). A classification of chronic pain for ICD-11. *Pain*, *156*, 1003–1007. <https://doi.org/10.1097/j.pain.0000000000000160>
- Tymecka-Woszczerowicz, A., Wrona, W., Kowalski, P. M., & Hermanowski, T. (2015). Indirect costs of back pain - Review. *Polish Annals of Medicine*, *22*, 143–148. <https://doi.org/10.1016/j.poamed.2015.07.003>
- Upshur, C. C., Bacigalupe, G., & Luckmann, R. (2010). "They don't want anything to do with you": Patient views of primary care management of chronic pain. *Pain Medicine*, *11*, 1791–1798. <https://doi.org/10.1111/j.1526-4637.2010.00960.x>

- Verbeek, J., Sengers, M. J., Riemens, L., & Haafkens, J. (2004). Patient Expectations of Treatment for Back Pain. *Spine*, 29(20), 2309–2318. <https://doi.org/10.1097/01.brs.0000142007.38256.7f>
- Walker, J., Sofaer, B., & Holloway, I. (2006). The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. *European Journal of Pain*, 10, 199–207. <https://doi.org/10.1016/j.ejpain.2005.03.007>

How to cite this article: Allvin R, Fjordkvist E, Blomberg K. Struggling to be seen and understood as a person – Chronic back pain patients' experiences of encounters in health care: An interview study. *Nursing Open*. 2019;6:1047–1054. <https://doi.org/10.1002/nop2.290>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.