



# Back pain – a feeling of being mistrusted and lack of recognition: a qualitative study

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## KEYWORDS

Back pain;  
Spinal fusion surgery;  
Being mistrusted;  
Invisibility;  
Psychosocial;  
Communication;  
Recognition

**Abstract Background:** Research shows that suffering from back pain can be associated with great personal costs and that patients undergoing spinal fusion surgery experience particularly problematic illness trajectories and struggle with existential challenges related to living with pain for many years.

**Aim:** This study aims to explore how patients with back pain experience their illness trajectories and their interaction with the healthcare system.

**Method:** Data were collected through observations and semi-structured interviews. Data analysis was based on the French philosopher Paul Ricoeur's phenomenological hermeneutic theory of interpretation.

**Findings:** Before the spinal fusion surgery, back pain had a great negative influence on the patients' everyday lives. Insinuations of being a hypochondriac and having to hide their pain to avoid becoming a burden caused insecurity. Several patients experienced pain relieving effect when talking about their experiences. However, they

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felt that the healthcare professionals were pressed for time and were mainly interested in their physiological problems. Patients were left with a feeling of being mistrusted, powerlessness, insecurity and loss of identity.

**Conclusion:** Lifeworld-experiences are not given priority when dealing with patients suffering from back pain. To accommodate individual needs, aspects related to the patients' experiences of their illness trajectories should be taken into account regarding patient communication.

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### Editor comments

There is a phenomenal burden of back pain in society. Many sufferers perceive a lack of understanding by those around them of how their chronic condition affects their lives. It is well documented that those who suffer chronic pain feel that they are not believed by others, including health professionals. It is rare for health professionals to have the capacity to show an interest in the individual's experiences and, yet, having others listen to them can have a positive impact. The findings of this study help those caring for patients with chronic back pain to understand how important being listened to and actively 'believed' can be.

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## Background

Studies have shown that living with back pain is generally associated with personal costs. It is an intrusive element in patients' lives and affects not only the patients themselves but also their relationships and jobs (Azoulay et al., 2005; Damsgaard et al., 2015; Schlüter and Søndergaard, 2009).

A literature review and several studies report how patients' everyday life experiences are overlooked or ignored by healthcare professionals and that the only treatment suggested is pain-relieving drugs (Azoulay et al., 2005; Cohen and Deyo, 2013; Damsgaard et al., 2015; Hermansen, 2014; Holm, 2003; Jansbøl, 2014; Schlüter and Søndergaard, 2009). Other studies show that patients with back pain are being referred to physiotherapists, with recommendations for training exercises and some healthcare professionals suggest surgery while others advise against it (Byström et al., 2013; Macedo et al., 2009; Mirza and Deyo, 2007; Rushton et al., 2012; Saltychev et al., 2013). The disparity among healthcare professionals causes the patients to be sent back and forth in the system (Damsgaard et al., 2015; Friis, 2014; Hermansen, 2014; Holm, 2003) and this seems to create a feeling of existential insecurity, doubt and social isolation for patients. The literature shows how this can evolve into a feeling of being mistrusted and exaggerating problems (Damsgaard et al., 2015; Friis, 2014; Hermansen, 2014; Holm, 2003; Papaianou et al., 2009; Ugebrevet Mandag Morgen, 2014).

In Denmark, public expenses due to lower back problems comprise 16.8 billion DKK per year, of which some 65% are public transfers and around 35% are treatment related costs (Koch et al., 2011). The prevalence of back pain is high and the personal costs attached to living with back pain therefore affect many patients. In fact, several studies demonstrate that, for patients with back pain, life can be so chaotic and traumatic that they are in danger of depression (Block, 2009; Lefebvre, 1981; Osborn and Smith, 1998). Prior to undergoing back surgery, patients often bring major psychosocial challenges with them that include personal, emotional, cognitive and behavioural aspects that can be associated with less favourable surgical outcomes (Block, 2009; Block et al., 2003). One study (DeBerard et al., 2001) compared the outcomes of spinal fusion surgery in patients who had been referred for preoperative psychological evaluation (based on the recognition of the presence of psychosocial concerns) versus those who were not referred for such evaluation. The referred patients had much higher medical treatment costs than those who were not referred. Similarly, a follow up study found that good emotional health was associated with higher levels of physical functioning at 12 months and 24 months after the surgery (Trief et al., 2006). These findings are supported by other studies which demonstrate that patients experience a variety of psychosocial challenges (Block, 2009; Papaianou et al., 2009; Rolving et al., 2014).

Studies employ various quantitative methods such as screening and questionnaires which are important when trying to develop more effective ways of capturing and studying pain. However, the very multidimensional nature of pain in terms of physical and psychosocial aspects means it is difficult to quantify (Osborn and Rodham, 2010). The unpredictability of pain provokes and demands explanations that cannot be answered merely by conventional biomedical evidence (Cahana, 2007). A literature review exploring patient satisfaction showed that there is no coherence between the way patients fill in questionnaires and how they talk about their lived experiences in an interview (Riiskjær et al., 2011b). During interviews patients make use of a more nuanced language. Patients are loyal to healthcare professionals and only voice dissatisfaction when they are able to explain themselves and be precise about it (Riiskjær et al., 2011a).

By acknowledging that both quantitative and qualitative approaches can bring knowledge to the illness trajectory of patients undergoing spinal fusion surgery, we argue that the existential lifeworld phenomena of well-being can provide a necessary and deeper insight into the understanding of patients.

In our literature review (Damsgaard et al., 2015) we have shown that there is a lack of knowledge and understanding of the illness trajectory of patients undergoing spinal fusion surgery. This article, therefore, describes a study that explores this aspect as well as the interaction with the healthcare system.

## Aim

The aim of the study was to explore how patients with back pain experience their illness trajectories and their interaction with the healthcare system.

## Methods

### Design

The study involved interviews supplemented with observations and applied Paul Ricoeur's phenomenological hermeneutic theory of interpretation in processing the collected data (Ricoeur, 1979). According to Ricoeur, the aim of a phenomenological hermeneutic interpretation of a text is to understand the world opened in front of the text. Thus, interpretation is to move from what the text says to what the text speaks about (Ricoeur, 1976). Striving to interpret, understand and create meaning and thereby achieve deeper insight and new knowledge, the patients' lived experiences were therefore

explored through descriptions gained in the interviews (Fogh, 1997; Kvale, 1997; Ricoeur, 1979).

### Participants

Data generation was performed by the first author at an orthopaedic department in an elective surgery centre at a Danish regional hospital. The orthopaedic ward consisted of 25 beds. Regardless of the specific diagnosis, ten patients undergoing spinal fusion surgery were consecutively included. Due to personal reasons, two patients declined to participate in the study for which reason the following two patients were asked. Four men and six women aged 48–82 participated.

### Data collection

To obtain deeper insight, and thereby qualify the interviews, the researcher made observations in the orthopaedic outpatient department beforehand (i.e. followed a patient, attended a spinal fusion surgery and was present in the hospital ward, the hospital hotel and at patient information meetings) (Dahlberg et al., 2001, 2008; Hastrup et al., 2012; Husserl, 1970; Martinsen and Norlyk, 2012).

To achieve openness in the interviews, patients were asked broad and open-ended questions in which they were asked to describe how they experienced their illness trajectory (Fogh, 1997; Kvale and Brinkmann, 2009; Lindseth and Norberg, 2004). Subsequently the interview was conducted as a conversation where the interviewer remained attentive and responsive in order to ask follow-up questions that could elaborate relevant aspects in the patients' stories (Fogh, 1997). The participants were interviewed twice. The first interview took place just after surgery during hospitalisation. The opening question was: "Can you please tell me about how you have experienced living with back pain?". This was followed by the question: "Can you please tell me about how you have experienced your interaction with the healthcare system?".

The second interview took place in the patients' homes approximately two months after discharge. Transcripts of the first interview were read and reread several times to identify important issues to follow up. Initially, however, the interviewer began with the opening question: "Can you please tell me about how you experienced the decision of undergoing surgery?". This was followed by the question: "Can you please tell me about how life is after the surgery?". The interviews were recorded, lasted between 60 and 90 minutes and were subsequently transcribed verbatim.

## Ethical considerations

The study followed the Northern Federation ethical guidelines for nursing research in Nordic countries (Northern Nurses' Federation, 2003). Written and verbal information about the purpose of the study, the right to withdraw and that anonymity was guaranteed was provided. The patients received a letter including an explanation of the study and a consent form to sign. After approximately one week, this was followed up by a telephone call from a nurse. The patients were asked if they wanted to participate and if they had any questions. Approval from the Danish Data Protection Agency was obtained (case number: 1-16-02-65-13).

## Data analysis and interpretation

The analysis and interpretation of the data comprised an on-going, three-level process (see Table 1); starting with a naïve reading, followed by a structural analysis and, finally, a comprehensive understanding (Ricoeur, 1979).

In the naïve reading, the text was read to achieve an initial understanding of the data "what is said" – and a beginning sense of the interpretation – "what the text speaks about" (Gulddal and Møller, 1999; Hermansen and Rendtorff, 2002; Ricoeur, 1979). This process provided a general sense of the text as a whole as well as an overall initial understanding of the meaning of how patients undergoing spinal fusion surgery experienced their illness trajectory and their interaction with the healthcare system.

In the structural analysis, the naïve reading was substantiated to achieve meanings that constituted the essential meaning of the lived experience, i.e. a deeper understanding of "what was actually said". The analysis was characterised by an intensive dialogue with the text, moving between the interview texts and emerging patterns of meaning (Dreyer, 2009; Norlyk, 2009).

The last level of interpretation was conducted as a comprehensive understanding that entailed revising, broadening and deepening the awareness through critical reflection (Hermansen and Rendtorff, 2002; Rendtorff, 2000; Ricoeur, 1979). The themes derived from the text in the structural analysis became the basis of the discussion of the findings. In this in-depth interpretation, relevant theoretical perspectives as well as existing research were included and explored in order to achieve new knowledge (Ricoeur, 1979). This was followed by discussing the themes and subthemes according to existing research.

The in-depth interpretation included theoretical perspectives concerning 'Invisibility' and 'Social

Identity' as understood by the German philosopher Axel Honneth. Reflections regarding communicative actions and the concept of 'System and Lifeworld' as understood by the German sociologist and philosopher Jürgen Habermas were also applied.

## Findings

### Naïve reading

The naïve reading of the texts showed that the paramount issue for patients was their back pain and, in this context, psychosocial issues also played a significant role. The typical example was that for several years before the surgery patients had been plagued by back pain which had had a negative impact on their daily lives in terms of work, family and relationships with friends. The pain had also led to a change in the way they perceived themselves – the pain had come to define them as human beings and made them insecure.

In this context, the crucial point was that others were not able to see and understand the situation they were in because their suffering was not visible to the naked eye. Also, the interaction with the healthcare system contributed to the patients feeling insecure. They experienced a process that was marked by conflicting statements from different care providers regarding diagnosis and treatment options and they felt that the healthcare professionals almost exclusively cared about their condition – they were interested in them as patients not as people.

### Structural analysis

In the structural analysis, two main themes were identified: *To live with invisible pain and a feeling of being mistrusted* and *To live with the struggle for recognition*.

#### To live with invisible pain and a feeling of being mistrusted

The fact that back problems and pain are not visible and identifiable to other people was highlighted by most patients as the reason why they did not feel that their illness was recognised as a real problem. The patients referred to their pain as 'invisible'. There were no physical signs as opposed to, for example, patients suffering from hip pain where limping is visible and ascertainable. Although in constant pain, the patients could smile and act as if nothing was wrong.

But the invisibility of the pain meant that the patients had become particularly sensitive and alert to what other people might think. The patients' lives

**Table 1** Example of the analysis process – from quote to theme.

Meaning units/quotations “What is said”	Units of significance “What the text speaks about”	Themes and sub-themes
<p>“But there’s no reason for me to phase out Oxycontin only to start taking Oxynorm. Then he quietly says, ‘Do you feel, you can’t do without them’? What do you mean? ‘Well, there are people who become addicted’. I think we’re talking past each other. I actually <i>want</i> out of it. That feeling of being under suspicion shook me. I thought, is there something wrong with <i>me</i>? I almost believed that.”</p> <p>“You have to put up with a lot of pain, but you can’t live like that in the long run. I couldn’t lie to her either. It was obvious. I’m very open and honest, and think that you have to tell it like it is, and therefore, I’ve also been conflicted about it. We must be able to talk about everything. That’s what I said to my children, and then I did the opposite myself.”</p> <p>“It should be the case that when someone asks you how you are, they’re willing to listen – that is healing. For example, someone put his hand on my shoulder and asked if I was all right. So I said no, not really! And you know what, I told him everything. He sat quietly and took everything in. He was very understanding.”</p> <p>“A little chat would be nice. But it is mostly: Do you have a fever, do you have pain?”</p> <p>“. . . well, he explained it to me, but I couldn’t remember what it was he was going to do to me. I couldn’t remember what he called it.”</p>	<p>The fact that back problems and back pain are not visible to other people is perceived as the reason why patients do not feel that their illness is recognised as a real problem.</p> <p>This feeling is triggered by questions, experiences of innuendo and suspicious remarks from the outside world insinuating that the back pain is not as bad as the patient describes it to be.</p> <p>These kinds of experiences cause the patients to downplay their back problems; for example, by failing to tell their family about their pain and hiding it instead.</p> <p>The patients experience the communication with the healthcare professionals as very important and that it could even have a pain relieving effect. However, the interaction with the healthcare professionals is often pressed for time and the communication is characterised by conversations in which information is presented in a way that makes it difficult to understand.</p>	<p><b>To live with invisible pain and a feeling of being mistrusted</b></p> <ul style="list-style-type: none"> <li>• A life with experiences of insinuations and being mistrusted</li> <li>• To lose faith in your own judgement, experiencing a sense of unreliability, powerlessness and insecurity about your identity.</li> </ul> <p><b>To live with the struggle for recognition</b></p> <ul style="list-style-type: none"> <li>• To listen</li> <li>• Recognition and time</li> <li>• Mutual understanding.</li> </ul>

with back pain had become characterised by insecurity and feelings of powerlessness. These feelings were, in most cases, triggered by experiences of mistrusting remarks and insinuations from the outside world, indicating that their pain was not as bad as the patient made it out to be, that the patient may have been trying to 'con' their way into receiving public services or that the patient was a hypochondriac.

Many patients had experienced situations at their workplace when they repeatedly had to explain and defend themselves regarding their condition. For example, one patient told of how it made him feel discouraged and sad when colleagues questioned how he could be in so much pain while still being able to do his job:

*"They asked me 'how can you ride your bike when you hurt so much? How are you able to come to work? Why don't you call in sick?' In the end, I didn't have the energy to answer them".*

Such experiences typically caused the patients to 'put on a brave face' in front of their immediate family and downplay their back problems. Patients told how they, in order not to be a burden, omitted telling their family about their pain and instead tried to hide it. However, it was experienced as a burden for patients to hide how they really felt and it triggered moral qualms as they, for instance, lied to their children about not being in pain. One patient clarified this by recounting an experience with his daughter:

*"You have to put up with a lot of pain, but you can't live like that in the long run. I couldn't lie to her either. It was obvious. I'm very open and honest, and think that you have to tell it like it is, and therefore, I've also been conflicted about it. We must be able to talk about everything. That's what I said to my children, and then I did the opposite myself".*

Some patients had experienced situations where they felt mistrusted and had to defend themselves; not only to colleagues, family and friends, but also to healthcare professionals. Furthermore, they told how they had experienced situations where they had felt under suspicion for trying to 'cheat' their way to more pain medication than they had been prescribed:

*"But there's no reason for me to phase out Oxycotin only to start taking Oxynorm. Then he quietly says, 'Do you feel, you can't do without them'? What do you mean? 'Well, there are people who become addicted'. I think we're talking past each other. I actually want out of it. That feeling of being under suspicion shook me. I thought, is there something wrong with me? I almost believed that".*

Such experiences caused the patients to feel violated and insecure and they lost confidence in their own judgement – they came to doubt themselves and whether they were imagining the pain. Therefore, untrustworthiness was a phenomenon they associated with their situation.

In other words, the patients felt that the back pain had become so influential in their everyday lives that it had changed the way they perceived themselves.

### **To live with the struggle for recognition**

The patients considered communication with healthcare professionals extremely important and it was considered crucial that they were met by an acknowledging attitude. They described how a positive interaction with healthcare professionals could actually have a pain relieving effect. They felt that their pain was recognised when the healthcare professionals listened and gave them the opportunity to talk about issues and problems that concerned them:

*"It should be the case that when someone asks you how you are, they're willing to listen – that is healing. For example, someone put his hand on my shoulder and asked if I was all right. So I said no, not really! And you know what, I told him everything. He sat quietly and took everything in. He was very understanding".*

However, too often, patients experienced that the interaction with healthcare professionals was characterised by being pressed for time. The time at hand was almost exclusively used for explanations and questions regarding practicalities, e.g. regarding medication or how a treatment would take place:

*"It would be nice to have a little chat. But it is mostly: 'Do you have a fever, do you have pain?' It should be allowed to say: You know what, I'm feeling mentally uncomfortable. There are some things I haven't processed".*

It was not only time that was crucial for the patients – the interaction with healthcare professionals was also characterised by conversations about many details that were not always presented in a way that patients could follow and understand:

*". . . well, he explained it to me, but I couldn't remember what it was he was going to do to me. I couldn't remember what he called it. He explained it to me several times, but well, all those fancy expressions, I don't understand them. I couldn't remember them".*

Some patients felt that healthcare professionals failed to create relationships where they were able

to talk to them about treatment options in an understandable way. Such experiences contributed to the patients losing hope of getting better and led to a feeling of powerlessness.

## Comprehensive understanding

### A feeling of being invisible

The data show that the patients' back pain had had a significant impact on their daily lives and had also led to a change in the way they perceived themselves – the pain had come to define them as human beings. The fact that others could not see and understand the situation they were in was a crucial factor. The experience of insinuating remarks and a sense of being mistrusted caused insecurity and led to patients downplaying their back problems in order not to be a burden.

Axel Honneth writes about the importance of the human experience of being recognised as an individual and the opposite – lack of recognition. In the article *Invisibility: On the Epistemology of 'Recognition'* (Honneth, 2003) he connects the phenomenon of 'recognition' closely to visibility, while 'violation' is connected to invisibility, where the other person may be seen or registered, but is not assigned authority (Juul, 2011) – not recognised as an equal and trustworthy person.

Honneth refers to the book "Invisible Man" whose protagonist feels humiliated when he repeatedly experiences that other people see through him. The invisibility is not a physical condition. He is not literally invisible. It is the experience of other people's rejection that causes him to feel non-visible (Ellison, 1952):

*"I am an invisible man. No, I am not a spook like those who haunted Edgar Allan Poe; nor am I one of your Hollywood-movie ectoplasms. I am a man of substance, of flesh and bone, fiber and liquids – and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me. . . . When they approach me they see only my surroundings, themselves, or figments of their imagination – indeed, everything and anything except me."* (Ellison, 1952)

Through this narrative, Honneth explains how a human being can experience not being recognised, but rather feel 'overlooked' and violated in social contexts (Honneth, 2003; Honneth and Margalit, 2001). This is perceived as disappearing as a person and it has nothing to do with physical non-presence, but the non-existence of social significance.

In our everyday use of language, there are inherent patterns of approval or disapproval, so when the patients felt mistrusted and met by insinuations and negative remarks, they were 'injured' in regard to a positive understanding of themselves. According to Honneth, every human being is dependent on a positive self-image which is supported by others and the experience of being disrespected carries with it the danger of an injury that can bring the identity of the person as a whole to the point of collapse (Honneth, 1995).

When patients found themselves in social contexts where their pain was not recognised, it caused them to feel that they were not being recognised as human beings. The feeling of being mistrusted leads to them beginning to doubt their own experiences and becoming insecure. It can even mean that some patients hide their pain in order not to be a burden. In this way the experience of invisibility can emerge from the patients themselves. Over and over, the patients experienced being invisible in social contexts, thereby establishing a vicious circle which confirmed the feeling of lack of recognition.

### The patients' lived experiences and the healthcare system

Patients experienced pathways that were marked by conflicting statements from the healthcare professionals about diagnoses and treatment options and they felt that they were almost exclusively interested in their physical condition and not in them as human beings – the interaction with the healthcare system meant that some patients felt that they 'disappeared' as a human being.

Jürgen Habermas speaks about how the lifeworld is 'colonialized' (overpowered) by the system (Habermas, 1986a, 1986b; Nørager, 1998). Patients' everyday perspectives are met by a biomedical understanding that mainly focuses on the physical defect/the back pain but, according to the patients, overlooks the fact that living with back pain causes existential challenges. From a biomedical understanding of man – which to some extent characterises the healthcare professionals' approach – the main focus is on healing, disease, the best professional treatment, evidence and professional judgement. However, this is not necessarily the focus of the patient – each patient encounters illness in their own way. From this perspective, it becomes easier to understand why the patients expressed that the healthcare professionals were not interested in them as people and that they felt like objects in the treatment process – and why they became insecure and developed low self-esteem. The

biomedical perspective does not take into account the fact that the patients' illness experiences are made up of a complex reality which envelops their illness situation. Here, dialogue and relational conditions are essential to identify the social and individual needs and preferences (Honneth, 1995, 2003, 2006; Honneth and Margalit, 2001).

The existential view of well-being is pivotal and provides a direction of care and practice that is not only curing but is also focused on the patients' health as a whole including both the physical and the psychosocial aspects (Dahlberg et al., 2009; Galvin and Todres, 2013). As the Swedish nurse and professor Karin Dahlberg stresses:

*"To enhance a more holistic patient approach – a view of well-being – practice must be informed by a more in-depth understanding of the lifeworld experiences of the patients. This can be pursued through intense curiosity about the descriptions of others' experiences – what things are for them". (Dahlberg et al., 2009)*

The caring philosophy 'Lifeworld-led care' is developed based on a perspective that recognises the complexity of health and illness (Dahlberg et al., 2009; Norlyk et al., 2013; Todres et al., 2007). Embedded in this approach is an understanding of man's 'well-being' which focuses on opportunities based on experiences from everyday life (Dahlberg et al., 2009).

## Discussion

In agreement with the conclusions of other studies, the experience of being mistrusted, untrustworthiness, losing faith in one's own judgement and powerlessness are important existential and psychosocial aspects that could influence the outcome of the perceived effect of back surgery (DeBerard et al., 2001; Trief et al., 2006). The present study shows that the patients' interaction with healthcare professionals and their various statements can cause insecurity. The fact that patients, paradoxically, can come to doubt the value of their own knowledge of their condition is new and important knowledge.

A study investigating cancer patients and their rehabilitation shows that a fragmented perspective of man based on diagnosis, treatment and cure dominates in the discourse of the hospital world (Mikkelsen et al., 2008). The authors concluded that the fragmentation serves as inclusion and exclusion criteria for conversation about care and treatment. In light of Habermas' theoretical perspectives, their study shows that some patients therefore feel abandoned in an *existential void* after discharge. The

study draws attention towards focusing on communication about the experiences of these 'voids' consisting of existential and psychosocial dimensions (Mikkelsen et al., 2008).

The present study results show that it is essential to recognise and prioritise patients' everyday experiences/lifeworld during communication, so that their illness problems become visible and form the basis for the common conversation. This is in line with Mikkelsen et al. and, furthermore, imputes an additional dimension by emphasising the importance of a more holistic care mind-set.

In light of the present study's results, it is crucial that, in communicating with patients, their lifeworld is recognised and forms the basis and the framework for action in connection with care and treatment that focuses on the patient.

## Limitations of the study

We wanted to disclose the essential meaning of being in the lifeworld of the patient (Lindseth and Norberg, 2004) with back pain. A text never has only one meaning – there is, according to Ricoeur, not just one probable interpretation (Ricoeur, 1974). However, all possible interpretations are not equally probable to the interpreter – the most probable interpretation of the text is the one that makes sense of the greatest number of details as they fit into a whole and one that renders all that can be brought forth by the text (Klemm, 1983). The internal consistency of the interpretation and the plausibility in relation to competing interpretations were therefore considered throughout the entire process through discussions between the authors (Lindseth and Norberg, 2004).

## Conclusion and implications for practice

This study highlights that the patients are experiencing a sense of powerlessness and being mistrusted as is expressed in a sense of insecurity and 'disappearing' as a person, i.e. being 'invisible'. Therefore, focusing on the physiological problems is insufficient to secure well-organised patient pathways for patients with back pain. It is essential to include existential and psychosocial aspects in a dialogue based communication with the patients. This new knowledge calls attention to a need for the healthcare professionals' awareness and ability to build on lifeworld aspects in the communication in order to recognise and secure the patients' well-being and recovery.

## Conflict of interest statement

There are no conflicts of interest for the authors of this manuscript.

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