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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; Papaiannou 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; Papaiannou et al., 2009; Rolving et al., 2014).

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