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A struggle for recognition and meaning

A phenomenological-hermeneutic study of the illness trajectory of patients undergoing spinal fusion surgery

PhD dissertation

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List of original papers

Paper I

Damsgaard, Janne Brammer; Jørgensen, Lene Bastrup; Norlyk, Annelise; Thomas, James; Birkelund, Regner (2015). *Acknowledging the patient with back pain: A systematic review based on thematic synthesis.* In European Journal of Person Centered Healthcare Vol. 3, Issue 1 pp 37-47 (Published)

Paper II

Damsgaard, Janne Brammer; Norlyk, Annelise; Jørgensen, Lene Bastrup; Birkelund, Regner. *Back pain – a feeling of being mistrusted and lack of recognition: A qualitative study*. In International Journal of Orthopaedic and Trauma Nursing (In press, published online January 2016)

Paper III

Damsgaard, Janne Brammer; Jørgensen, Lene Bastrup; Norlyk, Annelise; Birkelund, Regner. *Spinal fusion surgery*: *From relief to insecurity*. In International Journal of Orthopaedic and Trauma Nursing (Submitted, February 2016)

List of tables

Abbreviations

SFS	Spinal fusion surgery
Back pain	Chronic low-back pain
Back pain	Low-back pain

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1 Introduction

This thesis explores the illness trajectory of patients undergoing spinal fusion surgery (SFS). It applies a phenomenological-hermeneutic perspective.

A large group of people suffer from back pain which often implicates lengthy, tiring and costly illness trajectories. Over the years, people with back pain and organisations speaking on their behalf have voiced criticism over long and often uncoordinated care pathways in the healthcare system; and some people suffering from back pain feel that they are not taken seriously and that they are met with insinuations that they have psychological problems and try to cheat their way into social benefits.

As healthcare professionals at an orthopaedic department performing SFS, we meet patients who are facing a particularly difficult situation because SFS is usually the last therapeutic option available and they bring to the encounter many experiences from their contact with several public sectors, multiple examinations and previously unsuccessful treatments. In an effort to respond appropriately to this challenge, the healthcare system has devoted much effort to formulating evidence-based recommendations, ensuring a precise division of tasks and furthering coordination and communication among the healthcare professionals involved. Still, in 2010, the Danish Health Authority concluded that there was a need for a concerted strategy. The five Danish regions have therefore now formulated a programme for lumbar back pain patients to heighten professional quality, to create unified and appropriate cross- and interdisciplinary pathways and to ensure a more expedient use of healthcare resources. The programme stipulates that the patient must receive a timely and systematic treatment from the very first encounter with the healthcare sector.

In addition, much effort has gone into staging local initiatives to enhance, for example, cross- and interdisciplinary co-operation with other involved parties (e.g. other departments and family doctors) to simplify the patient pathways as much as possible. To deliver the best possible effort, patients undergoing SFS are also being invited to information meetings. Moreover, they can be referred to a team with special knowledge and a focus on the patient's pain.

These efforts notwithstanding, a preliminary overview of the literature shows, however, that patients continue to raise issues of concern related to the *healthcare system,* such as prolonged waiting times, working procedures, treatment and information, the number of professionals and communication between healthcare professionals and patients. Moreover, patients also raise issues of an *existential* nature. Searching for explanations for their pain constantly having to justify it, patients struggle with feelings of untrustworthiness, of not being believed and of being powerless.

Within this complex context, we conducted a patient-centred study inviting patients to narrate their experience while undergoing SFS.

2 Background

The purpose of this chapter is to outline the background for the study, state the research rationale and set the scene for the research.

The chapter also adds knowledge to the paper entitled “*Acknowledging the patient with back pain: A systematic review based on thematic synthesis*”, reviewing literature within the period from 1998 to February 2013 (see results in Paper I, Chapter 5). This review is updated with a literature review spanning the period from March 2013 to September 2015 (see paragraph 2.2-2.3).

2.1 Back pain and spinal fusion surgery

Chronic low-back pain (back pain) is today one of the most common and costly healthcare problems in terms of incurred medical care expenses and lost productivity, disability payments and personal suffering (Moore 2010). In the United States, back pain has become the leading cause of disability and lost production (Trief et al. 2006). The prevalence and economic impact of back pain are tremendous and seem to be increasing (Dagenais et al. 2008, Luo et al. 2004, Manchikanti et al. 2009). In Denmark, public expenses defrayed due to back problems amount to 16.8 billion DKK per year (Koch et al. 2011).

The increase in back pain has been accompanied by a rise in surgery rates for back pain, notably during the past two decades, with SFS being the most common procedure performed (Deyo et al. 2005, Rajaee et al. 2012, Rasmussen et al. 2009, Harris, Dao 2009, Neukamp et al. 2013, Strömquist B. et al. 2013). However, this traditional surgical approach falls short of being adequate (Moore 2010, Christensen et al. 2003, Cohen, Deyo 2013, Mirza, Deyo 2007, Saltychev et al. 2013, Block et al. 2003). A follow-up study on lumbar surgery shows that up to 25% of the patients reported unimproved or worse pain following surgery and up to 40% were unhappy with SFS outcomes (Abbott et al. 2011, Strömquist et al. 2007). Similarly, in Denmark 15-40% of patients undergoing lumbar fusion did not expect to improve significantly on pain and physical function (Christensen et al. 2003). The possible reasons for the rather mixed SFS outcomes are many, including instrumentation failure, inadequate surgical technique and poor patient selection (Abbott et al. 2011). Other factors suggested to lie at the root of the poor pain and disability-related outcomes include pre-surgical pain and function, negative personality traits, emotional status, anxiety and depression, fear avoidance beliefs, negative coping, smoking status, gender, exercise and duration of back pain (Abbott et al. 2011, Rolving 2015).

A study from 2014 by Kløjgaard et al. found that some patients preferred nonsurgical interventions (Kløjgaard et al. 2014). This study supports existing results by indicating a patient preference for surgical procedures only if the symptoms are severe and persistent and if the patients have a very negative attitude toward their present state. However, the study also suggests that most patients believe that surgery may outperform nonsurgical treatment procedures in relieving pain; and patients seem to reach a point where they believe that surgery is the only option (ibid.). In this context, it is important to know that the patients tend to prefer or 'to do what their doctor tells them to do'. This shows that healthcare professionals have a very important duty in communicating clearly the expected results of treatment and creating the basis for a joint treatment decision. The study argues that this can even improve treatment outcome (ibid.).

Clinical psychologist James Moore argues that the healthcare system's response to the high prevalence of back pain and its accompanying personal and societal costs falls short of adequacy (Moore 2010). Indeed, the failure of the biomechanical model to improve outcomes for back pain has paved the way for a biopsychosocial model recognising that back pain is rooted in cognitive, emotional, behavioural and social/environmental factors as well as biomedical ones (ibid.) Research on chronic pain strongly suggests that psychosocial factors are at least as important as biomedical ones in predicting and influencing the course of pain (Carragee et al. 2005, Boos et al. 2000, Chou, Huffman 2007, Block et al. 2003). The psychosocial factors influence the initial onset of back pain, the transition of back pain from acute pain to chronic pain, the maintenance of chronic pain and the patient's responsiveness to treatment (Moore 2010).

To sum up, the physical challenges encountered by patients with back pain are to some degree described in the literature; but in relation to patients undergoing SFS, psychological research in general psychosocial research in particular is scarce. Indeed, only few empirical studies have explored the patient's *lived experiences* seeking to understand what it feels like being a patient undergoing SFS. Hence, we do not know in depth what is important to these patients.

2.2 Unfolding the biomedical and the biopsychosocial model

The following text elaborates on the two models discussed in the present thesis, i.e. the biomedical paradigm (model) and the biopsychosocial model as introduced by the American psychiatrist George L. Engel (Engel 1977). The text also discusses the concepts of 'pain' and 'illness trajectory'.

In the biomedical paradigm, the primary aim is to uncover the biomedical causes of disease (Deacon 2013). This paradigm holds that all illness can be explained biologically and assumes that psychological and social processes are divorced from the disease process. It emphasises a mind-body dualism in which the mind and the body function as separate entities. The treatment of illness is prioritised over the promotion of health, and health is viewed as the absence of disease; hence, treatment targets an underlying biological dysfunction (Deacon 2013, Adibi 2014). The biomedical model minimises the relevance of psychosocial contributions and assumes the eliminative reductionist position that psychological phenomena can be fully reduced to their biological causes.

In 1977 Engel introduced the biopsychosocial model which offers a more profound understanding of health and illness, adding the emotional, subjective aspects of illness and disease as well as the social aspects. A vast amount of literature testifies to the relevance of the psychosocial and socio-economic impact on the illness trajectory (Kangovi et al. 2014, Osborn, Rodham 2010, Block et al. 2003, Kirmayer 2007). It can, however, be argued that it is important to clarify and sharpen the profile of the biopsychosocial model. For example, psychiatrist Laurence Kirmayer argues that the concept 'social' in the model must be understood in a broader sense that encompasses 'sociocultural' differences within, for instance, the understanding of pain syndromes between culturally diverse groups of patients (Kirmayer 2007).

Indeed, pain is recognised as belonging to the most fundamental of experiences and as a defining feature of human existence (Käll 2013). It is at the same time strictly individual in so far as it is always subjectively experienced (ibid.). Pain is also deeply entrenched with cultural, historical, political, social and symbolic meaning that situates it in specific time and place and therefore not confined solely by the boundaries of individual experience (ibid.). Hence, pain must be approached from an interdisciplinary stance and from different disciplinary perspectives within humanities and social sciences, and we must move beyond an understanding of pain in purely physical terms, drawing attention to how cultural and social norms and expectations regarding identity and behaviour are closely connected to experiences of pain and how such experiences are brought to expression (ibid.).

In the present thesis, the focus is on patients suffering from (often long-term) back pain. The study does not draw on a specific model in regard to the patients' illness course. As Paterson argues, personal and social contexts change, the patients' perspectives shift, showing that their lives feature on-going, continually shifting processes in which they experience a complex dialectic between themselves and their 'world' (Paterson 2001). However, according to Kirkevold, the literature on coping with chronic illness suggests that diseases have different trajectories with characteristic phases and that coping tasks change as the illness evolves; hence, it is appropriate to elaborate on the concept of 'illness trajectory' (Kirkevold 2002). To illuminate the complex issues of manging chronic disease, Corbin and Strauss (1991) developed a trajectory model focusing on eight phases. The model implicates patients, family and health providers. Their conceptions influence the trajectory scheme and encompass the plans and actions initiated by the patients themselves and others involved in managing the disease. Corbin et al. stress the complexity and pervasiveness of the challenges associated with many chronic illnesses, suggesting that attention must be directed towards bodily changes, changes in daily life as well as their existential consequences, changes in self-understanding and values and orientation in life (ibid.).

2.3 An updated review of related qualitative research studies 2013-2015.

2.3.1 Living with back pain

A metasynthesis by Bunzli et al. representing 18 qualitative studies involving 713 participants found that a mismatch exists between the biomedical beliefs held by clinicians and patients and the biopsychosocial nature of back pain (Bunzli et al. 2013 p. 907). Healthcare professions, lay people and chronic pain populations were found to '*endorse a biomedical paradigm over a biopsychosocial approach in the clinical back pain management*' (Bunzli et al. 2013 p. 907). The study showed that a biomedical explanation is critical to the perceived legitimacy of the disability and hence for '*receiving support from family, workplace and welfare agencies*.' Indeed, the lack of a satisfactory aetiological explanation for the 'invisible' pain leaves patients at risk of not being believed (Bunzli et al. 2013 p. 907, 910). Stigmatisation was a theme raised in almost all included studies. For example, the media were highlighted as painting an image of people with back pain as '*being fraudulent, seeking secondary gains*.'(Bunzli et al. 2013 p. 911) The patients felt that society views people with back pain as '*burdens with neither value nor virtue and thus threatening social order*' (ibid.). Furthermore, healthcare professions are identified as painting an image of '*a demanding, difficult and drug-seeking patient*' (ibid.), and healthcare professionals' inference that pain of psychological origin is felt by patients as a stigma '*questioning their integrity*' (ibid.). Many participants feel that employers view them as '*lazy, unreliable and undesirable*'; and this impacts negatively on their sickness records and job security (ibid.). In light of an uncertain future, anxiety and distress are widely described and were reported to give rise to feelings of depression. The psychological effects of pain amount to an '*assault on the self*'; and patients often feel a dichotomy between the past and the present self (Bunzli et al. 2013 p. 912-913).

A study from 2013 by Snelgrove et al. reported participants being '*trapped in pain experiences*' with lives dominated by constant, intrusive and often unbearable pain (Snelgrove et al. 2013 p. 135). Pain levels fluctuated, but to most of the patients back pain meant '*relentless, unchanging lives with a focus on the present and past with little future orientation*' (ibid.). It was suggested that enduring the demands of pain over long periods of time, '*embedded biomedical beliefs, dependency on medication and medical treatments and a narrow range of coping strategies*' contributed to comprehensive enmeshment of pain and a strong sense of loss (ibid.). On the other hand, those who experienced pain respite showed less enmeshment, future orientation, changed self-management strategies and illness beliefs that led to improved pain engagement (ibid.).

Another study argues that although biopsychosocial interventions and approaches show positive effect, patients with back pain are facing social dilemmas when managing pain in social contexts (Larsen et al. 2013 p. 819). Getting a diagnosis involves how to act, learning how to '*culturally perform*' pain, i.e. a specific diagnosis carries cultural meaning that defines specific behavioural norms and perceptions (ibid.). A diagnosis comes with both '*a social and a biomedical meaning from which the patients generate certainty and take cues for socially accepted performance*' (Larsen et al. 2013 p. 824). This explains why some patients '*feel misunderstood when confronted with a biomedical discourse in a clinical setting*.' The study highlights that the biomedical knowledge patients learn in clinical settings may be difficult to apply in their own social and local contexts (ibid.). Not having a diagnosis or having a diagnosis associated with unexplained symptoms creates '*a feeling of being in a state of 'limbo'*, not knowing how to act, explain or 'perform' symptoms.' Nor are medically unexplained symptoms socially legitimate since social contexts do not know how to respond to these symptoms (ibid.).

2.3.2 Experiencing the interaction with the healthcare system

In a study on the conceptualisation of *the journey towards surgery* (Johnson et al. 2014 p. 1), increasing pain and functional deterioration altered the experience of time. Attention was drawn to the ways in which time manifests itself throughout the everyday experience of individuals suffering long-term pain (ibid.). Patients made essential changes in how they filled their days; they experienced '*lost and wasted time and faced temporal disruption of the order of their lives*' (ibid.). A surgical date marked in their calendar became their focus. However, this date did not remain static; it moved in response to changing perceptions of duration and real-time alterations by the healthcare system. These findings highlighted that patients' experience of time is complex and multi-dimensional and '*not at all equitable with the healthcare system's linear, monochronic conceptualisation of time*' (Johnson et al. 2014 p. 10). The surgery date can therefore appear closer to or further away than it is in actual clock time. Patients experienced waiting as '*living in a* *limbo*' (Johnson et al. 2014 p. 8). Up to surgery, the findings demonstrated a need for healthcare professionals to acknowledge these differences and '*to recognise the fluid and dynamic nature of time and the broader temporal issues embedded in patients' perceptions, interpretations and experiences*' (Johnson et al. 2014 p. 10).

A study of the empirical lifeworld construction in the field of surgery shows that '*dignity can be compromised*' in a clinical practice strongly focused on efficiency and economy (Rasmussen, Delmar 2014 p 1). Attention was also drawn to another study stating that '*it is about creating small everyday circumstances in which the dignity can flourish*' (Hall, EO. & Høy, B. 2012 p. 287). Furthermore, a Swedish study was referenced showing that in surgical nursing focus tends to be on installing new techniques, '*removing the diseased*' and efficiency and fulfilment of productivity demands at the expense of maintaining patient dignity (Vendlegård et al. 2010 p. 2). Rasmussen's & Delmar's study concludes that it appears particularly important to be respected and '*acknowledged as a person of importance'*. It is underlined how the patient '*wishes to be a co-player and to be actively involved in care and treatment*' (Rasmussen, Delmar 2014 p. 5).

Patients with low socioeconomic status during the post-hospital transition face particular challenges (Kangovi et al. 2014 p. 283). Investigating perceptions of hospitalisation, discharge and the post-hospital transition, Kangovi et al found that patients '*feel powerlessness during hospitalisation*' due to illness and socioeconomic factors; misalignment of patient and care team goals; lack of saliency of health behaviours due to competing issues; socioeconomic constraints on patients' ability to perform recommended behaviours; abandonment after discharge; and loss of self-efficacy resulting from failure to perform recommended behaviours. Patients described discharge goals that were confusing, unrealistic in regard to significant socioeconomic constraints and conflicting with their own immediate goals. Kangovi hypothesises that this goal misalignment leads to a cycle of low achievement and loss of self-efficacy that may underlie poor post-hospital outcomes (ibid.).

Recovery involves 'redefinition' and 'readjustment' and is '*contingent not on the absence of pain*', but rather on acceptable levels of symptom attenuation (Myburgh et al. 2015 p. 47). Recovered participants tended to anchor their perceived status mainly on pain '*no longer being an issue*', whilst the 'not recovered' patients anchored their perceived status on continued pain which undermines their potential for full recovery (ibid.). Psychological trauma was an important factor associated with non-recovery, and the lived experience of past injury/illness strongly shaped recovery expectations. The participants' previous injury was used as '*a means of comparison to appraise recovery expectations*' (ibid.).

A study by Noe et al. explored *expectations, worries and wishes* in relation to challenges before returning home after initial hospital rehabilitation for traumatic spinal cord injury (Noe et al. 2014 p. 1). Although the study focuses on a different patient category than the present study, its findings are relevant to patients in general. Four categories of barriers and problems were identified, including facing uncertainty when leaving the peers; hoping to get back to work and a safe economy; understanding from the community; and relying on resilience of significant others (ibid.). The study shows that there is '*a need for healthcare professionals to address patients' close relations and to initiate dialogue with patients and their families on how the injury may impact close relations to promote a good life on new terms*' (ibid.).

2.4 Summary leading to aim

Healthcare professions and patients seem to endorse a biomedical paradigm over a biopsychosocial approach in the clinical management of back pain. The absence of an aetiological explanation means that patients feel at risk of not being believed. Dignity, being believed and experiencing respect are core elements in many of the reviewed studies. However, patients with back pain feel stigmatised and need to re-establish themselves as credible characters. Indeed, many patients are 'trapped in pain experiences' implicating suffering, frustration, anger, guilt and despair.

Poorer socioeconomic factors predict feelings of powerlessness during hospitalisation. Some patients described discharge goals as confusing, unrealistic due to socioeconomic constraints and in conflict with their own goals. In this context, healthcare professionals have an important task in communicating clearly about the expected results of treatment and the basis on which treatment decisions are taken because this may improve the treatment outcomes. In support of the argument that healthcare professionals should initiate dialogue with the patient, lived experiences of the past play an important role in redefining life and determining recovery expectations. Here, communication of expectations, worries and wishes in relation to challenges before returning to home was important.

Living in ‘a limbo’ was an issue raised in two studies one of which found that getting a diagnosis involves learning how to act in both biomedical and social contexts. The biomedical knowledge can be difficult to apply in the patients’ own social and local contexts; and this leaves them in a state of limbo, not knowing how to act, explain and ‘perform’ symptoms. The patients’ conceptualising of time was complex and multi-dimensional and did not reflect the linear, monochronic conceptualisation of time embedded in the healthcare system. Surgery can therefore appear closer or further away than it is in actual clock time. Patients experience this as living in a limbo.

In conclusion, being a patient with back pain is associated with physical, psychological, psychosocial and existential challenges. However, amongst patients suffering from back pain, patients undergoing SFS are facing particularly great challenges. These patients move through a complex journey that involves an extraordinary phase of distress which is an important subject for further exploration. Knowledge on how the patients experience their illness trajectory is needed.

3 Aim and research questions

The aim of this study is to explore how patients undergoing SFS experience their illness trajectory.

Two research questions guided the study:
1. How do patients with back pain experience their illness trajectory and the interaction with the healthcare system?

2. How do patients experience their situation from the point of making the decision to undergo spinal fusion surgery to living their everyday life after surgery?

These questions are explored in three papers:

Paper I, a literature review entitled "*Acknowledging the patient with back pain: A systematic review based on thematic synthesis*". This paper reviews related qualitative research within the research field.

Paper II, "*Back pain – a feeling of being mistrusted and lack of recognition: A qualitative study*" reflects the first part of the study; hence, it addresses research question number 1.

Paper III, "*Spinal fusion surgery: From relief to insecurity*" reflects the second part of the study; hence, it addresses research question number 2.

4 Methods

The purpose of this chapter is to describe the methods – i.e. the research design, participants, setting, data generation, ethical considerations, the data analysis and the interpretation. Furthermore, the chapter will describe the theoretical perspectives applied to obtain a comprehensive understanding of the issues raised.

The conceptual framework within the present dissertation draws inspiration from Paul Ricoeur and combines inductive thematic strategies consisting of the methods observation and qualitative interview. The method used in the literature review draws inspiration from James Thomas and Angela Harden and is further described in Paper I. See also chapter 5.1 "Introduction to the literature review Paper I".

4. 1 Research design – observations and semi-structured interviews

Referring to Ricoeur's arguments about 'Grafting hermeneutics into phenomenology' (Ricoeur 1974a p. 6-11), the thesis deploys a phenomenological-hermeneutic approach inspired by Ricoeur's work. According to Ricoeur, '… phenomenology remains the unsurpassable presupposition of hermeneutics; and at the other hand, phenomenology cannot carry out its program of constitution without constituting itself in the interpretation of the experience of the ego.' (Ricoeur 2007 p. 38-39). As Hermansen & Rendtorff state '… consciousness is always consciousness of something to someone.´ (Hermansen M, Rendtorff, J D 2002 p. 13-14).

However, Ricoeur rejects the phenomenological reductionism as a means to understand man's inner experience. The reductionist approach implies putting into brackets any objective experiential preconditions and then to describe experiences as the constituents of the ensuing sense-making (ibid). Ricoeur rejects the possibility of describing an absolute essence because the phenomenological description is eventually conditioned by preunderstandings that arise in response to man's existential situation (ibid.).

To Ricoeur, a phenomenological description is not sufficient; it must be supplemented with hermeneutics and interpretation (ibid.). Ricoeur claims that man's symbolic expression harbours a

’surplus of meaning’ that needs to be unveiled through interpretative theory (ibid.). The symbol has a double structure consisting of an overt and a covert meaning collectively helping us understand the conditions shaping man’s existence and lived actions (ibid.).

This position addresses itself to ‘the lingual condition – the *sprachlichkeit* – of all experience’ (Ricoeur 2007 p. 38-39). Indeed, ‘experience can be said, it demands to be said’ (ibid.). To Ricoeur, ’…to bring it into language is not to change it into something else but, in articulating and developing it, to make it become itself.’ (ibid.). The most fundamental phenomenological presupposition of a philosophy of interpretation is that every question concerning ‘being’ is a question about the meaning of ‘being’. In that respect, to Ricoeur, ‘the ontological question is a phenomenological question. It is a hermeneutical problem only insofar as the meaning is concealed …’(ibid.) However, in order to become a hermeneutical problem – a problem about concealed meaning – the central question of phenomenology must be recognised as a question of meaning (ibid.).

Being a human being involves existing in the present – as well as sensing and perceiving the world, having expectations for the future. It also involves having existed – i.e. having a past that is shared with others (Kemp 2001). The past and the present give temporal breadth to self-recognition, which is founded on a life history and involves commitments about the long-term future (Ricoeur 2005). To Ricoeur, humans understand themselves through their past. We identify ourselves and build self-awareness through experiences and memories - an idea which Ricoeur refers to as the ‘miracle of memory’ (ibid.) and an idea embraced by the present study.

Patients’ lived experiences were therefore investigated within the context of the meaning they ascribe to their past, present and future. For this purpose, we used a qualitative design, making observations and performing semi-structured interviews (Kvale, S. & Brinkmann, S. 2009). Paul Ricoeur’s hermeneutic theory of interpretation was used for the analysis and the interpretation of the data which consisted of texts (Ricoeur 1979b, Ricoeur 2002, Ricoeur 1973b).

4.1.1 Openness in investigating the patient's perspective and the researcher's role

Ricoeur is a philosopher and therefore does not propose ideas for approaches in empirical research such as, for example, interviews and observations. Therefore, the present thesis draws on the epistemological and methodological thoughts of professor of nursing Karin Dahlberg who suggests an open-design approach dubbed *Reflective Lifeworld Research* (Dahlberg et al. 2008 p. 20-21). Still, this approach is not a 'method' *per se,* i.e. a method that is set on fixed or locked rules (Dahlberg et al. 2008 p. 24-25). The approach is rooted in the lifeworld philosophical theory developed within the traditions of phenomenology and hermeneutics (ibid.). The approach respects the differences between the two philosophical strands, and it uses these differences to explicate ideas that can be practiced in relation to different aspects and nuances of the lifeworld (Dahlberg et al. 2008 p. 95). Dahlberg states that the approach draws mainly on the philosophers Husserl, Heidegger, Merleau-Ponty and Gadamer and their point that life manifests itself in *experience* (ibid.). 'Phenomenology and hermeneutics seek the patterns of meaning of experience, the structures and principles as well as unique experiences' (ibid.). Within this perspective, the thoughts of Dahlberg are applied to further supplement and enlighten complex concepts like, for example, openness or preunderstanding.

To grasp the patients' lifeworld perspective, a phenomenological approach ('turn') consisting of two components – a turn to 'the thing' being studied, the phenomenon, and *sensitivity* to 'the thing' were used (Dahlberg et al. 2008 p. 97). The aim was to be clear about what it means to be open and sensitive in approaching the phenomenon of interest and to avoid taking for granted scientific theory, common sense, theories or any particular perspectives. But being open is more than just an aspect of the method - openness is the expression of a way of being (Dahlberg et al. 2008). Openness is a true willingness to listen, to see and to understand - having the capacity to be surprised, sensitive and open to anything unpredicted and unexpected. Dahlberg emphasises that openness is a criterion of objectivity (ibid.).

However, being 'too close' involves running a risk of losing openness as well as objectivity. A reflective distance had to be maintained; i.e. enough distance is needed to get close (ibid.). The researcher therefore allowed herself 'being in the dark', having faith in the process of discovery, daring to be vulnerable, trusting sensitivity to guide - keeping in mind that sometimes glimpses of light would emerge. It was accordingly deemed important on the one hand to practice openness in a way that the data generation did not become a routine procedure, and on the other hand to be scientific and systematic. If there is a truth, it must be found through a dialectical process, Gadamer says (Gadamer 2004); i.e. the researcher must have the patience to wait for the phenomenon to reveal its own complexity rather than impose a structure on it (Dahlberg et al. 2008).

4.1.2 Pre-understanding

Preunderstanding can be a preconceived meaning or prejudice in regard to the studied phenomenon. As a researcher, one can have emotional attachments, failing to see anything other than a familiar landscape. Preunderstanding can also include a preponderance for particular theories or thought models which then can become part of one's research. A researcher who blindly follows a theory, research presuppositions and ready-made interpretations is not open. Indeed, preunderstanding is a foundation for understanding, but can also stand in the way of openness and, hence, deeper insight.

The researcher's role

The level of insight gained into patients' experiences depends on which role the researcher plays (Kvale, S. & Brinkmann, S. 2009). The interviewer's role is to direct the informant's intentionality and awareness towards the phenomenon of interest. The researcher's role was reflected upon before the data generation began.

Living with an all-consuming pain is an often long and challenging journey in which the patients were characterised as experts. It was also acknowledged that the patients are in a stressful and vulnerable situation; so during the data generation, it was crucial to establish a trustful relation constantly focusing on ethical aspects of the interaction with the patients. The following areas of interest were considered:

A ‘being in the world’ approach

“*All understanding is embodied and includes emotions*” (Dahlberg et al. 2008 p. 150). Hence, the interviews in many ways illuminated lifeworld aspects by bringing the patients closer to their own experience and expanding their awareness and understanding. Conversation has the power to bring back memories and experiences that have not been a reality for a long time (or of which one is not aware). Within this perspective, the interview was considered an opportunity for the patients to express important thoughts. This inter-subjectivity, this ‘being with’, was a part of the researcher’s focus while conducting the interviews. Although emotional relief was not the primary purpose of the interview, the interview gave the patients the possibility to communicate about feelings and memories associated with their experiences with back pain. The ‘being with approach’ meant that great happiness but also tears, anguish, anger and even depressive thoughts could be displayed. Ethical aspects such as being open about whether the patient could go on or needed a break were considered throughout all interviews; and interactions between the patients and the researcher, and the patients were allowed to withhold thoughts, the researcher acknowledging their sovereignty as human beings.

Recognition, reflection and ‘bridling’

It is important to be aware of how preunderstanding affects the research process; and it is important that any preunderstanding is recognised, reflected upon and ‘bridled’ (Dahlberg et al. 2008 p. 121-134). Being unaware of one’s existing preunderstandings implies a risk that the research results reflect one’s past experience or unrecognised beliefs. If this happens, research is likely to merely confirm what is already known and it forgoes the chance of contributing new understanding (Dahlberg et al. 2008 p. 134-152).

In the present research project, preunderstandings were appraised through self-reflection, self-awareness and by being observant, attentive and sensitive to the world of experience. The aim was that the lifeworld should present itself in all its complexity (through observations, interviews and interpretation), seeing what was well-known in a new light, making visible the invisible, i.e. the taken-for-granted aspects. ‘*It is probably not possible to be fully aware of our preunderstandings – preunderstandings lie deep*’ (Dahlberg et al. 2008 p. 136), but confronted by what was perceived as new and strange, the researcher’s own preunderstanding became apparent.

Although the researcher is a nurse who had worked in different jobs at the hospital, the area investigated in the present dissertation was new to her. The researcher had general knowledge of the orthopaedic department, but she had no experience with or knowledge of patients having SFS. In many ways, this meant not knowing about possible preunderstandings within this particular field. But being aware that nobody is ever without preunderstandings and being as open as possible, the researcher took down notes concerning her first impressions and reflections throughout the project. This could, for example, include patients raising questions or expressing doubts or distress within a certain matter or questions regarding the healthcare professionals’ reactions and understandings. When possible, such impressions and reflections were further examined in order to explore what they were about. The impressions were also discussed within the researcher group and with other researchers working in other geographical settings and with different research subjects and methods.

To get a sense of the healthcare professionals’ perspectives, the researcher also engaged in reflections with the healthcare staff during the preparation of the project and while performing the observations and interviews at the hospital. The study was also introduced and presentations were made throughout the project period. Ethical aspects in regard to being told about internal challenges at the hospital, for example related to treatment care and organisational matters, were kept anonymous.

The impressions were used to open and broaden the researcher’s mind and reflections on the patients’ lifeworld revealed from the texts.

4.2 Participants and setting

The data were collected at an elective surgery centre in a regional hospital in Denmark. Ten patients undergoing SFS were consecutively included; six women and four men aged 48-82 years.

It was concluded that data on a total of ten patients would provide insight - i.e. ‘richly textured understanding’ (Sandelowski 1995, Kvale, S. & Brinkmann, S. 2009 p. 183) into how patients undergoing SFS experience their life situation before and after surgery.

The patients (see Table 1) each participated in two interviews: 1) one at the hospital 2-3 days after surgery and 2) one at home 2-3 months after discharge. All patients gave informed, written consent before the interviews (Appendix A, B).

Observations focusing on the *interaction* between the patients and the healthcare professionals were performed at random. A nurse informed all patients and relatives about the purpose of the observation and they all gave oral permission to make the observations (Appendix C).

Table 1. Characteristics of the patients

Gender	Age	Type of work	No detailed data on socioeconomic status; but data on level of education, characteristics of work, housing conditions and marital status were available from the interviews	Pain duration
♀	48	Factory worker	No education; working at a production line; living in a single-family house; a partner and two children in their teens	No precise data on onset and duration of pain. Overall, the reported experience of suffering from pain spanned from one year to most of the patients' lives.
♀	82	Domestic helper **(retired)**	No education; during most of her working life caring and cleaning for elderly citizens; living in a small older house; single; one son not living at home	
♀	60	Nurse	Educated as a nurse; working at a hospital since graduation from nursing school in her early twenties; living in a rented flat; single; one daughter not living at home	
♀	67	Postman	Educated within the postal system; delivering post by bicycle; living in a single-family house; a partner and two children not living at home	
♀	75	Shop owner **(retired)**	Educated in a clothing shop in her early twenties; working full time; living in a rented flat; single; one son not living at home	
♀	53	Social and healthcare assistant	No education until in her thirties; caring and cleaning for sick and/or elderly citizens; living in a rented flat; divorced, now living with a new partner and a son	
♂	74	Baker, driver **(retired)**	Educated as a baker, but because of problems with back pain he had to find another occupation resulting in many different jobs; living in a summer cottage; a partner; one son not living at home	
♂	59	Carpenter	Educated as a carpenter; working for a company building houses; living in a self-made single-family house; a partner; one son not living at home	
♂	75	Driver of construction vehicle **(retired)**	No education; doing hard manual labour all his life; living in a small older single-family house; a partner; a son and a daughter	
♂	64	Road worker	No education; doing hard manual labour all his life; living in a small older self-made house; a partner; a son and a daughter	

4.2.1 The overall setting

The interviewed patients lived between 30 to 70 km from the hospital and many were accompanied by relatives both at the meetings before surgery and on the day of the surgery. Beforehand, all patients had consulted the outpatient clinic and other healthcare professionals, for example anaesthetic personnel, x-ray personnel and the surgeon. Every patient was invited to a patient information meeting that lasted for approximately 2 hours at which the patients were given information by nurses, physiotherapists and occupational therapists. The patients consulted the hospital several times before surgery.

Observations took place at the outpatient clinic, the hospital wards, the operating room, the recovery room, the hospital hotel and at information meetings. At the hospital ward, which had 25 beds, the researcher followed a nurse during the care and treatment of patients undergoing SFS. The researcher attended staff meetings and lunch time breaks. The researcher also followed patients through admission, surgery, to the recovery room and back to the hospital ward.

4.3 Data generation

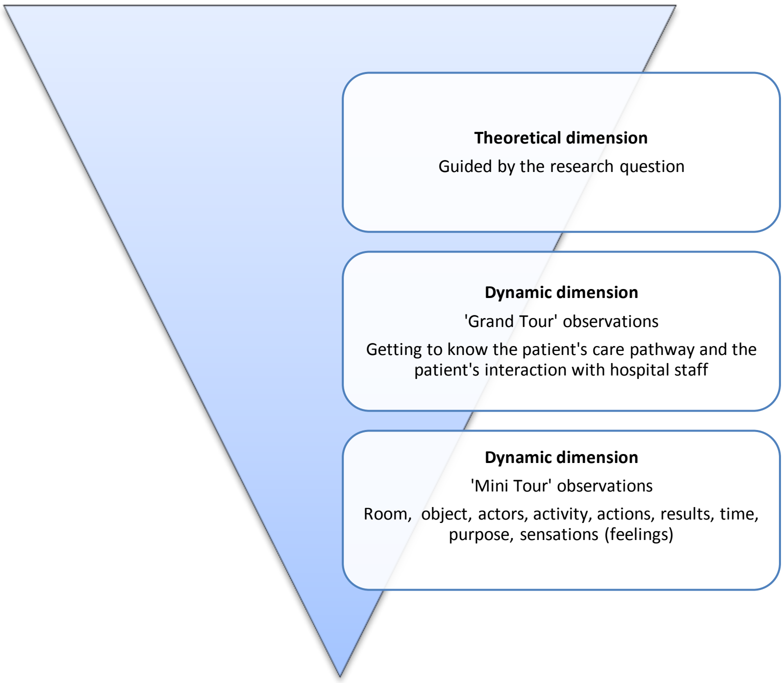
4.3.1 Observations

Observations were performed before the interviews were initiated (Spradley 1980, Hastrup et al. 2012). The observations were carried out in August 2013. The researcher did not follow the same patients throughout their care trajectories because the observations were intended solely to inform and qualify the subsequent interviews and to allow the researcher to obtain deeper insight into the communication between patients and the healthcare professionals by observing the tone of the communication, the bodily and verbal expressions and the various settings in which the interaction took place. Hence, these observations functioned as ‘a helping tool’ to obtain preliminary and general information (first impressions) within the field of interest.

To ensure a systematic approach in the observation process, so-called “Grand Tour observations” and “Mini Tour observations” (Spradley 1980)(Table 2) were conducted. Grand Tour observations aimed to open the researcher’s attention to what was going on in a broader sense, for example in regard to delays, waiting times and communication in general. These observations were supplemented with Mini Tour observations where the interaction was noted in detail, for example, in regard to expressions of feelings, social clichés, pauses or bodily expressions.

Table 2. Observation guide

(An illustration created on the basis of the chapter 'Making focused observations' p. 100-111 by J. P. Spradley. In 'Participant Observation, 1980)



The observations triggered the researcher to ask spontaneous, relevant questions (Spradley 1979, Spradley 1980). For example, the researcher spoke with the patients following them on their way from the hospital ward to the operating room, to the recovery room and back to the hospital ward. This gave the researcher an overall good sense of what it meant for the patients to be admitted to hospital and undergoing SFS.

The observations were documented by jotting- and fieldnotes. The notes were structured systematically and guided by an overall plan (Appendix D). During the observation period, the observations and the reflections were summarised. The gathering of notes, consisting of up to five pages per observation, resulted in a total of twenty pages of summaries typed into a computer

(Appendix E) and structured into areas of interest, for example: pain experiences, experiences living with a chronic illness, (power) relations, ways of communicating, marginalisation, relatives, time and continuity. The areas qualified the interviewer in relation to the subsequent interviews by ensuring a substantial ensuing dialogue with the patients.

4.3.2 The qualitative research interview

To achieve a deeper understanding of the illness trajectory of patients undergoing SFS, qualitative interviews were conducted. According to Ricoeur, *the 'essence' of a human being can be reached only through that of which one has spoken. This means that the expression is not merely a secondary thing to which one attaches meaning; on the contrary, the expression, the spoken word itself, is a creation of meaning* (Ricoeur 1979b p. 19). Ricoeur argues that within the spoken word lies a surplus of meaning which can be uncovered through interpretation, helping to understand the conditions for human existence (Ricoeur 2007).

To grasp the meaning of the patients' experiences, it was therefore crucial that the researcher met the patients in a communicative process such as the qualitative interview. To get an understanding of how patients undergoing SFS experience their illness trajectory and the interaction with the healthcare system, it was essential to meet with the interviewees as soon as possible after their surgery. Therefore, to ensure that the patients remembered and had the possibility to reflect upon their experiences concerning their hospitalisation, the first interview took place 2-3 days after surgery, and during the interview the patients were allowed to speak freely about how they experienced their illness trajectory including the interaction with the healthcare system. The second interview took place approximately 2-3 months after surgery and was initiated to get an even deeper understanding of what was important to the patients. Here the patients had the opportunity to narrate on issues arriving after the first interview or to elaborate on important issues that had come to their minds. The interviews were conducted from August 2013 to December 2013.

Entering the patients' lifeworld by interviewing them, it was essential to create an open conversation *"… so that we can be with each other on the subject"* (Gadamer 1960). This implicated that the researcher’s task was to ‘be with’ the informant and the meaning illuminated (the phenomena) so that both the interviewer and the interviewee understood the phenomenon better as a result of the interview (Dahlberg et al. 2008). Referring to Dahlberg, this can be achieved by ‘*infusing the interviews with a sense of immediacy*’ (Dahlberg et al. 2008 p. 188). In the interviews, this was carried out by trying to create a respectful, interpersonal relationship, being in a trusting ‘here and now atmosphere’, for example trying to avoid social clichés, trendy speech, jargon and generalisations, but directing the patient’s attention toward deeply anchored meanings rather than superficial attitudes or commonly held beliefs.

According to Kvale and Brinkmann, the interviewer is his own research tool. The researcher’s ability to sense what an answer means is crucial (Kvale, S. & Brinkmann, S. 2009 p. 154-161). To the researcher this required knowledge and interest in the subject being explored and the interaction between the interviewee and the interviewer during the interview as well as confidence with different ways of asking questions so that the interviewer could focus her full attention on the patient and the subject.

A semi-structured interview guide was used (Appendix F). The patients were asked open-ended questions which allowed them to describe their experiences. The first interview began with the opening question: “*Can you please tell me about how you have experienced living with back pain*?” This question was followed by the question: “*Can you please tell me about how you have experienced your interaction with the healthcare system*?” After the first interview, transcripts were read and reread to spot important subjects for the patients to elaborate on. The second interview began with the opening question: “*Can you please tell me about how you experienced the decision of undergoing surgery?*” This question was followed by the question: “*Can you please tell me about how life is after the surgery?*” A relaxing atmosphere with an approachable body language was established. The researcher’s intuition was directing the interview in regard to asking the patients to elaborate, asking follow-up questions or to letting silence and pausing unfold (Angel 2013). The interviews were ended when the patients stated that there was no more to say and when the researcher sensed that it was natural to stop (Kvale, S. & Brinkmann, S. 2009).

To Ricoeur, ‘*meaningful action is an object for science only under the condition of a kind of objectification that is equivalent to the fixation of a discourse by writing*.’ (2007 p. 150). Ricoeur ‘objectifies’ the text by releasing it from the author’s intentions or meanings, giving it a life of its own. From the perspective of research, the patients’ experiences must therefore be translated into texts in order to be interpreted and understood.

Each interview lasted between 60 and 90 minutes and was transcribed verbatim. Transcripts were read and reread several times to identify important issues on which to follow up in regard to, for example, ‘the decision and recommendation of the surgery’ being a crucial moment for the patients.

4.3.3 Ethical considerations

The ethical vision lying at the root of the present dissertation and its phenomenological-hermeneutic approach is inspired by Ricoeur’s concept of ‘la visée éthique, the ethical aim´ (Kemp 2001 p. 49), which is ‘a vision concerning the good life, among each other; in just systems’.

Approval for the present study was obtained from the Danish Data Protection Agency (journal number: 1-16-02-65-13, (Appendix G). The Regional Committee for Medical Research was contacted, but approval was not required because of the non-biomedical character of the study.

The guidelines in the Declaration of Helsinki and the guidelines of the Northern Nurses’ Federation were respected throughout the study (Declaration of Helsinki 1964, Northern Nurses' Federation 2003). The patients signed informed consent (Appendix B) and were informed orally and in writing about the purpose of the project. Patients were guaranteed anonymity, that participation was voluntary and that they could withdraw from the project at any time.

As proposed by the Danish philosopher and theologian K.E. Løgstrup, one must respect the ‘zone of untouchability’ (‘urørlighedszonen’) (Løgstrup 1982 p. 165-174). In the relation with the patients, it was therefore essential to stay within the subject of investigation (the phenomenon), respecting the patients’ integrity, ensuring impartiality but at the same time avoiding the relation and communication turning into generalising commonalities. Hence, throughout the process, a sensitive attentiveness and openness towards the patients was constantly reflected upon.

4.4 Data analysis and interpretation

4.4.1 Methodological phases in Ricoeur's theory of interpretation

The structural analysis of the text focused on the patients' experiences; i.e. on what made sense to them as patients. It follows from this approach that in this part of the process (the naïve reading and the structural analysis), we sought to 'bridle' our pre-understandings - what we already know and take for granted. According to Ricoeur, the aim of a phenomenological-hermeneutic interpretation is to understand the world as described through (opened in front of) the text: "*…the sense of the text is not behind the text, but in front of it. It is not something hidden, but something disclosed. What has to be understood is not the initial situation of discourse, but what points towards a possible world…"* (Ricoeur 1976 p. 87). Hence, one can therefore speak about the text being open – even, opening the world. Through the dialectic process between the text and the surrounding world in which the text is being incorporated through the interpretation, *another 'world' is being created* (Ricoeur 2002 p. 54). Consequently, understanding the text is to 'expose' one self to it, i.e. to move (dialectically) from what the text says to what it speaks about (Ricoeur 1981).

Ricoeur states that a text holds a surplus of meaning and that this meaning surplus may be accessed through an interpretive process encompassing a series of steps, i.e. an initial naïve reading followed by a structural analysis and a comprehensive understanding (Ricoeur 1976). The interpretive process is a dialectical one where the researcher moves between explanation and understanding (Ricoeur 2007 p. 105-124). To interpret the patients' experiences, the phases 'naïve reading' and 'structural analysis' were methodically analysed within a movement from 'what the text says', to 'what the text speaks about', thereby allowing themes and subthemes to emerge and eventually being interpreted within a comprehensive understanding including relevant theories. The process was concluded with a discussion including relevant research (Ricoeur 1976, Lindseth, A. & Norberg, A. 2004, Dreyer, P. & Pedersen, B. 2009).

Ricoeur does not describe an actual method, but rather a way of approaching a scientific interpretation and comprehension in a dialectical process. The following methodological phases presented below are therefore a more systematic and linear working process than actually suggested by Ricoeur.

4.4.2 Naïve reading

To achieve an initial overall understanding, the texts were read and re-read several times. The aim was to grasp the text as a whole, while being as open-minded as possible. It should be noted that during the data generation, a first impression of the patients' experiences had already been created. Within this process, horizons of meaning emerged through the texts. According to Ricoeur, this is important as a preliminary beginning of the interpretation process, and these early findings have to be validated (or adjusted) by the subsequent structural analysis (Ricoeur 1976).

4.4.3 Structural analysis

Striving to reach a deeper, more comprehensive understanding of a text, Ricoeur argues that a structural analysis is needed (Ricoeur 1976, Ricoeur 1973a, Ricoeur 1979b). The structural analysis was performed by gathering sections consisting of 'citations' from the entire data material. The transcribed interviews were read and divided into meaning units which could be a part of a sentence, a sentence, several sentences or a whole paragraph, i.e. a piece of text of any length that conveys a meaning. The meaning units were read through and reflected upon in light of the naive reading with which the interpretation process began. Units of significance were identified, i.e. units constituting the essential meaning of the lived experience, i.e. conveying a deeper understanding of what was actually said; hence, through the naïve reading and the structural analysis, themes were derived (see Table 3).

4.4.4 Comprehensive understanding

An interpretation was conducted in line with the *Comprehensive understanding* as proposed by Ricoeur (Ricoeur 1976) according to which the interpretation moves from the individual to the general. At this stage, the themes and the sub-themes were further interpreted and discussed in light of relevant theoretical and empirical research results (Ricoeur 1979b).

Table 3 Example of the analysis process – from quote to theme (also in Paper II)

Meaning units/quotations **”What is said”**	**Units of significance** **“What the text speaks about”**	**Themes and sub-themes**
↔	**Arrows indicating the dialectical process**	↔
"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 *want* out of it. That feeling of being under suspicion shook me. I thought, is there something wrong with *me*? I almost believed that. "	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. 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.	**To live with invisible pain and a feeling of being mistrusted** A life with experiences of insinuations and being mistrusted To lose faith in your own judgment, experiencing a sense of unreliability, powerlessness and insecurity about your identity
"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."	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.	
"It should be the case that when someone asks you how you are, they’re willing to listen - that is healing. For example, someone puts 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."	The patients experience the communication with the healthcare professionals as very important and that it could even have a pain-relieving effect.	**To live with the struggle for recognition** To listen Recognition and time Mutual understanding
"A little chat would be nice. But it is mostly: Do you have a fever, do you have pain? " "... 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. "	However, the interaction with the healthcare professionals is often pressed for time and the communication is characterised by conversations with information which is presented in a way that makes it difficult to understand.	

Table 3
The text was structured and explained by units of meaning (‘what is said’) and units of significance (what the text speaks about) (Ricoeur 1979a p. 27-31).

The structure builds on Ricoeur’s argumentation which is rooted in the Swiss linguist and semiotician Ferdinand Saussure’s distinction between the concepts ‘signifiant’ (in English ‘a signifier’), i.e. the form which the sign takes (here meaning units/quotations); and ‘signifié’ (in English ‘the signified’), i.e. the concept the signifier represents (units of significance) (Ricoeur 1979a p. 30).

Themes and subthemes were identified on the basis of the units. The arrows illustrate that this process can be characterised as dialectical, indicating that the analytic process moves forwards and backwards between the three stages to substantiate the arguments for the themes.

Major findings

A dialectical movement can be seen within the process through which two major findings emerged. During the analysis and interpretation process, the themes were understood and re-understood. For example, it was revealed that it was important to the patients to tell about their past challenges with back pain, whereas once they were relieved of (most) of their pain being discharged the patients' present everyday life and hopes were in focus. This constitutes a (movement) trajectory of temporality based on the past, the present and the future. This 'path' was shaped within the analytical process inviting to look at things in a new way and going beyond what already exists (Ricoeur 1976 p. 88).

The themes derived through the naïve reading and the structural analysis may be translated into two major findings:

- Doubting one's experiences and hiding the pain not to be a burden
- Although surgery relieved the patients of some pain, the initial hope and relief in relation to the decision to undergo surgery was followed by feelings of emptiness, insecurity and a weak self-image

In this context, two issues should be noted. Firstly, the argumentation about 'recognition' and 'meaning', which is based upon findings where patients feel powerless and insecure, should be seen also as a contribution to the discussion of what is important in relation to the issue of patients feeling relieved and well. Secondly, the (major) findings are a result of an interpretive process and, as such, not meant to provide exhaustive outline of areas relevant to the subject of SFS. 'Deviant cases' such as patients feeling relieved and well after the surgery are not to be understood as a claim that no or only very few such cases exist (see the beginning of paragraph 6.2.2); such cases do, of course, exist, but they are not the primary focus in the discussion of the findings. This is not tantamount to arguing that a stronger focus on patients' experiencing themselves as relieved and well is not a relevant subject in need of further investigation; and a discussion of this issue could embrace themes addressing:

- Patients' understanding of health and illness
- Different ways of coping with pain and life challenges
- Patients' interaction with the healthcare system in relation to communication and socioeconomic status

4.5 Theoretical-philosophical perspectives

The present chapter presents the theoretical and philosophical aspects related to the findings of the present dissertation. In the present thesis, aspects concerning ‘invisibility’ and ‘recognition’ are discussed on the basis of the ideas of the philosopher Axel Honneth. Reflections regarding the concept of ‘system and lifeworld’ draw on the work of the sociologist and philosopher Jürgen Habermas. In regard to feelings of emptiness, we refer to sociologist Hartmut Rosa’s ideas about ‘change’ and ‘alienation’; and existential aspects of transitions in life are discussed in light of the theory proposed by nurse and sociologist Afaf Meleis.

Habermas and Honneth are both scholars of the so-called Frankfurt School. As a student of Habermas, Honneth has now taken over his professorship and succeeded him as a director of the influential Institut für Sozialforshung in Germany. As a student of Honneth, Rosa belongs to the so-called ‘fourth generation’ of critical thinkers. Some of the core issues in this line of thought involve the critique of modernities and of capitalist society, the definition of social emancipation and the perceived pathologies of society. These are extensive theoretical areas as are also the (above-mentioned) concepts included in this thesis; still, it is important to stress that the present thesis offers no extensive discussion of these theoretical perspectives but confines itself to apply and discuss these perspectives in light of the focus of the research question and hence the focal point of the thesis, i.e. ‘the struggle for recognition and meaning’. The inclusion of Meleis serves to cover the areas from a nursing and transitioning perspective.

Moreover, the discussion draws on Hans-Georg Gadamer’s ideas about the perception of the body (see Paper I where Gadamer’s thoughts are discussed). Paul Ricoeur’s thoughts are used methodically within his theory of interpretation (see section 4). However, referring to both Gadamer and Habermas, Ricoeur’s concern is also with being human, memories, recognition (see Paper I), alienation and communication. This will be discussed further (see section 6).

4.5.1 Understanding social relations

Social invisibility

A core argument in social relations theory following Honneth is that intersubjective relationships are critical to understanding social relations (Honneth 1995, Honneth 2005). A key aspect within intersubjective relationships is what Honneth dubs 'social meaninglessness' or 'social invisibility'. Such meaningless or invisibility is captured, among others, in the expression 'looking through' somebody, which is seen as an act of showing disregard for others by behaving towards them as if they were actually not in the room (Honneth 2001).

According to Honneth, social visibility has to do with '*an active striking out' that is aimed at prompting others into cognising us* (ibid. 114). This describes a core element in Honneth's thinking, i.e. the practical effort (for example using facial expressions) displayed in an attempt to make ourselves noticed. In this way, we provoke visible reactions causing other persons to express the fact that we have been perceived or noticed (ibid. 114). To be sure of one's visibility, the other person is prompted into actions that affirm our existence. Consequently, a person can only establish his or her invisibility through the absence of such types of reactions. The absence of such forms of empathic expressions is an indication of the fact that one is not visible socially (Honneth 2001).

Empathic forms of expression

The individual identification of a person is realised through public expressions supported by 'suitable actions', gestures or facial expressions appropriate to the situation. We possess a common knowledge of what constitutes these empathic forms of expression, and their absence is a sign of invisibility, of humiliation.

Accordingly, Honneth describes the difference between 'cognising' (*erkennen*) and recognising (*anerkennen*). We cognise a person by identifying him or her; and by recognising, we refer to '*the expressive act through which this cognition is conferred with the positive meaning of an affirmation*' (ibid. p. 115).

These expressions are '*highly differentiated signals of readiness to interact*' (ibid. p. 117). According to Honneth, this motivational readiness is, for example, a smile with facial expressions signalling encouragement or willingness to help. With such gestures, we can signal sympathy, attention and social approval.

These expressive responses linked to recognition are therefore in a way 'moral actions' in which we 'do justice' to the person recognised. This means that we are 'equipped' with *a moral authority* over one another:

> "Whether someone smiles lovingly or merely greets one respectfully, whether someone extends his hand empathically or merely nods his head in a benevolent way, in each case a different type of emotional readiness to engage morally with the addressee is signalled with the expressive gesture." (ibid. p. 122).

This means that corresponding to the multitude of gestures are different assessments of worth, and the expressive responses therefore demonstrate '*a motivational readiness to do justice to the worth of the other person as an intelligible being*' (ibid. p. 123). On the other hand, social invisibility represents a form of moral disrespect because the absence of gestures of recognition demonstrates that the other person '*is not attributed the worth due to an 'intelligible' person*' (ibid. p. 123).

4.5.2 The uncoupling of system and lifeworld

Jürgen Habermas addresses topics stretching from social-political theory to aesthetics and from epistemology and language to philosophy of religion, and his ideas have significantly influenced not only philosophy but also political-legal thought, sociology, communication studies, argumentation theory and rhetoric, developmental psychology and theology. Two broad lines of enduring interest can, however, be discerned - one having to do with the political domain, the other with issues of rationality, communication and knowledge.

In this thesis, we focus on Habermas' theory about the 'system and the lifeworld'. This is a sophisticated social model allowing us to understand the present late-stage of capitalistic society today (Habermas 1987, Nørager 1998).

Lifeworld

The lifeworld is constituted as the transcendental frame of possible everyday experience (Habermas 1987). Here narration, i.e. lay concepts of the 'world' and true stories of the everyday world (lifeworld), is a specialised form of constative speech that serves to describe sociocultural events and objects. Habermas expresses it like this: "*The narrative practice not only serves trivial needs for mutual understanding among members trying to coordinate their common task; it also has a function in self-understanding of persons"* (ibid. p. 136). Habermas argues that we have to objectivate our belonging to the lifeworld as *participants in communication*. Hence, only when we recognise that our actions *form narratively presentable life stories can we develop personal identities*. We can only develop social identities if we recognise that we hold membership of social groups by participating in interactions and that we are thereby caught up in *narratively presentable histories of collectivities* (ibid.). According to Habermas, collectivities only maintain their identities to the extent that our ideas overlap sufficiently and condense into *unproblematic background convictions* (ibid.). If the individual life stories are not in harmony with collective forms of life, disturbances of the socialisations process are manifested in psychopathologies and corresponding phenomena of alienation (ibid.).

The cutting down of the lifeworld

To Habermas, the fundamental problem of social theory is how to connect in a satisfactory way the two conceptual strategies indicated by the notions of 'system and lifeworld' (Habermas 1987). Habermas argues that the lifeworld is based on communication, agreement and consensus. The economic and political systems require instrumental rationality.

However, Habermas also argues that the lifeworld gets increasingly 'cut down' into a so-called 'subsystem'. During this process, 'system mechanisms' (for example money and exchange of power) get further and further detached from the social structures through which social integration takes place. Economic and bureaucratic spheres emerge into social relations via money and power. Here 'identity-forming social memberships' are neither necessary nor possible; they are made peripheral instead (ibid. p. 154).

Habermas speaks about these mechanisms as 'the uncoupling of system and lifeworld' (Habermas 1987 p. 153-197). Referring to the sociologist Niklas Luhmann, Habermas argues that the lifeworld is pushed back behind media-steered subsystems and is no longer directly connected to action situations, but merely becomes background for formally organised (rational) interactions. Therefore we adopt either the system perspective (getting more and more complex) or the lifeworld (getting more and more rationalised) perspective. Everyday language gets overloaded and replaced by de-linguistified media/generalised media of communication referring to mechanisms such as prestige and influence (Habermas 1987 p. 153-197).
Such strategic technicising mechanisms are '*bypassing processes of consensus-oriented communication*' (ibid. p. 183). They simplify a mutual understanding based on communication aiming at truthfulness and rightness and replace it with generalisations. To Habermas, this induces a systemic lifeworld pathology - a so-called *colonialisation* (Habermas 1987 p. 196).

4.5.3 Change, alienation and axes of resonance

Directionless change

According to Hartmut Rosa, our institutions and practices are marked by the 'shrinking of the present', a decrease in time during which expectations based on past experience reliably match the future (Rosa 2013). This seems to make our relationships to each other and to the world fluid and problematic. It fundamentally determines the character of modern life and creates conditions like melancholia and depression. Such experiences intensify when the changes in our lives (in the social world) are no longer experienced as '*elements in a meaningful and directed chain of developments', i.e., as elements of 'progress', but as directionless, 'franctic' change* (ibid. p. 40). Hence, positive (dynamic) change is perceived when the episodes of change add up to a (narrative) story of growth, progress or history. Accordingly, '*the perception of 'standstill' is the consequence of the experience of 'directionless, random, disconnected episodes of alteration, transformation or variation*' (Rosa 2010 p. 40). Here things change, but they do not develop, they 'don't go anywhere'. According to Rosa, this transforms the forms of human subjectivity (the subjective world) our 'being in the world' – our identity as human beings. This carries a significantly alienating potential (Rosa 2010 p. 40-42).

The loss of a meaningful connection between the past, the present and the future

Referring to Axel Honneth, Rosa states that the observed increasing 'exhaustion' of the self (rising levels of depressions and burn-out) is attributable to a struggle for recognition which starts again and again every day, in which 'no secure niches or plateaus can be reached' (ibid. p. 61). The pace of social change, the struggle for recognition in everyday life is aggravated in this way and threatens the subjects with constant insecurity and an increasing sense of futility. 'This mis-recognition is the consequence of falling behind – people fear being 'left behind'' (ibid. p. 61). People who fall into depression, Rosa argues, are experiencing a dramatic change in their time-perception, '*they fall from dynamic, or hectic, time, into a temporal quagmire where time no longer seems to move, but to stand still'* (Rosa 2010). '*Any meaningful connection between the past, the present and the future appears to be terminally broken*' (ibid. p. 70). The struggle for recognition is a constant driving force, and it is important to take this temporal dimension into account.

Episodes of experience (erlebnissen) or experiences which leave a mark (erfahrungen)

Rosa draws attention to the distinction between *erlebnissen* (i.e. episodes of experience) and *erfahrungen* (experiences which leave a mark, which connect to, or are relevant for, our identity and history; experiences which touch or change who we are) (Rosa 2010). Drawing on the philosopher Walter Benjamin, Rosa argues that we may be approaching an age where we are rich in episodes of experience (*erlebnissen)*, but poor on lived experiences (*erfahrungen)(Rosa 2010 p. 95)*. Here the concept of 'memory' is important. According to Benjamin (and to Rosa), we need 'souvenirs', external memory traces, to remember the mere episodes of experience, while we would never forget 'true' experiences in the sense of *erfahrungen*. According to Rosa, we fail to make the time of our experiences 'our' time. 'The episodes of experience, and the time devoted to them, therefore remain *alien* to us. To Rosa, the lack of appropriation of our own actions and experiences cannot but lead to severe forms of self-alienation (Rosa 2010 p. 95).

So according to Rosa, '*what we care about constitutes our identity and the loss of such a sense (of relevance and direction) cannot but lead to a distortion in the relationship towards oneself*' (Rosa 2010 p. 97). Therefore: '*Alienation from the world and alienation from the self are not two separate things but just the two sides of the same coin. It persists when the 'axes of resonance' between self and world turn silent*' (ibid. p. 97). To Rosa, it appears that the idea of a good life must be a life that is rich in experiences of 'resonance', leaving 'marks' in our lives, changing who we are. This is an existentialist or emotional rather than a cognitive concept depending on our '*being in the world*' (ibid. p. 101).

4.5.4 Transition experience

According to Meleis, the transition experience is defined as the experience during a passage from one state to another state (Meleis 2010). It accommodates both continuities and discontinuities in the life processes of human beings (Meleis, A.I. & Chick, N. 1986). In that way transitions are related to change and development and can be seen as the periods in between stable states. Undergoing surgery or being discharged are examples of situations implicating transition.

'*Because there are connotations of both time and movement, transition can be thought of as linking change with experienced time*' (ibid. p. 239). Transition, as a passage from one life phase, condition (status) to another, is a complex concept within elements of process, time span and perception. The process involves the disruption and the person's response to this disruption; the time span extends from the first anticipations of transition until stability; and perception reflects how the threat to the self-concept is experienced.

According to Meleis, there are several characteristics of transition: Transition is a *process* referring to a flow associated with an ending, followed by a period of confusions and distress, leading to a new beginning. The most pervasive characteristic of transitions is '*disconnectedness associated with disruption of the linkages upon which the person's feelings of security depend*' (ibid. p. 240). Meleis exemplifies this by referring to the disconnectedness in relation to '*familiar reference points; incongruity between expectations based on the past and perceptions of the present; and discrepancy between needs and the availability of, as well as access to, means for their* *satisfaction'* (Meleis, A.I. & Chick, N. 1986 p. 241). Connectedness, on the other hand, requires that one actively relates to one another and to the environment.

Moreover, how things are *perceived* characterises the transition; if one does not relate, one cannot find meaning attributed to the transition. Indeed, differences in perception may influence reactions and responses which may hinder progress toward a healthy transition. The way the transition is perceived relates to a*wareness*. To be in transition, a person must have some awareness of the changes. With this in mind, *patterns of response* characterise transition and arise out of behaviours during the transition process. These behaviours embody 'patterns' that reflect both intrapsychic structures and processes as well as their wider sociocultural contexts (Meleis, A.I. & Chick, N. 1986 p. 242, Meleis et al. 2000). Examples are disorientation, distress, feeling connected, interacting, being situated, developing confidence for example in the level of understanding the different processes inherent in diagnosis, treatment, recovery, and living with limitations while developing strategies for managing the transition and mastering new skills and achieving a sense of balance in one's life having a new sense of identity (Meleis et al. 2000). In this sense, processes (and outcomes) of transitions are defined by definitions and redefinitions of self and situation (Meleis, A.I. & Chick, N. 1986).

Transitions unfold over time; the process moves the person in the direction of health or towards vulnerability. According to Meleis, it is therefore important that through respectful communication preceptors support early uncovering, assessment and intervention to facilitate healthy transition outcomes.

5 Findings

In the following chapter, the findings are presented in form of the three papers:

Paper I
Acknowledging the patient with back pain: A systematic review based on thematic synthesis

Paper II
Back pain – a feeling of being mistrusted and lack of recognition: A qualitative study

Paper III
Spinal fusion surgery: From relief to insecurity

5.1 Introduction to the literature review Paper I

Paper I is a systematic literature review. The methodological approach was based on a thematic synthesis proposed by James Thomas and Angela Harden (Thomas, Harden 2008, Barnett-Page, Thomas 2009, Harden, A., Garcia, J. et al. 2004, Thorne et al. 2004).

The exclusion process
A total of 1,086 hits were identified in the initial search of which 905 were excluded based upon a reading of headings (see Paper I 'Inclusion and exclusion criteria' and Table 4 'Overview of data collection'). For example, the heading indicated a quantitative study or a different objective, for example reporting on different issues from within the perspective of other than people or patients with back pain. The next readings consisted of a thorough appraisal of the remaining 105 abstracts and resulted in further exclusion of respectively 45, 28 and 16 texts. At this stage, a paper was excluded because of, for example, ambiguity in terms, claiming to report qualitative data but using quantitative methods or focussing on patients groups with special diagnoses, for example, spinal cord injury. Finally, the 'method' Berry Picking was used which reduced the remaining papers from 16 to 8; hence, the initial sample of eight papers must be seen as purposive rather than exhaustive because the purpose is interpretive explanation rather than prediction (Thomas, Harden 2008).

Quality assessment

Quality assessment studies were performed using Kirsti Malterud's criteria (Malterud 2001); and to examine the contributions of each study, the eight studies were also assessed post hoc after a synthesis had been formed on the basis of a sensitivity analysis (Thomas, Harden 2008, Carroll et al. 2012). To enhance transparency in identifying the core steps involved in the synthesis, the main guidelines ENTREQ (Enhancing Research in Reporting the Synthesis of Qualitative Research) were followed (Tong et al. 2012) (Appendix H, I, J).

The analytic and synthesis process

According to Thomas and Harden, a difficulty in synthesising qualitative data from qualitative studies is to determine 'what counts as data?' (Thomas, Harden 2008). Cambell et al. (2003) extracted what they called 'key concepts' from the studies. However, finding the key concepts in qualitative research is not always straightforward. According to Sandelowski and Barroso (2002), identifying the findings in qualitative research can be complicated by varied reporting styles. In the literature review, Paper I, all text labelled as 'results' or 'findings' were taken as study findings.

The synthesis evolved over three stages which overlapped to some degree: the free line-by-line coding of the findings; the organisation of these 'free' codes into related areas to construct descriptive themes; and the development of analytical themes (see Table 2, Paper I). The intention was to identify, systematise and integrate the findings of several qualitative studies that may elucidate, from a health perspective, different groups' attitudes to and perceptions of barriers, the consequences of these areas and focal areas of interest (Damsgaard et al. 2015). Each line was coded to capture the meaning and contents of each sentence. The reviewer looked for similarities and differences between the codes in order to start grouping them. This process resulted in two main descriptive themes: 'Being a person with back pain' and 'Health professionals' biomedical view on the individual'. According to Thomas and Harden (2008), the synthesis is the most difficult and controversial stage to describe, since it is dependent on the reviewer's judgement and insights. At this stage, according to Thomas and Harden, one 'goes beyond' (Thomas, Harden 2008, Barnett-Page, Thomas 2009) the contents of the original studies by using the descriptive themes that emerged from the inductive analysis of the study findings to fulfil the purpose of the review, i.e. to identify, systematise and integrate the findings elucidating attitudes to and perceptions of barriers, the consequences of these areas and focal areas of interest. Throughout the discussion, more abstract and analytical themes began to emerge: ‘The ‘divided’ view of the individual’ and ‘Back patients’ illness experiences’, altogether resulting in the generation of the main theme and synthesis: ‘Acknowledging the patient approach from cause to process. A synthesis’.

The results of the systematic literature review are presented in Paper I and discussed in the chapter ‘Discussion’. A new literature review spanning the period from March 2013 to September 2015 was performed to update the literature review. These results of the review are presented in the chapter ‘Background’ (paragraph 2.3) and discussed in the chapter ‘Discussion’.

Paper I

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ARTICLE

Acknowledging the patient with back pain: A systematic review based on thematic synthesis

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Abstract

Rationale and aims: Research shows that back patients' illness experiences affect their interaction with the healthcare system. It is important to examine the exact nature of these experiences in order to shed valuable light on how back patients perceive their illness and hospitalisation. The aim of this literature review is to gain a better understanding of back patients' illness experiences and to identify, systematise and integrate the findings of different qualitative studies that may elucidate barriers and the consequences or focal points in connection with care and treatment.
Methods: The methodology for this literature review is based on the thematic synthesis used by James Thomas and Angela Harden. The literature review also draws on the sociological theories and arguments of Ulla Harriet Jensen and Trine Dalsgaard in which health professionals biological perception of the individual dominates the healthcare system and translates into a certain way of perceiving and explaining illnesses and symptoms.
Results: The thematic analysis shows that it is through experiences and memories that we create our identity and consciousness. Ignoring the illness experiences can therefore be seen as disregarding, the patient as a human being. With this in mind, it is easier to understand why back patients often feel marginalised and mistrusted in their interactions with the healthcare system. Respectfully including the patients' experiences is fundamentally about acknowledging the back patient as a human being.
Conclusions: A synthesis of the included studies demonstrates the need for healthcare professionals to pay attention to back patients' narratives in order to acknowledge them as human beings. This acknowledgement involves an ethical dimension and a sense of responsibility, manifested as respectful inclusion of the patient's experiences. The body can never be understood merely as a biological entity and therefore illness is far more than having symptoms, diagnoses and treatment. The synthesis thus proposes an acknowledgment of this and a more holistic approach.

Keywords

Acknowledgement, back patient, duality, illness experience, patient experience, patient satisfaction, person-centered healthcare, phenomenology, systematic review

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Introduction

Back conditions and back pain are among the most common causes of reduced working capacity and lengthy, tiring and costly illness trajectories. According to international research, back pain ranks among the costliest conditions worldwide [1-5]. A thorough review of the literature in the field has further revealed that back conditions are associated with heavy personal costs [6-12]. It is therefore of the utmost importance that these conditions are dealt with as efficiently and effectively as possible, as failure to do so can have severe implications for Society as a whole. In addition, research shows that back patients' illness experiences greatly affect their interaction with the healthcare system. With this in mind, it is important to gain a better understanding of back patients' experiences and pinpoint what is important to them in their interactions with the healthcare system.

There is disagreement in the literature with regard to how patient satisfaction with healthcare is conceptualised and operationalized [13-15]. The concept of patient satisfaction ranges from patients' satisfaction with operations, to satisfaction with hospital facilities or relationships with healthcare professionals. Many of the relevant studies in this context are based on questionnaires and employ the concept of satisfaction more broadly, thus making it difficult to determine which aspects of care and treatment are being assessed. Danish patient satisfaction surveys, for example, indicate that there are significant discrepancies between questionnaire and interview responses. When patients are interviewed, they rarely express absolute satisfaction or dissatisfaction, but rather describe their experiences in a much more nuanced way. In questionnaires, however, patients show solidarity with the staff and are reluctant to voice criticism until they can *explain* themselves precisely [16].

As we have outlined, then, research suggests that back patients' illness experiences can strongly influence their interactions with the healthcare system [7-11,17-19]. It is through experiences and memories that, as humans, we create our identity and consciousness [20]. Ignoring patients' illness experiences can therefore be seen as disregarding the patient as a human being, explaining why back pain patients frequently feel marginalized, mistrusted and disrespected. Knowledge is therefore highly beneficial to the healthcare system and very important to explore further, especially given that no literature has yet thematised and synthesized knowledge in this particular area. The purpose of this qualitative literature review was thus to gain a better understanding of back patients' illness experiences.

Method

Research question

The research question, "How do back patients experience their illness trajectory and hospitalization?" constituted the scope of the areas included. This ensured that the studies included were based on qualitative methods and shared a focus on the patient's perspective.

Inclusion and exclusion criteria

The search included English, German, Swedish, Norwegian and Danish literature such as books, book chapters or peer-reviewed articles. Excluded were quantitative studies; studies with a focus on children or teenagers < 18 years; studies aimed at relatives, other orthopaedic patient groups or specific physiotherapeutic rehabilitation (Table 1). In addition, a search protocol, overview of the data collection (Table 4) and characteristics of the included studies (Table 5) were created.

Since previous exploratory literature searches had indicated that there is a paucity of research in the area, the initial search was necessarily broad. The search words used were: 'experience', 'life experience', 'life change events' combined with 'surgery patient', 'rheumatology patient', 'medical patient'. These search words were combined with the keywords: 'hospitalisation', 'inpatient', 'back patient', 'back pain', 'spinal fusion', 'lumbar spinal fusion', 'spinal stenosis', 'decompression back surgery' and 'back surgery'.

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Qualitative studies • English, German, Swedish, Norwegian, Danish literature • Back patients both hospitalised and not hospitalised	• Quantitative studies • Studies with focus on children or teenagers < 18 years • Studies aimed at relatives • Other orthopaedic patient groups or specific physiotherapeutic rehabilitation

Search strategy, quality and relevance appraisal

The first step of the process involved a systematic literature search of international and Danish databases with a focus on health science. The search was limited to the period 1998-2013. The databases included: PubMed, CINAHL, Den Danske Forskningsdatabase, Bibliotek.dk, SveMed+, PsycINFO. The database RefWorks was used to manage the references.

A quality assessment was carried out using published criteria, cf. Malterud [21], which focused on how the design and conduct of each study had been reported. These assessments were employed to inform judgments on both the internal validity of the studies and the validity of the findings of the synthesis. To examine the relative contributions of each study, the 8 included texts also were assessed *post hoc* after the synthesis was completed in terms of strengths and weaknesses on the basis of a sensitivity analysis, *cf.* Thomas and Harden [22,23]. The assessment focused on 12 quality criteria; 5 of the criteria are related to how well purpose, background, rationale, methods and findings have been accounted for; 4 criteria are related to the validation strategies and include data collection strategies, method of analysis and thus the overall validation of the findings and 3 criteria are related to the appropriateness of the data collection methods with regard to how knowledge is obtained [24-27].

Methods of synthesis

Thematic synthesis

Our systematic literature review was based on the thematic synthesis used by Thomas *et al*. [22,28-30]. The intention was to identify, systematise and integrate the findings of several qualitative studies that may elucidate, from a health perspective, different groups' attitudes to and perceptions

Table 2 Overview of the synthesis process and emerged themes, Phases 1-3

Phase 1. Line-by-line coding	Phase 2. Descriptive themes
Pain, in-between, marginalisation, disrespect, information, putting yourself forward/speaking up/asking questions	Being a person with back pain
Illness experience, narratives, identity, morality, inclusion, social position, respect	Health professionals' biomedical view of the individual
Phase 3. Main analytical theme including synthesis	
Acknowledging the back patient: The divided view of the individual Back patients' illness experience Acknowledging patient approach - from cause to process. A synthesis	

of, barriers, consequences and focal areas. Our review therefore had a clear use scenario, which is why thematic synthesis was thus considered applicable in the present context [28,31-34].

Thematic synthesis consisting of three phases

The thematic synthesis took its point of departure in 3 partly overlapping phases: 1) The free line-by-line coding of text; 2) Construction of descriptive themes & 3) Development of analytical themes [22]. In Phases 1 and 2, themes were able to be created across the various studies to capture relevant meaning and content from the sentences. As the coding of each study progressed, themes were collated and developed, resulting in the gathered material evolving into a new common perspective. This marked the beginning of the synthesis. To check the consistency of the synthesis and whether additional levels should be added, the coded texts were examined a final time at the very end of Phases 1 and 2. The process thus yielded a number of codes to be systematised according to similarities and/or differences and grouped at the end to capture the overall meaning. This process resulted in a number of global descriptive themes. (See 'Overview of synthesis process and emerged themes', Table 2)

Phase 3 enabled an analysis of the findings using explanations and theory (Table 3) from Ulla Harriet Jensen's study of 'Sociological aspects of diagnosis and treatment of back patients in Denmark' as well as from French philosopher Paul Ricoeur's perception of acknowledgement and German philosopher Hans-Georg Gadamer's perception of embodiment [18,20,35]. These allow approaches for the creation of arguments that go beyond the content of the original studies, resulting in analytical themes that may reveal barriers, consequences or specific focal points relevant to practice. Thomas and Harden illustrate the purpose of the phase and the synthesis by referring to Sally Thorne's text who describes qualitative synthesis as: "… integrations that are more than the sum of parts, in that they offer novel interpretations and findings. These interpretations will not be found in any one research report but, rather, are inferences derived from taking all of the reports in a sample as a whole*."* [36]. This section thus concludes with a synthesis of the findings based on Todres, Galvin and Dahlberg's perspectives (Table 3) on Lifeworld-led Healthcare [37-39].

To enhance transparency in identifying the core steps involved in the synthesis, the main guidelines ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research Statement) suggested by Tong were followed [40].

Results

A framework (structure) of the emerged themes, analysis, results and discussion

In order to provide transparency for all stages and processes the following must be considered as an overview over the emerged themes, analysis, results and discussion. The descriptive themes are conceptualised as being "results" and the analysis - because it is going further than the primary studies and drawing on external theory - as "discussion". Phases 1 and 2 produces 2 main descriptive themes from which the results emerge.

Being a person with back pain

The theme will be divided into 3 sub-themes which also is a representation of the results: a) "In-between patients"; b) "They assumed that I knew stuff that I didn't" & c) Putting yourself forward/speaking up and asking questions.

Health professionals' biomedical view of the individual

Phase 3 (the analytic and main theme) conceptualised as "discussion". The third phase involves integrating the different parts of the analysis into a main unifying and synthesising theme called 'acknowledging the back patient'. The main theme was divided into 2 sub-themes

Table 3 Overview over the main arguments in the synthesis

Ulla Harriet Jensen [18]	Psychological and sociocultural aspects are included in the biomedical practice only when the back condition is easily diagnosable. In cases where the illness is undiagnosable on the basis of "objective findings", the patient's psychological, social and cultural conditions are less likely to be considered and acknowledged. Instead, these conditions become indicative of something else, such as psychological problems or a conscious or subconscious unwillingness to work. When the diagnosis process does not allow for inclusion of the patient as empirical subject, there is a risk that patients' illness experiences become detached from the clinical context as well as from the patient's lifeworld and turn into disconnected markers, which will then attract the practitioner's attention. There is thus a clear tendency for healthcare professionals to interpret back patients' narratives from the point of view of their own (biomedical) perspective, resulting in the narrative about life with back pain being snatched from the back patient's context. The mutual acknowledgement is thus based on the healthcare system's premises rather than the patient's.
Paul Ricoeur [20] & Peter Kemp [45]	Humans understand themselves through their past, their experiences and thus through their self (the I), which represents identity not diversity. Individuals relate to themselves through speech, action, narrating in general and narrating about themselves. It is our experiences and memories that help us identify with ourselves and build self-awareness. Acknowledgement is a socialpsychological and ethical concept that presupposes that people appear as persons to themselves as well as others. Acknowledgement is about reflective and responsible decision-making in open or uncertain situations.
Hans-Georg Gadamer [35]	The body can never be understood merely as a biological thing or as an object. We can never free ourselves from this embodiment, never come away from or stand outside of ourselves as subjective bodies. Accordingly, the human being does not "have" a body, but "is" the body.
Todres *et al.*; Dahlberg *et al* . [37-39]	Argues for a patient approach inspired by the philosophy *Lifeworld-led healthcare*, which in turn is based on a perspective that includes the individual's lifeworld. Lifeworld-led healthcare involves more than just collecting the patients' viewpoints. Patient experiences are more detailed, complex and informative than that and consist of more than just evaluations and assessments. We cannot fully understand the quality of an illness as it is lived without also understanding what it means interpersonally and culturally. In illness, we can no longer count on the freedom to participate in everyday activities as we once did and therefore illness is far more than having symptoms, diagnoses and treatment.

Table 4 Overview of data collection

Step	Action	Hits
	Number of hits per search	1.086
1	First reading of headings resulted in a reduction to	181 texts
2	Second reading of headings resulted in a reduction to	105 texts
3	Abstracts were read 3 times 1. reading reduced the number to 2. reading reduced the number to 3. reading reduced the number to	 60 texts 32 texts 16 texts
4	*Berry Picking* resulted in a reduction to	8 texts
	8 texts assessed cf. s*ensitivity analysis*	

Table 5 Characteristics of included studies

References	Aim	Methodology	Participants	Data collection
Davis [9] UK	To explore the patient experiences of the surgical journey from decision to operate, to hospitalization, discharge and recovery.	A prospective qualitative study.	Seven patients. Both men and women. All participants between 48 and 75 years. Five were male.	Two focus group discussions.
Vroman [10] USA, New Zealand	To examine the broader experience (acute as well as chronic) and low back pain in the community.	A qualitative descriptive design influenced by narrative types described in "The Wounded Storyteller" by Frank, A. 1995.	Participants between 19 and 83 years of age. Both men and women.	Participants answered an open-ended question. The narratives were analyzed using thematic content analysis.
Lillrank [11] Finland	To discuss how Finnish women experienced initial back pain and the long and uncertain process of getting a name, a medical diagnosis for their discomfort and how they made effort to cope with pain.	A qualitative and descriptive design influenced by P. Ricoeur and C. Mattingly.	30 Finnish women between 20 and 66 years of age.	Autobiographic writing competition called "The back Bone in Your Life".
Slade [12] Australia	To determine participant experience of exercise programs for nonspecific chronic low back pain.	A qualitative study and grounded theory.	18 people aged over 18 years were included.	Three focus groups facilitated by an independent, experienced facilitator.
Abbott [17] Sweden	To describe within the context of Classification of Functioning, Disability and Health (ICF), patient's experiences post-lumbar fusion regarding back problems, recovery and expectations of rehabilitation and to contrast with the content of outcome measures and the ICF low back pain core sets.	Cross-sectional and retrospective design.	Twenty lumbar fusion patients recruited through Karolinska University Hospital's Orthopaedic Clinic in Huddinge Sweden, between 2005 and 2007. Patients between 18 and 65 years of age. Both men and women.	Semi-structured interviews.
Åbyholm [7] Norway 1. part + 2. part	The aim of the study was to explore the experiences and coping strategies of patients with chronic low back pain.	A qualitative study.	A strategic sample of 22 patients with chronic low back pain. Fourteen women and 8 men, with a mean age of 46 and a mean duration of illness of 15 years. Eighteen had been treated with low back surgery.	Semi-structured interviews.
Jensen [18] Denmark	To focus on how a sociosomatic perspective on illness can be integrated into a biomedical practice in relation to illnesses with and without an adequate organic-pathological basis.	Fieldwork conducted 2002-2005.	Back patients and professionals at a clinic for back pain as well as among clients and social workers at a social services department in Denmark.The back patients have been referred to the clinic by their own GP often after prolonged back pain (min. 4 weeks).	Interviews with approx. 50 patients 1-3 times during the course of a year from initial contact to clinic.
Dalsgaard [19] Denmark	To examine how the lack of a legitimate diagnosis leaves people suffering from inexplicable symptoms feeling marginalised, insecure and last but not least unsure of their social position.	Anthropological analysis, PhD project 2005 – If only I had been in a wheelchair. An anthropological analysis of narratives of sufferers with medically unexplained symptoms.	Informants with non-specific medical symptoms, allocated from 3 different patient organisations with a focus on fibromyalgia, whiplash and electrical hypersensitivity. Participants ranged in age from 22-82.	A total of 30 patients involved. Participant observation, interviews and group discussions.

and a synthesis accomplished *via* a consideration of: a) The divided view of the individual; b) Back patients' illness experiences & c) Acknowledging patient approach - from cause to process. A synthesis.

Data collection

The search yielded a total of 1086 texts. The first phase involved looking at headings, which reduced the number of texts to 181 [41,42]. In the second phase, the abstracts and keywords of the articles were perused, reducing the number of texts to 105. In Phase 3, the abstracts and keywords were read an additional 3 times, which further reduced the number to 60, 32 and 16 respectively. In Phase 4, 16 articles were read word for word and subjected to so-called *Berry Picking* [43] - a method that takes into account the fact that insight is gained not through a linear process, but rather through a series of decisions as new information is gained. Finally, citation checking was conducted looking at the reference lists of included studies and Google Scholar was consulted to investigate which papers cited the authors and their texts. This process resulted in the final inclusion of 8 texts. (See 'Overview of Data collection' - Table 4)

Primary research studies

The data for analysis were extracted from the Results sections of the papers and consisted either of *verbatim* quotations from study participants or findings reported by authors that were clearly supported by study data [44]. The characteristics of the included studies are presented below in Table 5 schematically from the point of view of aim, methodology, participants and data collection.

Phases 1 and 2

The findings of Phases 1 and 2 are presented below in the form of 2 main descriptive themes.

Being a person with back pain

This descriptive theme uncovers the challenges associated with being a person with back pain. The articles reveal elements of existential character, such as lack of acknowledgement and acceptance by the surroundings as well as mobilisation of courage to put yourself forward and speak up [7-9]. The challenges are particularly evident in familiar and work-related contexts as well as in the meeting with healthcare institutions [17]. It is life experiences such as these that back patients bring along to the meeting with their healthcare professionals.

"In-between patients"

Some back patients describe feeling like 'in-between patients' for years and have to endure a feeling of marginalisation until a diagnosis has been made: "

> "I began to believe that I was imagining my pain. Many doctors even 'supported' me in that belief. I should be sent to another doctor, a psychiatrist." [11].

The back patients describe how a lack of (physical) explanations from the healthcare professionals challenge their core perception of themselves: their identity. Living with back pain is described as an all-consuming element that interferes with all areas and functions of life. The included literature contains many descriptions of back patients encountering healthcare professionals who focus exclusively on the physical aspects of the back pain condition at the expense of the general illness experience. Few healthcare professionals were regarded as paying sufficient attention to, or acknowledgement of, back patients' narratives, which has the effect of making patients feel mistrusted and thus disrespected.

The literature shows that there are different ways of coping with this situation. Some patients 'put up a fight' and describe how they eschew the victim role. They try to be proactive by, for example, seeking and acquainting themselves with the relevant technical information to feel better equipped to continue their daily routine and activities of life. They try not to allow pain to define their perception of life and themselves; pain becomes something that they have to cope with. They depict back pain as a fight between the intrusive pain and a fundamental belief that the pain should never influence their daily activities:

> "I fight the pain even when it wears at me and it makes me tired, I won't let it win." [10].

Other patients describe how they tend to acquiesce, accept and eventually lose their will to fight. The pain has taken over their life, they have surrendered and the pain has become their identity:

> "Sometimes I feel it has taken over my life." [10].

Living with back pain for a prolonged period of time appears to affect a person's fundamental perception of him/herself.

"They assumed that I knew stuff that I didn't"

Back patients describe how healthcare professionals take the hospital world and its processes for granted:

> "I think because it is the first time I have ever been an inpatient in a hospital, I think people have assumed I knew stuff I didn't." [9].

The examined studies show that procedures that may seem straightforward to the healthcare professionals, such as why a patient has been moved to the recovery ward or attached to an intravenous drip, really do need to be explained to the patient [9]. Back patients are worried about the post-operative process and explain that being better informed would reduce their sense of nervousness. However, it is important that the information is provided in the right way:

> "I can sit here and say yes, yes, yes, and I am hoping I am taking it all in, but by the time I have gone out, there has been so much going round, I forget it." [9].

Support at all levels of the care process, whether from healthcare representatives or family members, is thus highlighted as being very important:

> "I brought somebody with me, and I had them taking notes which helped because I was listening face to face while they were removed from the situation and taking notes, so when I got home, I could go over everything … this had been said and that had been said." [9].

"Putting yourself forward"

Back patients explain that it is crucial for them to 'put themselves forward', 'speak up', 'tell their story' and ask questions. Their surgeon is an important resource in this regard, especially when it comes to information about the operation:

> "I asked questions (to the surgeon) … the details that I needed would not have been forthcoming. It's about putting yourself forward." [9].

The included literature shows that the patients are often people whose life experiences have affected their sense of identity:

> "If I had to sum up how back pain affects my life, I'd had to say it affects everything …our back is the core of our bodies, which, when unable to function normally or effectively, affects our whole being." [10].

The altered sense of identity determines what the patients hear, understand and dare ask questions about in their meeting with the healthcare professionals:

> "I am a kind of laid-back sort of guy … but I think somebody more vulnerable could possibly have found Prof XX very scary. He was running ¾ of an hour late and he just wanted to get people in and out … I didn't have a chance to ask questions." [9].

These accounts reveal how vulnerable some patients feel and this is why they feel a strong need to talk about their experiences:

> "… spent 60 minutes completing multiple tasks in the questionnaire about back pain, yet I needed to tell my story." [10].

What back patients encounter, however, is a hectic healthcare system that ignores the importance of this sharing in its quest for efficiency.

It thus gradually becomes clear that back patients find it difficult to express themselves, describe their experiences and ask the very questions which are weighing on their minds. To compensate, many of them attempt to adopt a more active role by looking for answers online:

> "I found it very useful for me to research stuff on the web not to become an expert on medical advice but to understand in more detail in a way you can't discuss with the surgeon. They look from a different perspective to you rightly or wrongly. To say it in a nice way, it's a bit of factory for them." [9].

The healthcare system's lack of concern for back patients' experiences and questions may explain why many of these patients express fear and worry about what they are "allowed" to do after the operation. They often introduce their own restrictions out of fear that they might accidentally do something that would exacerbate their condition.

Health professionals' biomedical view of the individual

A recurrent theme that is described in different ways in almost all the included studies is the individual's meeting with the healthcare system, which predominantly operates with a "divided" view of the individual (the back patient):

> "The experts' suggestions reveal the deep-seated Western belief in the superiority of the mind over the body. It is also a moral judgment – you could, if you only would, master the pain. They did not really listen to me; I was fixated in my symptoms; I was disappointed not being taken seriously." [11].

This, according to the various studies, can lead to moralizing behaviour on the part of the healthcare professionals, manifested as *failure to acknowledge* patient experiences. The back patient may perceive this behaviour as essentially disrespectful. Many of the included studies state that this biomedical perception of the individual dominates the healthcare system and translates into a certain way of perceiving and explaining illnesses and symptoms [19].

Several back patients point out that the healthcare professionals' main focus is to arrive at a diagnosis and patients explain how they experience a loss of self-perception and social position while waiting for the final diagnosis to be made [8,10,11,19]. Back patients experience their pain as all-consuming and interfering with all aspects of their lives. The patients stress that their illness narratives are not recognised on equal terms with their physical symptoms and that this can give rise to disrespectful and moralizing behaviour on the part of the healthcare professionals with regard to the subjective pain experience [11]. According to many studies, back patients are categorised as untrustworthy, which they perceive as insulting. Lillrank concludes her study by saying that healthcare professionals fail to understand and acknowledge that patients experience their physical conditions both objectively as *being* in pain as well as subjectively as *experiencing* pain.

Other studies claim that back pain represents a threat to a person's identity, but stresses that it helps to *talk* about it [10]. However, the study we cite points out that healthcare professionals prefer narratives that adhere to the sequence *diagnosis→treatment→recovery*, because recovery often equals successful medical intervention, in which they themselves play a central role. Healthcare professionals, it appears, are drawn to and even sometimes expect patients to share these narratives about their illness. It is part of the expected patient role: (back) patients are nursed and exempt from their usual duties, but in return, they are expected to recover. Interestingly, the study explains that it is difficult for staff to cope with patient narratives that convey a sense of hopelessness and anger and which accuse healthcare professionals of being unable to understand what has or may have 'gone wrong'. The study emphasises the need for healthcare professionals to be able to listen, acknowledge and recognise the value of patients' narratives. Several other studies support such observations by proposing a shift in care and treatment from the *divided* view that ignores back patients' experiences to a more *holistic* view of the individual [8-11,18,19].

Taking its point of departure in Thomas and Harden's structure, our analysis developed through a discussion into a synthesis with the heading - Acknowledging the back patient. This led us to develop action plans taking full account of the barriers, consequences for practice and focal points we observed (Table 2). The main analytical theme, 'Acknowledging the back patient', is divided into 2 sub-themes and a synthesis: 'The divided view of the individual; Back patients' illness experiences' and the synthesis 'Acknowledging patient approach - from cause to process. A synthesis.'

Discussion

We advance that acknowledging the back patient requires several principal considerations. These are, we contest, as outlined below.

The 'divided' view of the individual

When examining the included period from 1998 to 2013, it appears that back patients' challenges and criticisms of the healthcare system remain unchanged. Back patients continue to highlight marginalization issues, excessive waiting times and a lack of continuity, as well as problems with communication and information in their interaction with healthcare staff. The descriptive themes depict an image of deficiencies that the healthcare system in Denmark and other places has attempted to solve; however, patients' illness experiences continue to be ignored. Focus remains it seems, on the"true" causes of the back patient's disease, which places emphasis on the back patient's *biologicalbody*, rather than the *whole* person. The healthcare system operates on the basis of the biomedical view of the individual and the analysis, in accordance with Harriet Jensen's results, suggests that the psychological and sociocultural aspects are included in 'biomedical practice' only when the back condition is easily diagnosable. In cases where the illness is undiagnosable on the basis of "objective findings", the patient's psychological, social and cultural conditions are less likely to be considered and acknowledged. Instead, these conditions become indicative of something else, such as psychological problems or a conscious or subconscious unwillingness to work [18].

Back patients' illness experiences

It thus appears that healthcare professionals operate on the basis of a dualistic way of thinking which does not allow for a shared frame of understanding that may legitimise back patients' *experiences*. Acknowledging patients' subjective experiences is an integral part of many healthcare professionals' approach, but if this approach is implemented only *partially,* it will be built on a psychosomatic understanding that tends to reduce back patients' physical experiences to a *psychological* cause, which 'biomedical thinking' continues to regard as 'inherently suspect'.

The concept of *acknowledgement* was analysed by French philosopher Paul Ricoeur in his book '*Parcours de la reconnaisance*' [20]. Ricoeur defines acknowledgement as a social, psychological and ethical concept that presupposes that people appear as *persons* to themselves as well as others. To Ricoeur, acknowledgement is about reflective and responsible decision-making in open or uncertain situations such as those experienced by back patients [45]. Ricoeur believes that humans understand themselves through their past, their experiences and thus through their self (the 'I'), which represents identity, not diversity. Individuals relate to themselves through speech, action, narrating in general and narrating about themselves [20]. Given this, it becomes clearer why back patients repeatedly emphasise feelings of marginalisation, mistrust and disrespect in their meeting with the healthcare system. The fundamental acknowledgement of the back patient as an *individual,* as a subject, is therefore at stake.

According to Ricoeur, it is our experiences and memories that help us identify with ourselves and build self-awareness, which is why back patients feel disrespected, personally, as well as socially, when their illness experiences are excluded from their treatment plans. The literature supports such observations by stating that back patients' illness experiences are all too often included only as *an object* of the healthcare professionals'/doctor's analysis in the same way as the patient's body.

There is no room in the diagnosis process for fundamental significance in the form of acknowledgement of the back patient as a *person*. When the diagnosis process does not allow for inclusion of the patient as *empirical* *subject*, there is a risk that patients' illness experiences become detached from the clinical context as well as from the patient's lifeworld and turn into disconnected *markers*, which may or may not then attract the practitioner's attention [18]. There is thus a clear tendency for healthcare professionals to interpret back patients' narratives from the point of view of their own (biomedical) perspective, resulting in the narrative about life with back pain being 'snatched' from the back patient's 'real life' context. The mutual acknowledgement is thus based on the healthcare system's premises, rather than those of the patient's.

Acknowledging the patient approach - from cause to process. A synthesis. Frame of reference. Why does it matter?

As we have discussed in some detail above, the biomedical model is actively denying essential parts of the patients' life stories excluding such knowledge from decision-making and making patients feel marginalized and peripheral to the decision-making process. According to the German philosopher Hans-Georg Gadamer, the body can never be understood merely as a biological 'thing' or as an 'object' [35]. Certainly, we can never free ourselves from this embodiment, never come away from or stand outside of ourselves as subjective bodies for as long as we are alive. Accordingly, the human being does not "have" a body, but "is" the body. When healthy, for example, we have a natural attitude to our subjective body and to the idea of health itself, which we take normatively for granted. When ill, however, we do not enjoy 'easy' and natural access to the world - our relationship with the world is disturbed. In illness, we can no longer count on the freedom to participate in everyday activities as we once did to prior illness and illness is far more than having symptoms, diagnoses and treatment. It is also the loss of abilities that hinder easy and unmindful living. A breakdown of one's body means a breakdown of life [39]. A headache for example may mean an inability to concentrate; back pain may mean an inability to go to work. From this perspective it becomes clear why the biomedical/dualistic model is then failing on its own terms and is increasingly less and less successful in achieving its objective of facilitating recovery and healing. Our synthesis concludes that better treatment and outcomes would result if the relational dynamics were included in this perspective.

Lifeworld-led healthcare

The analysis and discussion we present above show, we contend, that back patients challenge their healthcare professionals and indicate that the biomedical perspective neglects back patients' illness experiences. Back patients experience a lack of 'acknowledgement' from their surroundings and perceive this as a violation of their personal and social identity, which in turn makes them doubt who they are. It is therefore crucial to argue for a more inclusive and process-oriented approach that draws patients' experiences into the care and treatment process and it is the role of healthcare professionals to contribute to the creation of an acknowledging environment that encourages patients to 'speak up'.

The arguments of our analysis can perhaps be synthesisied by Todres, Galvin and Dahlberg's arguments in favour of a person-centered approach inspired by the philosophy *Lifeworld-led healthcare,* which in turn is based on a perspective that includes the individual's lifeworld [37-39]. However, *Lifeworld-led healthcare* involves more than just *collecting* the patients' viewpoints. Patient experiences are more detailed, complex and informative than that and consist of more than simple evaluations and assessments. The descriptions of patients' experiences make it easier to relate to the relations and cultural contexts (the lifeworld) that they belong to. Indeed, we cannot fully understand the quality of an illness as it is lived without also understanding what it means interpersonally and culturally. Descriptions of patients' lifeworld cover not only a description of the body as an object, but also, in line with Ricoeur's points concerning acknowledgement and Gadamer's perception of embodiment, as an understanding of how the individual lives and functions in the world. This kind of approach provides access to a deeper insight into patients' experiences. It also forms the basis of additional studies of how back patients experience their illness trajectory and hospitalisation. It is for all of these reasons that we advance our study as an important contribution to the person-centered healthcare literature.

While the first 2 phases of our synthesis adhere closely to the findings of the original studies, Phase 3 related the descriptive findings of the synthesis to wider theories about healthcare and identity. The present thematic synthesis attempted to take this into account by describing the analysis and synthesis process both clearly and precisely. To assess the strengths and weaknesses of the synthesis as well as the potential consequences of either including or excluding findings from various studies, an additional sensitivity analysis (see also Table 5 'Characteristics of included studies') was conducted (cf. Thomas and Harden) [24-27,33]. The 8 studies were found to be relevant and were included despite their dissimilarity. The literature review subsequently argues in favour of back patients' illness experiences being incorporated into their meeting with the healthcare system.

Conclusion

Our thematic synthesis shows that patient experiences are of paramount importance to individuals with back pain in relation to their experience of and meeting with the healthcare system. The back patients and other individuals with back conditions included in the 15-year review period from 1998 to date have all expressed dissatisfaction with a biomedically dominated healthcare system that relegates patients to feeling marginalised and afraid to 'speak up'. Our thematic analysis shows that back patients' experiences clash with the biomedical view of the individual characteristic of the healthcare system, which perceives individuals as divided into body, mind and soul and not a functionally integrated whole. The back patients' experiences are too often excluded, resulting in patients feeling ignored and thus disrespected.

A synthesis of the main points of the analysis indicates that it would be appropriate to introduce a more acknowledging patient approach with a balance between (disease) *causes* and conditions, which would influence back patients' progress from ill to well. The focal point of our synthesis thus proposes acknowledging the need for a far more holistic approach to the care of patients whose identity is formed partly by the experiences they carry with them.

Conflicts of Interest

The authors declare no conflicts of interest.

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Paper II

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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.

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.
JS-T

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).

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
"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 *want* out of it. That feeling of being under suspicion shook me. I thought, is there something wrong with *me*? I almost believed that." "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."	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. 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. 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.	**To live with invisible pain and a feeling of being mistrusted** • A life with experiences of insinuations and being mistrusted • To lose faith in your own judgement, experiencing a sense of unreliability, powerlessness and insecurity about your identity.
"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." "A little chat would be nice. But it is mostly: Do you have a fever, do you have pain?" ". . . 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."	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.	**To live with the struggle for recognition** • To listen • Recognition and time • Mutual understanding.

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 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 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

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Spinal fusion surgery: From relief to insecurity

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KEYWORDS
Pain;
Spinal fusion surgery;
Powerlessness;
Decision;
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Disconnectedness;
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Identity;
Communication;
Meaning

Abstract ***Background:*** During their decision-making process patients perceive surgery as a voluntary yet necessary choice. Surgery initiates hope for a life with less pain but also creates a feeling of existential insecurity in terms of fear, isolation and uncertainty.

Aim: The aim of this study was to explore how patients experience their situation from the point of making the decision to undergo spinal fusion surgery to living their everyday life after surgery.

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

Findings: The recommendation and decision to undergo spinal fusion surgery felt like a turning point for the patients and brought hope of regaining their normal lives, of being a more resourceful parent, partner, friend and colleague with no or less pain. Thus, deciding to undergo surgery created a brief feeling of relief. However, life with back pain had changed the patients' understanding of themselves. Consequently, some patients postoperatively experienced insecurity and a weakened self-image with difficulties creating meaning in their lives.

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Conclusion: Being recommended and undergoing spinal fusion surgery initiates hope for a life with less pain and altered life conditions. At the same time, paradoxically, this creates a feeling of existential insecurity in terms of facing the surgery and the future to come. It is, therefore, important to recognise and include the patients' everyday life experiences concerning how they give (or may not give) meaning to their illness, i.e. their understanding of how it is affecting them. These aspects are essential for the patients' definition and re-definition of themselves and thus crucial to draw upon in the relationship and communication between patient and healthcare professional.

Editor comments

For many patients who have suffered chronic back pain being offered surgery gives them hope for the future. It also gives them a feeling that their pain is 'validated' and 'respected' by others. Listening to the voices of such patients and trying to interpret their experiences can help healthcare professionals to provide care that is more compassionate and emotionally intelligent. This is also true of engaging with the findings of this study. It illuminates the trajectory of the experiences and feelings of this group of patients to such a degree that it can help professionals to provide care that is more sensitive to back pain sufferers' needs for effective psychological care both before and after the surgery. This demonstrates, yet again, the immense value of qualitative research such as this.

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Background

Back pain is described as exclusively 'malefic' and powerfully destructive to the physical and psychological well-being of the individual and their family (Azoulay et al., 2005; Damsgaard et al., 2015, 2016; Smith and Osborn, 2015). Back pain ranks amongst the costliest conditions worldwide (The Pain Proposal Steering Committee, 2010) and, according to a report from the National Institute of Public Health in Denmark, the public expense as a consequence of problems with the lower back amounts to as much as 16.8 billion per year (Koch et al., 2011). It is, therefore, in the interest of both patients and society to ensure that patients with back pain are being treated and rehabilitated as effectively as possible.

Several international studies focusing on patients treated surgically indicate that 15–40% of those undergoing spinal fusion cannot expect to improve significantly (Block et al., 2003; Christensen et al., 2003). Studies from the USA show that patients will experience less pain after the surgery, but most continue to have residual pain and physical impairments (Trief et al., 2006). When receiving information on the inconclusive effect of surgery patients need to decide whether to have surgery or not. A study exploring experiences during the decision-making process showed that the operation is perceived as a voluntary yet necessary choice. Many patients draw the conclusion that they cannot change the fact of illness and have to accept surgical treatment because the ultimate goal for them is to stop the pain (Lin et al., 2012).

Deciding to undergo surgery initiates hope for a life with less pain but at the same time creates a feeling of existential insecurity in terms of fearing the surgery and the future to come (Papaioannou et al., 2009). Choosing surgery is linked with many psychosocial challenges as found in a study showing that *preoperative* experiences, characterised by fear, isolation and uncertainty, exert significant influence on patients (Worster and Holmes, 2008).

Many patients have been living with chronic back pain for years. The pain related challenges are diverse and continue to affect their lives after discharge (Berg et al., 2013; Cain et al., 2012). When confronted with a chronic illness patients move through a complex trajectory that involves an "extraordinary" phase of turmoil and distress (Kralik, 2002). However, some patients may make the transition towards an "ordinary" phase that involves incorporating chronic illness into their lives (Kralik, 2002). Life after discharge can be characterised as a transition from overcoming the pain and the operation to being on course hoping for recovery in a changed, but perhaps not fully recovered, body (Norlyk and Harder, 2011).

It is, therefore, not a surprise that being a patient with back pain can be so chaotic and traumatic that it can even develop into actual depression (Arts et al., 2012; Block, 2009; Falvinga et al., 2012; McIntosh and Adams, 2011; Moore, 2010; Nickinson et al., 2009). This is supported by a study from the Netherlands which found that 30% of patients undergoing spinal fusion surgery experience symptoms of anxiety and depression both before and after surgery (Arts et al., 2012).

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As shown above, many patients undergoing spinal fusion surgery have persistent physical and psychosocial problems both before and after discharge. However, there is a lack of knowledge when it comes to identifying how the patient's lifeworld is affected. Exploring this is crucial in being able to recognise and address this in healthcare professionals' interaction and communication with patients and supporting them throughout the process.

Aim

The aim of this study was to explore how patients experience their situation from the point of making the decision to undergo spinal fusion surgery to living everyday life after surgery.

Methods

Design

This qualitative study employed semi-structured interviews and observations. The analysis and interpretation applied Paul Ricoeur's phenomenological-hermeneutic theory of interpretation (Ricoeur, 1979, 2002).

Participants and data collection

Regardless of the exact surgical procedure, all patients undergoing spinal fusion surgery at an Elective Surgery Centre at a Danish Regional Hospital were consecutively included. Ten patients (Table 1) between the ages of 48 and 82 years each took part in two interviews. To ensure that the patients remembered and had the possibility of reflecting upon their experiences concerning their hospitalisation – the first interview took place 2–3 days after surgery allowing them to speak freely about how they experienced their illness trajectory including the interaction with the healthcare system. The second interview took place approximately two months after surgery and was initiated to get an even deeper understanding of what was important to the patients. Transcripts were read and reread several times to identify important issues to follow up on revealing the decision and recommendation of the surgery as a crucial moment for the patients. In this way the second interview allowed the participants to elaborate on issues that had emerged during the first interview.

To supplement the interviews the researcher observed the interaction between the patients and the healthcare professionals, i.e. the communication at the outpatient clinic, in the wards, the operating room, the recovery room, the hospital hotel and at information meetings.

The interview questions were open-ended, allowing the participants to speak freely. Based on observations and literature about patients with back pain, the researchers developed some overall and broad themes concerning patients' experiences living with back pain and their interaction with the healthcare system. The second interview included themes about the patients' experiences of the decision to undergo surgery and how they experienced life after surgery. The interviews were conducted between August 2013 and December 2013, lasted between 60 and 90 minutes and were subsequently transcribed verbatim.

Ethical considerations

All patients were informed both verbally and in writing about the purpose of the project. They were assured that participation was voluntary, that they would be able to withdraw from the project at any time and that all data would be made anonymous (Declaration of Helsinki, 1964). The ethical guidelines of the Northern Nurses' Federation were respected throughout the study (Northern Nurses' Federation, 2003).

Table 1 Characteristics of the patients.

Patient	Gender	Age	Social status	Pain duration
A	Woman	48	Factory worker	No precise data on onset and duration of pain. Overall, the reported experiences of suffering from pain spanned from one year to most of the patients' lives.
B	Woman	82	Domestic helper (retired)	
C	Woman	60	Nurse	
D	Male	74	Baker, driver (retired)	
E	Male	59	Carpenter	
F	Male	75	Driver of construction vehicle (retired)	
G	Male	64	Road worker	
H	Woman	67	Postman	
I	Woman	75	Shop owner (retired)	
J	Woman	53	Social and healthcare assistant	

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Table 2 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
"And then I come down here. A whole new world opened up for me. Here were people who knew how I felt. I had really needed someone to say; we know exactly what you mean. It was a miracle. He said: 'I have read about everything you've been through.' It was like something fell into place for me. I became a whole person again. Everything was initiated immediately – everything was planned".	Prior to making the decision to undergo spinal fusion surgery, the patients had experienced incidents with colleagues, family members and healthcare professionals, where they had felt subjected to insinuating remarks as well as feeling under suspicion of exaggerating their back pain. These incidents had triggered experiences of powerlessness and of not being acknowledged as individuals – they had become insecure. Therefore, being met by healthcare professionals who recommended surgery became a turning point for them. It meant that the patients felt relief and experienced renewed hope of a better future with less pain.	**A feeling of hope and relief** • Life-changes – a turning point • Hope for recovery
"It's as if I've been living in a bubble for years and when things calmed down. . .I suddenly had so much time on my hands that I scared myself because now I had to think. A kind of sadness came over me. My back had completely defined my life. How do I move on from here?"	The back pain had had such a fundamental influence on the patients' lives that it had almost come to define them as people. This meant that after discharge, many patients paradoxically experienced a sense of emptiness and insecurity. The surgery influenced the patients' self-image which had been defined through a life with back pain.	**Less pain but feeling empty and insecure** • Feeling insecure • A feeling of emptiness and alienation

According to Danish law, approval from the Regional Committee for Medical Research was not required because of the non-biomedical character of the study. Approval from the Danish Data Protection Agency was obtained (Journal number: 1-16-02-65-13) and their requirements for safe data storage were adhered to.

Data analysis and interpretation

The data analysis and interpretation consisted of a three-level process (Table 2): naïve reading, structural analysis and comprehensive understanding (Ricoeur, 1979). In the naïve reading, transcripts from interviews were read and reread to achieve an overall initial understanding of the text, i.e. an early interpretation. In the structural analysis, the early interpretation of the naïve reading was substantiated by a closer examination of the data. This was carried out by gathering sections of texts in larger meaning units consisting of sections of text from across the entire data set. The meaning of the sections of text was then further explained allowing the researchers to achieve a deeper understanding of 'what the data are saying' to 'what the text actually speaks about' in terms of emerging themes and subthemes (Gulddal and Møller, 1999; Ricoeur, 1979, 2002). At the level of comprehensive understanding, the analysed themes were interpreted and discussed in the light of relevant theories and existing research (Rendtorff, 2000; Ricoeur, 2002). To understand and explain what is going on from the patients' perspectives we draw on the theory of transitions by nurse and sociologist Afaf Meleis and on the ideas of alienation, directedness and meaningful social relations by sociologist Hartmut Rosa. This theoretical abstraction leads to a new explanatory position in the text and, thus, new insights (Ricoeur, 1979).

Findings

Naïve reading

The naïve reading of the texts showed that the patients' lives with back pain before the operation were characterised by phenomena such as insecurity and

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powerlessness but also by hope. The back pain had had such a profound impact on their lives that, after being discharged, many of the patients experienced difficulty creating a new meaningful life despite the fact that they now had less pain. They experienced a sense of emptiness and they had become insecure.

Structural analysis

According to the aim, two main themes were identified in the structural analysis. In connection with "the decision to undergo spinal fusion surgery", the theme: *A feeling of hope and relief* emerged. In connection with "living in everyday life after surgery" the theme: *Less pain but feeling empty and insecure* emerged.

A feeling of hope and relief

Based on the patients' narratives it appears that they, prior to their decision to undergo spinal fusion surgery, had experienced incidents with colleagues, family and healthcare professionals where they had felt subjected to insinuating remarks as well as feeling under suspicion of exaggerating their back pain. These incidents had triggered experiences of powerlessness and of not being acknowledged as individuals; they had become insecure. Therefore, having doctors recommend surgery had been a turning point for them. Even though the patients had been informed that the operation was not always successful and although some patients had experienced doubt after having met fellow patients (who revealed less successful courses of surgery) the offer of surgery meant that the patients felt understood and experienced renewed hope for a better future with less pain.

The patients linked surgery with their back pain now being acknowledged and that the doctors knew what had to be done. Based on the patients' narratives it appears that healthcare professionals made a great effort to show that the surgery procedures were under control. They handed out information and questionnaires and showed resourcefulness; for example by sending the patients to information meetings and to other healthcare professionals as preparation for surgery. Three days after the surgery, patient A said the following:

"And then I come down here. A whole new world opened up for me. Here were people who knew how I felt. I had really needed someone to say; we know exactly what you mean. It was a miracle. He said: 'I have read about everything you've been through.' It was like something fell into place for me. I became a whole person again. Everything was initiated immediately – everything was planned".

Experiences like these made the patients feel that the healthcare professionals understood them and could help them with their back pain. Several patients explained how conversations about the surgery had turned into intense moments during which they had experienced it as if the hectic bustle in the hospital had vanished for a moment. Three days after surgery, patient H said:

"I got the feeling of respect. He believed me. We were in our own bubble – our own rhythm without disturbance. He believed me and took his time with me. I left with a sense of hope instead of the feeling of having wasted anyone's time".

The decision to undergo surgery became pivotal and synonymous with hope for a future with less pain. The patients explained how it had lifted a heavy burden from them. While, for many years, they had taken it "one day at a time", as one of them put it, they now experienced being able to see opportunities for a brighter future. They hoped that they would be able to resume their lives as they were before their back problems began.

The decision to undergo surgery also led to the patients dreaming of once again being able to participate in the everyday life of their families, engage in friendships and become an active member of their workplace. In other words, they felt that they stood at a crossroad and would now have a better life.

Less pain but feeling empty and insecure

Although some patients were not completely pain free after the surgery, many of them talked about how they had been given "a brand new life". They found that once again they could move more freely after years of debilitating pain. However, even though the operation had been successful and freed them of most of their pain, several patients found that the sadness returned. They said that although the healthcare professionals had dealt with their back problems, the back pain had been so influential that it had become the focal point in their lives. Because of this they needed help to create an understanding of themselves that was not defined by a life of pain. One patient explained how, after being discharged, she had expected to feel happy and relieved but instead felt sad. She described how over many years the back pain had been a constant companion and how, after the surgery, she experienced that life had become empty. As a consequence she and several of the other patients had found it difficult to move on with their lives.

In other words, life with a changed body entailed changes for the patients. The back pain was no longer the all-encompassing feeling in their bodies

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which meant that the opportunity to be able to control everyday life had opened up for them. However, several patients had lived with pain for many years and now had to adapt to expectations (not only from themselves but also from family and colleagues) of returning to everyday life. Instead of feeling relief and joy, many patients experienced a new, unpredictable and unknown everyday life; they were unsure of whether they had recovered or not. Consequently it was important for them to have the opportunity to express themselves about these kinds of existential aspects on "their own terms" (as one of the patients put it) and not based on what healthcare professionals deemed relevant. Surgery was thus not synonymous with a life without problems, but could lead to new insecurities concerning their identity and their new life situation. It was, for example, expressed this way two months after discharge by patient D:

"It's as if I've been living in a bubble for years and when things calmed down. . . I suddenly had so much time on my hands that I scared myself because now I had to think. A kind of sadness came over me. My back had completely defined my life. How do I move on from here?"

Several patients felt ungrateful for not being happy now that the attempt to reduce their back pain had finally been successful. The surgery and the pain had changed the patients' perception of themselves. In other words, they experienced feeling insecure about who they were. For many patients the status quo was, therefore, that through the surgery they had obtained acknowledgement of their back pain but were left with an insecure self-image. The initial sense of relief had turned into insecurities. Two months after discharge, patient C said:

"And then I had the surgery – yes well, I actually don't know whether it has quite sunk in yet. I ought to have been overjoyed, but instead I felt empty. It's like a whole new chapter starts now. There are more demands from my family, and my workplace also wants to know what's going on. Now, I have to start something new, and I don't have a lot of pain anymore, but for some reason, I don't feel that kind of joy".

There seemed to be specific worries attached to a certain age; for example, some patients worried about finances and how to get back to work. Another concern was how their children were affected and some would be troubled with not being able to babysit their grandchildren because of too much pain. However, no matter the reason, the patients' concerns were all rooted in fundamental human challenges concerning living everyday life as a patient with back pain and therefore of an overall existential kind with no age related to it.

Comprehensive understanding

A feeling of hope and relief

Prior to the surgery, life with back pain had been characterised by feelings of powerlessness and insecurity. But the recommendation and decision to undergo surgery created feelings of hope and relief within the patients. The patients experienced the decision of surgery as an acknowledgement of the pain.

According to Afaf Meleis, health is not merely being physically well. Meaningful experiences together with hopes for the future are an important element of it. It is essential to feel that there is an understandable and meaningful connection between important events in life (Meleis, 2010; Meleis et al., 2000). Hence, for Meleis, going through a period of transition undergoing surgery and re-establishing stability and normality in life is crucial. Accordingly, it can be understood that the recommendation of surgery was experienced by the patients as a turning point in life from going through a long and tiring period with feelings of powerlessness to re-gaining stability, meaningfulness and renewed hope for a better life and less pain.

For Meleis, the importance of understanding a transition from the perspective of those who are experiencing it is crucial in relation to recovery (Meleis, 2010). Therefore, healthcare professionals' awareness of the meaning of a transition is essential. According to Meleis, feelings of connectedness can be created in the relationship with healthcare professionals who can answer questions and with whom patients can feel comfortable within the relationship (Meleis et al., 2000). Such relationships can, according to Meleis, provide patients with feelings of hopefulness that in themselves are therapeutically effective. Conversely, when support is lacking or communication with professional staff is less optimal, patients in transition can experience feelings of powerlessness, confusion, frustration and conflict (Meleis, 2010). Consequently, the presence of a supportive preceptor is identified as an important resource during transitions. Preceptors facilitate transition; an experienced healthcare professional can smooth a transition by being a guide and sounding board. For Meleis, it is important to include the cultural context (the patients' everyday life) in the understanding of their transition experiences. Accordingly, it can be understood that the 'journey' from having lived everyday life with great pain and feeling mistrusted to being recommended surgery,

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to some patients understandably can be synonymous with being respected. They are thereby acknowledged as a human being, initiating feelings of being relieved and having hope for the future.

Less pain but feeling empty and insecure – the constitution of identity

The emerging feelings of hope and relief after discharge were paradoxically for some patients being replaced with feelings of sadness, emptiness and insecurity. They had come to doubt who they were. This can be seen in the light of Hartmut Rosa's ideas of what constitutes our identity (Rosa, 2010).

In line with Meleis' thoughts of connectedness, Rosa (2010) argues that exhaustion of the self happens when the changes and dynamics in one's individual life or in the social world are no longer experienced as elements in a meaningful and directed chain of developments, i.e. as elements of 'progress', but rather as directionless and 'frantic' change. Our study found that some patients were able to come to terms with their new lives saying 'this is as good as it gets'. For several patients, however, pain had become almost all-consuming. Rosa (2010) facilitates the understanding that the patients were disorientated; feeling sad, empty and insecure without being able to create meaning in their lives. It can be understood that the patients hoped for a new life by being able to re-establish their role as a cured parent, partner and colleague. Their experiences, however, had been so overwhelming that there had developed a kind of familiarity in relation to the back pain, i.e. they had come to identify themselves as 'patients'.

According to Rosa (2010), experiences are crucial in the formation of our identity. Consequently, it can be understood that the patients' experiences of mistrust and powerlessness resonated their self-image; their back pain had characterised their lives for many years whereas life after surgery was unpredictable, unknown and uncertain. According to Rosa (2010), it can be said that the patients' pain, i.e. their illness experiences, had become a constituent element to their identity. In relation to the creation of our identity it can be said that:

"If it is 'the importance of what we care about' that constitutes our identity, the loss of such a sense, of a persistent hierarchy of relevance and of direction, cannot but lead to a distortion in the relationship towards oneself." (Frankfurt, 1988; Rosa, 2010, p. 97)

In keeping with Rosa (2010), 'a good life' is hence connected with what we care about; i.e. meaningful social relations, meaningful experiences creating our identity. Such experiences consist of meaningful existential and emotional experiences which unfold in and are linked with our everyday lives. According to Rosa (2010) this is, indeed, the counterbalance to the fact that patients feel sad, alienated, empty and insecure even if they have less pain.

Discussion

As shown, several patients experienced brief hope and relief in relation to being recommended and deciding to undergo surgery. Paradoxically, for some patients these feelings were overtaken by feelings of sadness, emptiness and insecurity after discharge, i.e. doubting who they were.

In line with our findings, a study by Hammer et al. (2009, p. 550) showed that hope gives meaning to life; that is 'having a zest for life anticipating future possibilities such as . . . expecting positive results, being cured or simply receiving a hopeful message from the physician'. In addition to the findings of our study, Kralik et al. (2002) found that chronic illness involves finding ways to live daily life by creating order from the disruption and disorder imposed by and associated with the pain; i.e. to Kralik this involves a need for both structure and process. However, Kralik also argues that healthcare professionals inherently focus on creating structures in their approach to patients whereby patients are positioned as passive subjects simply absorbing information. Consequently, Kralik et al.'s (2002, p. 265) study emphasises that managing life with chronic illness is more than 'doing' and should be entwined with a sense of 'being' and 'becoming'; i.e. engaging in a dynamic, active process of learning, trialling and exploring experiences and boundaries in everyday life. Similar to the findings of our study, this is indeed a process that involves identifying one's existential, psychological and physical responses to illness; constantly planning and managing daily life as a means of creating order. From this perspective it is important for the healthcare professionals to recognise the context (the patient's lifeworld) in which patients give (or may not give) meaning to illness and to be able to communicate about it.

In concordance with these findings, a study by Noe et al. (2014) explored expectations, worries and wishes in relation to challenges before returning home after initial hospital rehabilitation for traumatic spinal cord injury. Even though their study focuses on a different patient group than included in our study, its findings are still relevant. Categories of barriers and problems were identified

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including facing uncertainty when leaving one's peers; hoping to get back to work and a safe economy; experiencing understanding from the community and relying on resilience of significant others (Noe et al., 2014). Their study showed that there is a need for healthcare professionals to involve the patients' close relations. In accordance with our findings they found that to promote a meaningful life on new terms it is crucial that healthcare professionals initiate dialogue with patients and their families on how the illness may impact on their everyday life.

Limitations of the study

According to Ricoeur (1976) there is no absolute way to interpret a text; 'an interpretation must not only be probable, but more probable than another interpretation' (p. 76). From this perspective 'validation' was enhanced by showing transparency throughout the analysis process. Descriptions of the interpretation process were presented to illustrate the trustworthiness of the findings. Regarding this, one should also understand the structural analysis as a form of validation (Ricoeur, 1976). In addition, some might argue that a sample of 10 patients is too small. However, in qualitative research, it is stated that analytical generalisation is a possibility, meaning that the results of a study can be considered 'indicative' or transferrable in relation to other similar situations or settings (Kvale, 1997).

Conclusion and implications for practice

Being recommended and deciding to undergo spinal fusion surgery initiates hope for a life with less pain but at the same time paradoxically creates a feeling of existential insecurity in terms of facing the future to come. It is important to recognise and thereby include the impact of patients' everyday life experiences on how they give (or may not give) meaning to their illness and understanding of how this is affecting them. These aspects are essential for patients' definition and re-definition of themselves and it is crucial to draw upon these during communication between the patient and healthcare professional. Taking into consideration that a considerable number of patients suffer from anxiety and depression both before and after surgery it is crucial to help them re-gain meaning in life and to focus on their lifeworlds to find out *what they care about* and what is important to them.

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6 Discussion

Covering all three papers, this section discusses what is important to patients undergoing SFS in relation to the existentially challenging illness trajectory they undergo while struggling for recognition and finding meaning in life. The findings will be discussed in light of current research as presented in Chapter 2 paragraph 2.2 and the literature review, Paper I, and reference will be made to the theories discussed in Chapter 4. Please note that the present discussion thereby differs from the discussion in the papers where the theoretical reflections are only included in the chapter Comprehensive understanding, and where the comparison with other research studies is included in the Discussion chapters of these papers (see Paper I, II & III).

6.1 Living with back pain. A struggle for recognition

Patients undergoing SFS experience particularly problematic illness trajectories struggling with existential challenges related to being recognised as prudent human beings (Paper II & III). The struggle for recognition is a consistent theme throughout the papers.

6.1.1 A feeling of being mistrusted

The findings show that throughout their illness trajectory, the patients' relations with family, colleagues and healthcare professionals involved mistrusting remarks and insinuations indicating that their pain was not as bad as the patients claimed. To the patients, this implied that they were trying to cheat their way into receiving public benefits or that they were hypochondriacs. Such experiences prompted feelings of powerlessness and vulnerability and made them feel insecure (Paper I, II & III). The following quote illustrates this clearly: "*I got so many questions. I explained over and over again. They couldn't understand, in the end I felt like a hypochondriac trying to cheat. I did not know what to say or to do – you become powerless.*" This finding is supported by a meta-synthesis by Bunzli et al. who found that stigmatisation was a perennial theme in almost all the reviewed studies (Bunzli et al. 2013). The study shows that patients feel that society (media, employers and healthcare professionals) view people with back pain as untrustworthy and as 'burdens' with psychological problems and a questionable integrity (ibid.). This is supported in a study by Lillrank (Paper I) who found that patients feel as if they are caught 'in-between', enduring a feeling of marginalisation until a diagnosis has been made (Lillrank 2003). In this context, Jensen & Paarup found that 'objective findings' are crucial to the patients because the patient's psychological, social and cultural conditions are less likely to be considered if a diagnosis is not established. In the absence of a diagnosis, according to Jensen & Paarup, these psychological, social and cultural conditions become 'markers' or indicators of psychological problems or a conscious or subconscious unwillingness to work (Jensen, Paarup 2006).

The present study emphasises that the patients' history of living with back pain is so influential that it changes the entire everyday life and thereby the way patients perceive themselves (Paper I, II & III). Experiences of feelings of powerlessness and being mistrusted are, so to say, 'stuck' in the patients. Referring to Ricoeur (Ricoeur 2004), our experiences and memories are instrumental in identifying ourselves and building self-awareness; and assuming this perspective, it becomes clear why some patients with back pain undergoing SFS feel insecure, can lose confidence in their own judgment and come to doubt themselves and whether they are imagining the pain (Paper II). Indeed, according to a study by Snelgrove et al., the patients can be 'trapped in pain experiences' and this entrapment contributes to a comprehensive enmeshment of pain, a strong sense of loss and feelings of untrustworthiness striving for an 'aetiological explanation' for the 'invisible' pain (Snelgrove et al. 2013).

6.1.2 Living with invisible pain

The study found that it meant much that others were not able to see and thereby understand the situation. Because of the absence of physical signs of pain, the patients referred to it as 'invisible' (Paper II & III). The following quote illustrates this: "*Had it only been a broken arm. That you can see. But this is kind of invisible. Other people cannot see my back pain - this is a challenge to me*". Experiences of conflicting statements from different care providers together with insinuating remarks and feelings of being mistrusted made the patients doubt their own judgments and experiences; and this, in turn, paradoxically lead them finally to downplay their back problems in order not to be a burden (Paper II).

The invisibility theme is seen in earlier research within studies related to back pain; however, mostly in studies of other (chronic) illnesses (Hermanns 2013, Eilertsen et al. 2015, Pretorius, C. & Joubert, N. , White et al. 2008, Rhodes et al. 1999, Chiang et al. 2014, Mullins L. & Preyde, M. 2013, Thomas 2015). Although rather old, a study argues that '*seeing* the disease' on the basis of 'diagnostic tests'' constitutes an important element in the legitimation of pain (Rhodes et al. 1999). The study finds that three aspects make *testing* an area of concern for patients: a strong historical connection between *visual images* and the medicalisation of the interior of the body; a set of cultural assumptions makes seeing into the body central to confirming and normalising patients' symptoms; and the *concreteness* of diagnostic images themselves (ibid.). Similar to the findings within the present thesis, the study by Rhodes et al. shows that objectification of the body plays a strong part in the power of tests to provide either positive experiences, which encourage patients to align with the medical providers or, on the other hand, negative experiences of disconfirmation, which lead to alienation and a continued search for resolution (ibid.).

Supporting the findings within the present thesis, another study found that people with invisible disabilities are often stigmatised because they are unable to perform certain actions that nondisabled people can do; yet they may look like they are capable of performing those actions. This can be distressing for individuals with a chronic illness because their inability to perform certain tasks may be misinterpreted by others as being lazy or noncompliant (Hermanns 2013).

This is important knowledge and it explains the meaning of why pain experiences can determine what the patients hear, understand and dare ask questions about in their meeting with the healthcare professionals (Davis et al. 2013)(Paper I). According to Rosa, experiences 'leave marks' and constitute our identity (Rosa 2010), shaping the way we are able to 'speak up' (Paper I). Such knowledge is easily ignored in a busy healthcare day. Therefore some patients experience being included only as 'objects' in the healthcare professionals' analysis of the situation – the patients are not included as an 'empirical' subject - as a human being. This results in the illness experiences being detached from the patient's everyday world; the experiences turn into 'disconnected markers' which may (or may not) attract the practitioner's attention (Jensen, Paarup 2006).

Using Honneth's theory of social invisibility, it is found that the patients 'strike out' with the aim of prompting others to recognise them (Honneth 2001). But, conversely, some patients find themselves in relations where they are not met with empathic 'signs' or expressions confirming their presence and signalling willingness to recognising them. Consequently, this social invisibility indicates to the patients that they are not attributed worth as persons (Paper II). In line with this, a study by Rasmussen et al. found that dignity can be compromised in the clinical practice of surgery (Rasmussen, Delmar 2014). It was found that the clinical practice tended to focus on installing new technique and removing the diseased. In concordance with the results of our study, it is suggested that within such contexts, it is particularly important to include the patient as a co-player who is involved in the care and treatment and allowed to assume an active role, 'putting yourself forward' (Paper I).

6.1.3 Bodily changes

Living with back pain was a constant struggle marked by unpredictability – i.e., the body was setting the agenda. Turning to Hans-Georg Gadamer's theory, we can never free ourselves from embodiment – we can never come to stand outside ourselves as subjective bodies. Accordingly, we do not 'have' a body, but 'are' the body (Gadamer 1996). When healthy, for example, we take the body and health for granted. Conversely, in relation to the patients suffering from back pain, their perception of the world is disturbed by the pain. They experienced no longer being able to participate in everyday activities, living life as they used to. Consequently, the loss of abilities hindered easy and unmindful living - the breakdown of the body was a breakdown of life to the patients (Paper I, II & III). Such aspects of back pain can easily be ignored in a biomedical framework.

Using the terminology of Snelgrove et al., patients were 'trapped in pain experiences' dominated by constant, intrusive and often unbearable pain (Snelgrove et al. 2013). This 'entrapment' is elaborated on in a 'temporal' context in a study by Johnson et al. which showed that increasing pain and deterioration in function alter the experience of time (Johnson et al. 2014). The patients experienced lost and wasted time and faced disruption of the temporal order of their lives. The patients' experience of time was complex and multi-dimensional and did not reflect a linear, monochronic conceptualisation of time embedded in the healthcare system, for example. Hence, a surgical date could appear closer to or further away than it was in actual clock time which gave patients an experience of living in a limbo whilst waiting. This experience is echoed by the finding of the present study that some of the patients expressed that they felt locked in an existential 'void', feeling empty and insecure (Paper II & III). The changing body affects the entire lifeworld.

6.1.4 Recognition of the back pain. A feeling of a brief relief

This study found that in connection with the recommendation and decision to perform surgery, the patients experienced feelings of hope and relief. It was a turning point when the doctors recommended surgery. This is illustrated in this quote: "*A doctor once said to me: 'Don't expect to get a diagnosis … there is so much pain we cannot explain…'. So you can understand, I was really relieved when the doctor here at X-hospital said that I could have surgery …*". The patients associated the surgery with recognition of their (physical) pain (Paper I, II & III).

In line with the results of the present dissertation (Paper II), several studies show that making a diagnosis in regard to back pain is a main focus for the healthcare professionals (Slade et al. 2009, Vroman et al. 2009, Lillrank 2003, Dalsgaard 2006). However, according to the findings, which are supported by Bunzli et al., there seems to be a discrepancy ('a mismatch') between the biomedical beliefs held by clinicians and patients and the biopsychosocial nature of back pain. Both healthcare professionals and patients endorse a biomedical paradigm over a biopsychosocial approach in the clinical management of back pain because a biomedical explanation is critical to the disability being recognised as legitimate; and support from the family, the workplace and the welfare systems is contingent on such legitimacy (Bunzli et al. 2013). However, while waiting for a diagnosis, the patients experience a loss of self-perception and social position (Paper I). The study did not specifically explore what it meant to receive a diagnosis - however, a study by Larsen et al. shows that 'getting a diagnosis' involves direction in 'how to act', learning to culturally perform meanings in defining the pain. The study found that a diagnosis comes with both a social and a biomedical meaning which may explain why patients feel misunderstood when confronted with a biomedical discourse they find difficult to apply in their own social contexts (Larsen et al. 2013). Supporting the findings of illness experiences with contradictory statements from different care

providers, not getting a diagnosis creates a feeling of limbo, and the patients experience feeling socially invisible and insecure not knowing how to act (Paper I, II & III).
Habermas' theory of 'colonialisation and uncoupling of system and lifeworld' (Habermas 1987, Nørager 1998) may be instrumental in explaining the loss of self-perception, insecurity and social invisibility. The patients' local everyday perspectives are met by a biomedical understanding that mainly focuses on arriving at a diagnosis that *physically* explains the back pain. If the patients want to be visible, they have to accept the premises of the healthcare system and to embrace the biomedical understanding. However, according to Habermas' theory, the patients' individual life stories are not in harmony with 'the collective (the system's) forms of life', which create life disturbances that manifest themselves in psychopathologies and feelings of alienation. Keeping Honneth's thinking about social invisibility in mind – indeed, in this context, the patients are 'just' being identified, perceived or cognised (*erkennt*); and this leaves them in lack of a confirmation with the positive meaning of affirmation (Honneth 2001). Without this affirmation, signalling social approval, the patients remain non-recognised (*nicht anerkennt*), feeling disrespected and alienated, being locked in a (social pathological) condition of 'invisibility' (Paper I, II & III).
Paradoxically, though, the patients have feelings of (a brief) relief in regard to their physical impairment, but they lack an existential understanding on the basis of which they may create meaning in their new life after the surgery.

The following section will discuss the existential aspects in regard to the patients experiencing lack of meaning in life.

6.2 Life after spinal fusion surgery. A struggle for meaning

The subsequent section will discuss 're-establishing meaning in life' with the aim of informing the discussion of why, despite finally having a diagnosis and undergoing surgery, some patients having less pain re-experience (or continue) feeling empty and experience meaninglessness and being insecure.

6.2.1 Barriers embedded in the patient's transition from hospital to home

Searching for deeper insight into the patients' existential challenges in regard to their intrusive life changes, several studies report the presence of barriers embedded in the patients' transition from hospital to home. Exploring patients' challenges before returning to home, a study by Noe et al revealed several expectations, worries and wishes; for example, hoping to get back to work and getting a safe economy (Noe et al. 2014). Focusing on socioeconomic issues, another study by Kangovi et al. found that patients with low socioeconomic status were facing challenges (poorer outcomes) during the post-hospital transition in particular (Kangovi et al. 2014). The patients felt powerlessness during hospitalisation due to illness and socioeconomic factors, misalignment of patient and care team goals, lack of saliency of health behaviours, abandonment after discharge and loss of self-efficacy resulting from failure to perform recommended behaviours. The patients described discharge goals as confusing, unrealistic in regard to significant socioeconomic constraints and in conflict with their immediate goals.

Looking at the included patient's socioeconomic characteristics (Table 1), it becomes clear that they are all doing manual work. Physical workload has repeatedly been reported to predict low back pain (Kim et al. 2010, Andersen et al. 2007, Jørgensen et al. 2013) and physical workload is unevenly distributed across groups with different socioeconomic status, i.e. people with lower socioeconomic status typically have jobs with higher physical workload (Leino, Hanninen 1995). Apart from a high physical workload, other known risk factors for low back pain, e.g. obesity, smoking, physical inactivity, poor psychosocial work environment, tend to cluster in lower socioeconomic groups (Makinen et al. 2010, Hauke et al. 2011, Nielsen et al. 2008). Although exploring the socioeconomic perspective was not among the aims of the present study, these aspects add an important dimension to the understanding of why some patients can feel more misaligned and more afflicted by powerlessness, doubt and insecurity than others (Paper I, II & III).

In this context, the complexity of the patients' life-changing illness experiences becomes clearer. Indeed, using Afaf Meleis' thinking makes sense in regard to how vulnerability, anxiety and insecurity can emerge passing from one life phase to another (Meleis et al. 2000 p. 7), i.e. from 'being a patient' to being discharged and understood as 'cured'. Hence, it is not 'enough' to 'fix' the patient’s back pain. As argued in the study, it is crucial to establish connection between important events in the patients’ lives (the past), creating meaning within the present life and the future to come (Paper I, II & III). Such issues can easily be ignored in a biomedical framework.

6.2.2 Creating meaning in life

The present study illustrates that communication with the healthcare professionals was extremely important to the patients. They considered it crucial to be met by an acknowledging attitude. The patients even felt that positive interaction with the healthcare professionals had a pain-relieving effect. This was expressed by a patient in this way: “*He* [i.e. a healthcare professional] *called me in the evening asking if I was all right and I told him about this and that. Indeed, this was a kind thing to do – I really think that something like this was helping me …*”. However, it was also found that the verbal interaction with the healthcare professionals was often marked by urgency because of lack of time, and verbal encounters therefore addressed mainly practicalities in relation to medication or treatment, for example (Paper II & III).

Indeed, the present study shows that it is essential to recognise, prioritise and thereby understand the patient’s pain experiences via communication. This is contextualised in a study by Myburgh et al. which found that recovering involves ‘redefinition’ and ‘readjustment’. However, recovery is not contingent on the absence of pain, but rather on acceptable levels of symptom attenuation (Myburgh et al. 2015). This is important knowledge to include in the communication with the patients.

These findings are in line with Meleis’ argument that health and recovery are not only entirely tantamount to lack of physical symptoms, but rather to establishing congruence between former and present experiences and connection with future expectations. Consequently, stability, meaning and normality are crucial (Meleis, A.I. & Chick, N. 1986). Adopting a more general perspective on the topic, ‘lack of connection’ is (although in different shapes) in focus in Habermas’, Rosa’s and Ricoeur’s theories, each of them referring to social pathologies induced by mechanisms in society.

To Habermas, the system, including its economic and bureaucratic structures, 'colonialise' (overpower) social relations. As argued by Habermas, this constitutes the 'identity-forming social memberships' getting peripheral - bypassing processes of consensus-oriented communication (Habermas 1987).

A temporal focus is seen within Rosa's and Ricoeur's understandings of a good life.
According to Rosa, practices and institutions, for example healthcare institutions, are marked by 'the shrinking of the present' during which expectations based on past experiences reliably match the future. To Rosa, such conditions create feelings of alienation, melancholia and depression (Rosa 2010). Those who fall into depression, feeling alienated, experience a dramatic change in their time perception; they fall from dynamic, or hectic, time into a temporal quagmire where time no longer seems to move, but to stand still. Any meaningful connection between the past, the present and the future appears to be terminally broken (ibid. p. 70).

To Ricoeur, humans understand themselves through their past. Personal identity is a temporal identity (Ricoeur 2005). We identify ourselves and build self-awareness through experiences and memories. Referring to Ricoeur, being a human being involves existing in the present – as well as sensing and perceiving the world, having expectations for the future. The past and the present give temporal breadth to self-recognition which is founded on a life history and involves commitments about the long-term future (Ricoeur 2005). Adopting this perspective, the study finds that the patients' illness trajectory is not always perceived as a progressive, meaningful process, but, on the contrary, rather as isolated happenings without direction. To Ricoeur, this may lead to experiences of alienation (*Verfremdung*) (Ricoeur 2007 p. 284).

Here, according to Ricoeur, communication is essential. Ricoeur argues with Habermas, saying that 'It is at the heart of communicative action that the institutionalization of human relations undergoes the reification that renders it unrecognizable to the participants of communication' (Ricoeur 2007 p. 303). To Ricoeur, hermeneutics and a critique of ideology 'as a theory of institutions and of phenomena of domination, focused on the analysis of reifications and alienations' (p. 306), discovers and denounces the 'distortions' of the communicative capacity.'

Assuming this view, the patients' *pain experiences* were well known, whereas the present and the future to come were unpredictable and unknown, which made some patients feel alienated after discharge. Accordingly, it is found that a good life implicates meaningful relations and communication with 'axes of resonance/meaning' between the patients' past and present experiences creating direction for a (new) understandable future. Hence, individual everyday experiences such as powerlessness and feelings of being mistrusted and invisible must be included as relevant and necessary issues in healthcare communication. This is crucial to the (re)definition of the patients' self-image (identity), and inclusion of these issues may serve to counterbalance the patients' existential voids (Paper II & III). Accordingly, it is argued that each patient encounters illness in his or her own way, and that a more holistic view of well-being therefore is pivotal. Indeed, it is important for the healthcare professionals to recognise and prioritise the patients' existential and emotional 'being-in-the-world-experiences', in which they may or may not find meaning in illness, and to communicate with the patients about this.

6.3 Summary of discussion

Experiences 'leave marks' and constitute the identity, determining what the patients hear, understand and (dare) ask questions about in their meeting with the healthcare professionals. Waiting for a diagnosis and being trapped in pain experiences, the patients experience a loss of self-perception and social position – while, on the other hand, 'getting a diagnosis' involves direction in 'how to act', learning to culturally perform meanings in defining the pain. However, a diagnosis comes with both a social and a biomedical meaning which explains why some patients feel misunderstood when confronted with a biomedical discourse they find difficult to apply in their own social contexts. If the patients want to be 'visible' within society, they have to accept the premises of the healthcare system and to embrace the biomedical understanding. Therefore, when being recommended and deciding to undergo surgery, the patients paradoxically feel relieved in regard to the recognition of their physical impairment, but they lack an existential understanding of their individual illness experiences on the basis of which they may create meaning in their life after the surgery.

In regard to the patients' existential challenges, the discussion shows barriers are embedded in the transition from hospital to home. Especially patients with low socioeconomic status are facing challenges, feeling powerlessness due to illness and socioeconomic factors, misalignment of patient and care team goals, lack of saliency of health behaviours, abandonment after discharge and loss of self-efficacy resulting from failure to perform recommended behaviours. People with lower socioeconomic status typically have jobs with a high physical workload which has repeatedly been reported to predict back pain. Looking at the included patients, we see that they are all doing manual work; hence, the socioeconomic perspective adds an important dimension to the understanding of why some of the patients undergoing SFS can feel particularly misaligned, in doubt and insecure.

The discussion shows that communication about the patients' past and present experiences creating a meaningful direction for a (new) understandable future is important, but easily ignored in a biomedical framework. Therefore, individual illness experiences must be recognised and included in the healthcare communication.

7. Methodological considerations

This chapter will consider the trustworthiness, strength and transferability of the study in relation to the concepts of reliability, validity and generalisation (Kvale, S. & Brinkmann, S. 2009).

7.1 Considerations on reliability, validity and generalisation

According to Ricoeur, a text never has only one meaning, i.e. there is not just one probable interpretation (Ricoeur 1974b p. 62-78). However, all possible interpretations are not equally probable to the interpreter. Indeed, the internal consistency of the interpretation and its plausibility in relation to competing interpretations should always be considered (Lindseth, A. & Norberg, A. 2004).

Reliability

Reliability pertains to the consistency and trustworthiness of research findings (Kvale, S. & Brinkmann, S. 2009). Assessing reliability therefore involves discussing issues in relation to the interviews, the transcription and the analysis.

Interviews

The present study adopted an open and narrative approach including open-ended questions allowing the patients to describe their experiences. It was important to demonstrate to the patients a true willingness to listen and to understand, and as a researcher to allow oneself to be surprised, sensitive and open to anything unpredicted and unexpected. However, being too close to the interviewee also involves a risk of losing openness. Hence, a semi-structured interview guide was used in order to direct the interviewees' intentionality and awareness towards the phenomenon of interest. This implicated that the conversation had to be open to create a trusting atmosphere and that, for example, it was avoided using (too many) social clichés and generalisations in an attempt at directing the patient's attention toward deeply anchored meanings rather than superficial attitudes or commonly held beliefs (Dahlberg et al. 2008). To avoid the interviewers' questions being leading and producing knowledge only mirroring the interviewer's pre-understandings, observations were made before the interviews to allow the researcher to obtain insight into the interaction and the communication between the patients and the healthcare professionals. In this way, besides gathering information, the observations also served as a relevant way for the researcher to (validate) obtain and reflect on her approach and preunderstandings. This approach also allowed the researcher to reflect on aspects the patients and the healthcare professionals (possibly) took for granted, adopting a 'bridling' attitude (ibid.) waiting for the patient's experiences undergoing SFS ('the phenomenon') to reveal their own complexity. Overall, it was important to try not to be distracted by methodological rules and to dare to 'be in the dark' (ibid.), having faith in the process of discovery, daring to be vulnerable, trusting sensitivity to guide the craft of being a good interviewer (Kvale, S. & Brinkmann, S. 2009).

Transcription

Transcription was done by an experienced research secretary. It was agreed in advance how to transcribe, for example, to include pauses, accentuations and expressions of feelings such as laughter or sighs. In regard to passages that were difficult to understand, it was agreed that no guessing was allowed, and such passages were therefore not transcribed but left open. Moreover, the researcher went through the transcriptions, making notes explaining any particulars, to ensure that details were complete in regard to each specific interview such as, for example, adding characteristics of the interviewees or of the settings.

Analysis

Prior to the analysis, it was considered whether to use a computer programme to process the data. To keep as much sensitivity to details as possible, this option was foregone. The texts were read several times, text passages were highlighted using differently coloured text markers. The text was kept in folders with post-it notes reading ’What is said’ and ’What the text speaks about’ marking text passages of interest. The findings were discussed with the other members of the research team, other researchers working within the same field of investigation, and researchers from other disciplines - nationally as well as internationally.

According to Sandelowsky and Barroso, it is not for the reader him or herself to make sense of the findings (Sandelowski, Barroso 2002). They should be presented meaningfully and coherently to allow the reader insight into the process. It was therefore decided to use a diagram to illustrate the analytical process in each of the respective papers and in the present thesis, too (see Table 3). The diagram features specific text samples and allows the reader to follow the analytical process of assigning a theme to a particular piece of text. Similarly, observations were systematically captured in jotting- and fieldnotes (Appendix D & E) and subsequently typed into a computer. Collectively, these two processes add to the reliability of the interpretation process. For a more detailed account of how the aims and the research questions of the present project shaped the methodological and analytical approach, please see Chapters 3-4 above.

Validity

Validity concerns the truth, the correctness and the strength of a statement (Kvale, S. & Brinkmann, S. 2009). A valid conclusion is one that is derived correctly from its premises. A valid argument is one that is reasonable, well-founded, sound and convincing. Validity has to do with whether a method explores what it is intended to explore at all stages of the study (ibid.).

Data for the present studies were obtained from observations and semi-structured interviews. The relevance of using these methods for data generation lies in their ability to capture patients' lived experiences (Norlyk 2009, Dreyer 2009, Davis et al. 2013). Only very few studies have used qualitative methods for studying patients undergoing SFS, and no study has explored such experiences in the context of SFS while drawing on a combination of observations and interviews.

The observations provided insight into the practical settings and into the communication and interaction between the patients and the healthcare professionals (Hammersley, Atkinson 2007). This gave deeper insight into the context of which the patients formed part and informed the researcher's questions in terms of relevance (Brinkmann 2012).

It is generally acknowledged that the phenomenological-hermeneutic approach is very productive for investigating people's lived experiences (Ricoeur 1979a, Dahlberg et al. 2008). An examination of patients' experiences may take their narratives as its natural point of departure. Via interviews, it was possible to investigate the patients' personal, lived experiences and opinion through these narratives (Kvale, S. & Brinkmann, S. 2009); and the patients were allowed to express, explain and deepen their views and private experiences. Following Ricoeur, it was not the aim to explore the patients' intentions, but to move beyond that notion to arrive at a deeper understanding of what the text refers to in the world (Ricoeur 1973b). The focus was not to re-describe what they think they are saying; rather to provide an 'objective' description of what they experienced (Dreyer 2009).

Validation was also contemplated in regard to the number of patients. As recommended in the literature, how many respondents to include should be determined by data reaching a saturation threshold. Saturation is reached once patterns begin to emerge and once issues suggesting the same meaning begin to repeat themselves (Kvale, S. & Brinkmann, S. 2009). On this background, it was found that it was appropriate to include a total of 10 patients.

Generalisation

Science usually demands a certain measure of generalisation; according to positivist methodology, it is a goal to produce objective statements (regularities) that can be universally generalised. However, a humanistic point of view adopts the inverse stance, viz. that every situation is unique and that every phenomenon has its own structure and logic (Kvale, S. & Brinkmann, S. 2009). Accordingly, the question in qualitative research is not to ask if the findings can be generalised globally, but whether the knowledge produced in a specific interview can be transferred to other relevant contexts. Although the results are explored specifically within the context of patients undergoing SFS, it is argued that the psychosocial aspects concerning social invisibility and insecurity and the challenge of creating meaning in life are universal existential aspects that are transferrable to other contexts in regard to, for example, chronic illnesses implicating complex life-changing events. Indeed, the findings concerning patients downplaying or hiding their pain in order not to be a burden bring new perspectives to the clinical communicative practice and remind healthcare professionals that they should listen carefully and urge the patients to ‘speak up’. Another transferrable finding is that therapeutic intervention like undergoing surgery may give rise to a brief feeling of relief and hope that may, however, give way to a subsequent feeling of insecurity and lack of meaning. These findings are transferrable to contexts where patient groups with preceding long, complex illness experiences are going through transitions like being diagnosed, having surgery and returning home. This knowledge is relevant to practitioners communicating with patients both prior to and after surgery; notably so because we may adopt the stance that care and treatment are not finalised until the patients can handle their lives themselves or have been equipped with assistance supporting them to maintain stability in their lives.

7.2 Considerations concerning strengths and weaknesses

Among the strengths of the present study is the fact that patients were interviewed twice. The second interview gave the patients an opportunity both to reflect on any issues they wanted to raise or explore and to ask questions to the interviewer. Furthermore, the interviewees clearly felt more relaxed and comfortable at the second interview because they knew from the first interview what it was all about and because they had come to know the interviewer.

Likewise, it is considered a strength that the interviewer had prior knowledge from managing a large project overseeing the implementation of different clinical and procedural measures at the hospital. Similarly, the present study gains further strength from the researcher's prior experience as a teacher of qualitative methods and as a nurse having conducted qualitative interview studies. It might be considered at weakness that the researcher has been working within the hospital sector for a number of years and therefore may be party to some of its pre-understandings. However, according to Ricoeur, such pre-understandings are hardly avoidable; indeed, they lie at the root of any understanding (Ricoeur 1979b).

It might be considered a weakness that the study was conducted at a single hospital. Data from other hospitals following differently organised pathways could have informed the findings on how patients experienced the interaction and communication with the healthcare professionals. Likewise, supplementary interviews with healthcare professionals could have contributed other perspectives. However, such studies were not undertaken in the present study, the purpose of which was to focus exclusively on *patients'* experiences.

It is a strength that the present study draws on two methods; yet, additional, supplementary perspectives could have been obtained if more extensive observations had been made, for example by 'walking in the patients' footsteps', observing each included patient from his or her visit in the outpatients clinic, through surgery, until discharge and when resuming everyday life at home. Still, time constraints did not allow this. Another approach could have been to conduct focus group interviews which would have disclosed dimensions of group dynamics which could contribute further knowledge. However, such interviews were deselected because the aim was to obtain knowledge on *the individual* patient's lived experiences.

8 Conclusion

Social invisibility and thereby the struggle for recognition is a consistent theme throughout the study. The absence of physical signs of pain is of paramount concern, and feelings of mistrust and powerlessness are so influential that they change the entire way the patients perceive themselves, and they cause them to lose confidence in their own judgment, to doubt themselves and whether they are just imagining their pain. Paradoxically, this even leads the patients to downplay their back problems in order not to be a burden. Overall, such existential experiences shape the patients' identity and determine what they hear, understand and raise as questions. The discussion indicates that such challenges can be crucial, particularly to patients with low socioeconomic status who may feel more powerlessness due to misalignment than other less disadvantaged socioeconomic groups.

The patients' struggle for recognition and meaning also colour their experience of the recommendation and decision to undergo surgery. It is found that it is, indeed, a turning point for the patients when the doctors recommend surgery. The patients associate this with recognition of their pain. Surgery become synonymous with hope for a future with less pain and being able to re-engage in everyday life with family, friends and colleagues. In this perspective, the findings illustrate that the physical management of the back pain (a diagnosis) is important because a biomedical explanation is critical to the pain being recognised as legitimate within society. However, it is also found that the transition from living with back pain and undergoing SFS to being at home living everyday life is a life-changing event that has a profound psychosocial impact on the patients. The pain itself and 'being a patient' have come to define the patients as human beings, creating feelings of emptiness, sadness and insecurity. This leaves the patients in doubt of whom they are and of how to re-define themselves regaining meaning in life.

This knowledge is important and easily ignored in a biomedical framework and must be taken into account by the healthcare professionals communicating with the patients.

9 Implications for practice

The present study underlines how important it is that healthcare professionals engage with the patients' lived experiences and recognise the importance of these experiences to the patients' recovery process. In clinical practice, this implies that healthcare professionals should embrace a wider interpretation of the concepts of care and treatment; one that encompasses not only the biomedical perspective, but also the biopsychosocial (holistic) perspective. It is not enough to take care of the patients' physical impairments. In fact, recovery is not contingent on absence of pain. Embracing this view implies that healthcare professionals take an empathetic stance towards patients' lived experiences because these experiences are the key to understanding what the patient understands and tries to communicate. It is of paramount importance that healthcare professionals understand that patients who have been living with back pain for a long period can be facing existential challenges causing them to feel insecurity and to have a weakened self-image.

The present study shows that pain affected the patients so profoundly that they had difficulty re-establishing an identity that was not centred on their pain experience. Seen from a holistic perspective, it is important that healthcare professionals acknowledge and understand that care does not stop until the patient has re-found stability and meaning in life. It is crucial for the healthcare professionals to establish connection (congruence) between important events in the patients' lives, creating meaning within their present life and the future to come. Such feelings of connectedness can be created within an acknowledging relation between the patients and the healthcare professionals. Here, communication based on dialogue about *what is important to the patients* can provide patients with feelings of respect, hope and meaning which in itself is therapeutically healing. During the discharge process and during the follow-up on treatment, it is therefore crucial that care resources are assigned not only to tasks concerned with the patient's physical recovery, but also to any tasks addressing the individual's existential needs. Such tasks may be assigned, as appropriate, to the surgery ward and to any supportive organisational entities, be they social counsellors, employment officers, unions, family doctor, psychologist or rehabilitation centre. Of particular importance is that the surgery ward assumes a coordinating role and co-responsibility for involving the necessary collaborating partners upon the patient's discharge; and that it does so on the basis of the patient's lived experience ascertained from communicating with the patient.

10 Future research

The present study has produced knowledge about patients' experience of undergoing SFS and it contributes important insights into how living with pain can change patients' understanding of themselves. Particularly important to consider are aspects related to feelings of social invisibility and insecurity because they are fundamental to establishing a meaningful connection between experiences in the past, the present and the future. Such matters do not necessarily surface in the communication with the healthcare professionals where some patients are hiding their pain and feelings in order not to be a burden. The pain sufferer's experiences of 'being a patient' instil in some of the patients a feeling of insecurity (confusion) and doubt of whom they are after surgery and discharge. More research is therefore needed on how patients experience their illness trajectory while undergoing SFS.

The dissertation highlights the need for more research into the patient's perspective. Indeed, more knowledge is required on how patients' everyday life is affected by the illness; and special attention should be paid to how their pain experiences affect their self-image and their capability to regain meaning in life while undergoing SFS. The present study has shown that powerlessness and lack of recognition 'stick' in patients. This powerlessness creates feelings of lack of trust and loss of faith in the patient's own judgment which affects their identity and how they communicate with the healthcare professionals. There is a need for further research exploring how this is experienced and into the implications for patients in regard to their care and treatment.

The study found that a biomedical explanation is important to the patients. The patients' psychological, social and cultural conditions are less likely to be considered if no diagnosis is made.

In the absence of a diagnosis, these conditions become ‘markers’ of psychological problems or a conscious or subconscious unwillingness to work. Research is needed to explore the consequences of the endorsement of a biomedical paradigm for patients.

Undergoing SFS marked a turning point for the patients – it became synonymous with at ‘new’ and better life. But to some patients, living life with back pain had become so overwhelming that it had changed the entire life. They experienced no longer being able to live everyday life as they used to - their conception of the world was disturbed. The pain itself and ‘being a patient’ had come to define the patients as human beings. More knowledge in regard to how the patients re-establish meaning in life after surgery and in regard to how healthcare professionals encourage a qualifying process is needed.

11 Summary

The aim of the present thesis is to explore how patients undergoing SFS experience their illness trajectory.

The literature describes that suffering from back pain is an intrusive element in a patient's life that profoundly affects the patient and his or her family, friends and job as well. The patients experience lengthy and tiring illness trajectories that come with great personal costs; and several studies demonstrate that life with back pain can be so chaotic and traumatic that some patients develop depression. Patients suffering from back pain describe not being taken seriously and being met with insinuations about trying to cheat their way into social benefits. This seems to create feelings of existential insecurity, doubt and social isolation; and the literature shows that patients undergoing SFS are facing particularly serious challenges because this surgical procedure is usually the last therapeutic option available and because many bring to the encounter distressing experiences from contact with several public sectors, multiple examinations and previously unsuccessful treatments.

The present study was performed to obtain a comprehensive understanding of patients' experiences of undergoing SFS. Observations focusing on the interaction between the patients and the healthcare professionals were made in advance to qualify subsequent interviews. Ten patients undergoing SFS participated in two semi-structured interviews – one at the hospital 2-3 days after surgery and one at home 2-3 months after discharge. Consisting of fieldnotes and transcribed interviews, the data material was analysed and interpreted with inspiration from Paul Ricoeur's phenomenological-hermeneutic theory of interpretation.

The findings are presented in three papers. Paper I is a systematic literature review based on thematic synthesis. The aim was to gain a better understanding of the patients' illness experiences and to identify, systematise and integrate the findings of different qualitative studies that may elucidate barriers, consequences or focal points in connection with care and treatment of patients with back pain. Paper II aims to explore how patients undergoing SFS experience their illness trajectory and their interaction with the healthcare system. Paper III aims to explore how patients

experience their situation from the point of making the decision to undergo SFS to living in everyday life after surgery.

The thematic synthesis in the literature review points out that we create our identity through experiences and memories. Ignoring the patients' illness experiences within the healthcare system can therefore be seen as disregarding the patient as a human being, which paves the way for feelings of being marginalised and mistrusted. Respectfully including the patients' experiences is fundamentally about acknowledging the patients' lived experiences. The synthesis of the included studies demonstrates a need for healthcare professionals to pay attention to the patients' narratives in order to recognise them as human beings. This involves understanding the facts that the body can never be understood as merely a biological entity and therefore that illness is far more than having symptoms, getting diagnoses and undergoing treatments. A holistic approach with a focus on how the patients hear, understand and 'dare' ask questions is therefore proposed. It is found that in many cases, these aspects are being overlooked by the healthcare professionals.

In this perspective, the absence of physical signs is of paramount concern and can create breeding ground for insinuations in regard to the patients being hypochondriacs. This mistrust can induce feelings of invisibility, sadness, emptiness and insecurity. However, talking about such aspects with the healthcare professionals has a pain-relieving effect; hence, the present study shows that it is a turning point for the patients to be recommended and to decide to undergo SFS. Indeed, this is experienced as recognition of the pain - creating feelings of relief and hope which helps them re-engage into normal life, becoming once again a resource to family, friends and colleagues. But the study also shows that life with back pain basically has changed the patients' understanding of themselves and that insecurity and a weakened self-image prevail after surgery in some patients. The patient role has left so prominent a mark on the patients that it is difficult for them to re-define themselves and to create coherence and meaning in life.

Furthermore, the present thesis shows that due to their life-changing illness trajectories, patients can experience 'being trapped in pain experiences'; and feelings of powerlessness and of being mistrusted can 'stick' within the patients. In addition, increasing pain and functional deterioration can alter the experience of time, leaving the patients with a more complex and multi-dimensional understanding of time than that commonly governing how the healthcare system is organised temporally. Moreover, it is important knowledge that patients with low socioeconomic status can feel particularly abandoned, experiencing the discharge goals as confusing, unrealistic and in conflict with their own immediate goals. Such aspects should be taken into consideration when healthcare professionals communicate with the patients.

In conclusion and to accommodate the patients' individual needs, it is crucial to prioritise their everyday experiences. In this context, it is important for the healthcare professionals to understand that the patients' experiences of insecurity can be so powerful that they can develop into fundamental doubt about their own experiences and judgements and that this can even cause them to hide their pain not to be a burden. This study emphasises that the recommendation and decision to undergo SFS can create feelings of being recognised and feelings of relief. However, it is important for the healthcare professionals to be aware of the fact that the patient role and the insecurity can be so pervasive that patients may experience difficulties re-defining themselves and creating a new identity. Accordingly, it is crucial throughout the illness trajectory to include existential experiences to understand what gives (or may not give) meaning to the patients.

12 Resumé

Formålet med denne afhandling er at undersøge, hvordan patienter, der gennemgår SFS, oplever deres sygdomsforløb.

Forskningslitteraturen beskriver, at det at lide af rygsmerter er et indgribende element i patienternes liv, der påvirker såvel familie, venner og job. Patienterne oplever lange og udmattende sygdomsforløb med store personlige omkostninger, og flere studier viser, at livet med rygsmerter kan være så kaotisk og traumatisk, at patienterne er i fare for en egentlig depression. I det perspektiv oplever nogle patienter, at de ikke føler sig taget alvorligt, men i stedet mødes med insinuationer om at ville snyde sig til offentlige goder. Dette skaber følelser af eksistentiel usikkerhed, tvivl og social isolation hos patienterne, og litteraturen viser særligt store udfordringer for patienter, der gennemgår SFS, fordi operationen som regel først anbefales som sidste mulighed, hvorfor denne patientgruppe ofte bærer forudgående oplevelser med sig i form af mange kontakter til forskellige offentlige instanser, talrige undersøgelser og behandlinger, der ikke har virket.

For at opnå en dyberegående forståelse af, hvordan patienter, der skal gennemgå SFS, oplever deres sygdomsforløb, gennemførtes et fænomenologisk-hermeneutisk studie. Med henblik på at kvalificere de efterfølgende interviews blev der først udført observationer. Ti patienter, der skulle gennemgå SFS, deltog i to semistrukturerede interviews – ét under indlæggelsen 2-3 dage efter operationen og ét på patienternes bopæl 2-3 måneder efter udskrivelsen. Datamaterialet bestående af feltnoter og transskriberede interviews blev analyseret og fortolket med inspiration fra Paul Ricoeurs fortolkningsteori.

Afhandlingens fund er baseret på tre artikler. Artikel I består af en systematisk litteraturgennemgang baseret på en tematisk syntese. Formålet med artiklen er at opnå en bedre forståelse for patienternes sygdomsoplevelser og at identificere, systematisere og integrere fundene fra forskellige kvalitative studier og dermed belyse barrierer og konsekvenser eller centrale punkter i forbindelse med plejen og behandlingen af patienter med rygsmerter. Artikel II har til formål at undersøge, hvordan patienter, der skal gennemgå SFS, oplever deres

sygdomsforløb og interaktionen med sundhedssystemet. Artikel III har til formål at undersøge, hvordan patienterne oplever deres situation fra beslutningen om at gennemgå SFS til oplevelsen af hverdagslivet efter operationen.

Litteraturgennemgangens tematiske syntese peger på, at det er gennem oplevelser og minder, at vi skaber vores identitet. Ignorerer sundhedssystemet patienternes sygdomsoplevelser, kan det opfattes som mangel på respekt, hvilket kan skabe følelser af at blive marginaliseret og mistænkeliggjort. Dét at inkludere patienternes oplevelser handler derfor grundlæggende om at anerkende patienterne som mennesker. Syntesen af de inkluderede studier tydeliggør således et behov for, at sundhedsprofessionelle må inddrage sygdomsfortællinger for at anerkende patienterne. Dette involverer en forståelse af, at kroppen ikke kun er en biologisk enhed, og at sygdom er langt mere end dét at have symptomer, at få en diagnose og en behandling. Syntesen i litteraturgennemgangen lægger derfor op til en holistisk tilgang med fokus på, hvad patienterne hører, forstår og 'tør' stille spørgsmål om. Sådanne aspekter overses i mange tilfælde af de sundhedsprofessionelle.

I den sammenhæng viser dette studie, at fraværet af fysiske tegn på sygdom har stor betydning. Som en konsekvens af manglen på synlige sygdomstegn kan patienterne opleve insinuationer om at være hypokondere. Denne mistillid kan føre til, at patienterne tvivler på egne oplevelser og til, at de på paradoksal vis skjuler deres smerter for ikke at være til besvær. Dette medfører, at følelser af usynlighed, tristhed, tomhed og usikkerhed opstår. Det at tale med de sundhedsprofessionelle om sådanne eksistentielle aspekter kan have en smertestillende virkning; og studiet viser i relation hertil, at det er et vendepunkt for patienterne at blive anbefalet og at beslutte sig for SFS. Det opleves som en anerkendelse af smerterne, og det skaber lettelse og håb for patienterne om, at de kan genoptage deres normale liv og igen blive en ressource. Men studiet viser også, at livet med rygsmerter grundlæggende har ændret patienternes forståelse af sig selv, hvorfor usikkerheden og et svækket selvbillede for en del patienter indfinder sig igen i forløbet efter operationen. Patientrollen har gennem sygdomsforløbet defineret patienterne, og dette betyder, at de har svært ved at redefinere, hvem de er, og genskabe sammenhæng og mening i tilværelsen.

Diskussionen i denne afhandling viser, at patienterne som følge af deres komplekse sygdomsforløb ligefrem kan være ’fanget i smerteoplevelser’, hvorfor følelser af afmægtighed og af at være mistænkeliggjort nærmest kan ’sætte sig fast’ i patienterne. Et andet vigtigt element er desuden, at tiltagende smerter og en øget fysisk forværring kan forandre patienternes oplevelse af tid, der således kan opleves kompleks og mange-dimensioneret og ikke altid lineær som opfattet i sundhedssystemet. Det er desuden vigtigt at nævne, at patienter med lav socioøkonomisk status kan føle sig særligt forladt efter udskrivelse - de kan opleve udskrivelsesmål som forvirrende, urealistiske eller i konflikt med deres egne umiddelbare mål. Sådanne elementer er værd at tage med i betragtning for sundhedspersonalet, når de kommunikerer med patienterne.

Det konkluderes, at det for at imødekomme patienternes individuelle behov er afgørende at prioritere deres hverdagsoplevelser. I den sammenhæng er det vigtigt for de sundhedsprofessionelle at forstå, at patienternes oplevelser af usikkerhed kan være så kraftfulde, at de kan udvikle sig til en grundlæggende tvivl på egne oplevelser og dømmekraft, og endda kan medføre at smerter skjules for ikke at være til besvær. Dette studie sætter også fokus på, at dét at blive anbefalet og beslutte sig for SFS kan skabe følelser af anerkendelse og lettelse. I den sammenhæng er det dog vigtigt for sundhedspersonalet at være opmærksom på, at patientrollen og usikkerheden for flere patienter har påvirket dem så fundamentalt, at de kan have svært ved at (re)definere deres identitet. I sundhedspersonalets kommunikation med patienterne er det derfor afgørende gennem hele sygdomsforløbet at inkludere sådanne eksistentielle oplevelser for at finde frem til, hvad der giver (eller ikke giver) mening for patienterne.

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14 Appendices

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Appendix B	Informed consent sheet for participation in the project
Appendix C	Patient information (Observations)
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Appendix E	Example of a summary in relation to the observations (an excerpt)
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Appendix G	Approval, Danish Data Protection Agency
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Appendix A: Patient information (Interviews)

Patientinformation

Med dette brev vil jeg gerne invitere dig til at deltage i en videnskabelig undersøgelse om rygpatienters sygdomssituation og indlæggelsesforløb.

Hvem er jeg
Jeg er sygeplejerske, og har i en del år, ud fra forskellige fokusområder, arbejdet med at klarlægge patienters oplevelser med pleje- og behandlingsforløb på hospitaler.

Jeg er i øjeblikket ph.d.-studerende. Ph.d.-studiet er en forskeruddannelse – og i den forbindelse undersøger jeg, hvordan mennesker, der har fået en stabiliserende rygoperation, oplever deres sygdomssituation og indlæggelsesforløb. Projektet har titlen ”Kirurgiske rygpatienters sygdomssituation og indlæggelsesforløb”. Det er meningen, at undersøgelsen skal føre til en bedre forståelse for rygpatienters sygdomssituation og indlæggelsesforløb.

Hvordan foregår undersøgelsen
Hvis du ønsker at medvirke i undersøgelsen, vil du blive interviewet én gang efter din operation under indlæggelsen, og én gang efter din udskrivelse på et nærmere bestemt tidspunkt og gerne i dit eget hjem.
Interviewet varer ca. 1-1½ time. Interviewet foregår som en samtale mellem dig og mig og optages på bånd. Interviewet består i, at du fortæller om, hvordan du oplever dit indlæggelsesforløb, og hvad der har betydning for dig i forbindelse med at være blevet opereret i ryggen.
Det indtalte bånd slettes, når undersøgelsen afsluttes.

Du vil desuden måske møde mig til informationsmøder, ved ambulatoriebesøg og på afdelingen, hvor jeg vil være til stede for at få indsigt i, hvordan indlæggelsesforløbet former sig for rygpatienter. Du vil opleve, at jeg skriver noter, så jeg kan huske, det jeg har observeret.

I det færdige projekt vil teksten være anonymiseret, hvilket indebærer, at navn m.v. slettes.
Bånd og udskrifter af interviewmateriale behandles fortroligt og opbevares aflåst.
Du vil desuden skulle underskrive en erklæring vedrørende samtykke i forhold til deltagelse i projektet og adgang til din journal, hvis jeg får brug for oplysninger, der kan være vigtige for forståelse af din fortælling.

Dine rettigheder
Det er helt frivilligt, om du vil deltage i undersøgelsen, og du kan til enhver tid fortryde og afbryde undersøgelsen uden, at det får indflydelse på din videre kontakt med afdelingen.

Jeg håber, du har lyst til at deltage.

Med venlig hilsen
Janne Brammer Damsgaard, sygeplejerske og ph.d.-studerende

Appendix B: Informed consent sheet for participation in the project

Samtykkeerklæring vedrørende deltagelse i forskningsprojekt og journalindsigt.

Hermed bekræftes, at jeg, efter at have modtaget mundtlig og skriftlig information om ph.d.-projektet ”Kirurgiske rygpatienters sygdomssituation og indlæggelsesforløb”, indvilger i at deltage i undersøgelsen, og giver samtykke til indsigt i min journal.

Jeg er informeret om, at det er frivilligt at deltage i undersøgelsen, og at jeg til enhver tid kan trække mit tilsagn om deltagelse tilbage uden, at det vil påvirke min nuværende eller fremtidige behandling. Dette gælder også, selvom jeg har underskrevet samtykkeerklæring nederst på denne side.

Dato

Deltagerens/patientens navn:

Deltagerens/patientens underskrift:

Underskrift - mundtlig informationsgiver:
Janne Brammer Damsgaard, sygeplejerske og ph.d.-studerende

Appendix C: Patient information (Observations)

Patientinformation

August 2013

Dette er et informationsbrev om, at jeg i dag vil være til stede for at foretage observationer som led i en videnskabelig undersøgelse om rygpatienters sygdomssituation og indlæggelsesforløb.

Hvem er jeg

Jeg er sygeplejerske og ph.d.-studerende på Center for Planlagt Kirurgi, Regionshospitalet Silkeborg.
Ph.d.-studiet er en forskeruddannelse – og i den forbindelse undersøger jeg, hvordan mennesker, der er indlagt til en stabiliserende rygoperation, oplever deres sygdomssituation og indlæggelsesforløb. Det er meningen, at undersøgelsen skal føre til en bedre forståelse for rygpatienters sygdomssituation og indlæggelsesforløb.

Fremgangsmåde

Som indledning til kommende interview vil jeg, for at kunne udarbejde relevante spørgsmål, være med ved informationsmøder, i ambulatoriet, på operationsafdelingen, på opvågningen og på afdelingen hvor rygpatienterne er indlagt. Jeg vil i en kortere periode være til stede for at observere, lytte og tale med rygpatienter og personale om, hvad de oplever og tænker. Jeg vil af og til tage notater.

Anonymitet

Oplysninger om helbredsmæssige forhold og andre fortrolige oplysninger, som måtte fremkomme, er naturligvis omfattet af tavshedspligten.
Projektet er anmeldt til datatilsynet efter lov om behandling af personoplysninger, og informationerne opbevares i anonymiseret form frem til projektets afslutning i 2016, hvorefter de slettes.

Hvis du har nogle spørgsmål, er du velkommen til at kontakte mig.

Med venlig hilsen

Janne Brammer Damsgaard
Sygeplejerske, cand. cur., ph.d.-studerende
Forskningsenheden, Center for planlagt Kirurgi
Regionshospitalet Silkeborg, Hospitalsenhed Midt
Tlf. 7841 6444, e-mail: jadams@rm.dk

Appendix D: Descriptive observation matrix

	Observations	Reflections/Comments
Space		
Actor		
Activity		
Object		
Act		
Event		
Time		
Goal		
Feeling		
Adapted by Janne Brammer Damsgaard from James P. Spradley 1980		

Appendix E: Example of a summary in relation to the observations (an excerpt)

Observation at the out-patient clinic

OBSERVATIONS	REFLECTIONS, COMMENTS
Overlæge (OL) forsinket Sygeplejerske (SPL) fortæller, at hun altid venter med at advisere patienten (P) om dette for ikke at skabe unødig utryghed	Intens og følelsesmættet atmosfære
Konsultation: P og OL taler hurtigt	Har P forstået informationerne? P's sygdomserfaringer inddrages ikke rigtigt
OL informerer om, at det ikke kan garanteres, at operationen vil have den ønskede effekt	
Spørgsmålet "er det fair?" anvendes flere gange	Hvordan oplever P dette spørgsmål?
Sygeplejersken varetager papirarbejde, arrangerer tidspunkt for nye undersøgelser, henter P	Forvirrende for P fx at se på røntgenbilleder? Når OL læser informationer op fra skærm, er denne længere fremme i tænkningen end P?
Megen samtale foregår med fokus på PC, og den tekst og de røntgenbilleder, der skroller forbi på skærmen	P ser ud til at være i tvivl om, hvad der bliver sagt, men spørger ikke … OL er videre i processen Fokus væk fra P. - hører P det OL forklarer?
P har tilsyneladende mange store sygdomsproblematikker fx vedr. sygdomssituation og arbejdsliv	Når kun ganske kort at berøre udfordringer med førtidspension, liv i hjemmet og sit tidligere arbejde

Appendix F: Interview guide

Interview	**Interview-spørgsmål**
Første interview	Can you please tell me about how you have experienced living with back pain? Can you please tell me about how you have experienced your interaction with the healthcare system?
Andet interview	Can you please tell me about how you experienced the decision of undergoing surgery? Can you please tell me about how life is after the surgery?

Appendix G: Approval, Danish Data Protection Agency

Vedrørende projektet – Kirurgiske rygpatienters sygdomssituation og indlæggelsesforløb

Sagsnr. 1-16-02-65-13

Ovennævnte projekt er den 06-02-2013 anmeldt til Region Midtjylland. Der er samtidig søgt om tilladelse til projektet.

Det fremgår af anmeldelsen, at du er projektansvarlig for projektets oplysninger.

Behandlingen af oplysningerne ønskes påbegyndt den 01-03-2013 og forventes at ophøre den 31. marts 2016.

Data slettes, anonymiseres eller indsendes til Statens Arkiver senest ved projektets afslutning.

Oplysningerne vil blive behandlet på følgende adresse(r):

XXX

Projektet omfatter ikke en biobank.

Tilladelse

Der meddeles herved tilladelse til projektets gennemførelse. Region Midtjylland fastsætter i den forbindelse nedenstående vilkår.

Tilladelsen gælder indtil den 31-03-2017.

Appendix H: Guidelines for authors and reviewers of qualitative studies (K. Malterud)

Guidelines for authors and reviewers of qualitative studies	
	Comments
Aim	
Reflexivity	
Method and design	
Data collection and sampling	
Theoretical framework	
Analysis	
Findings	
Discussion	
Presentation	
References	

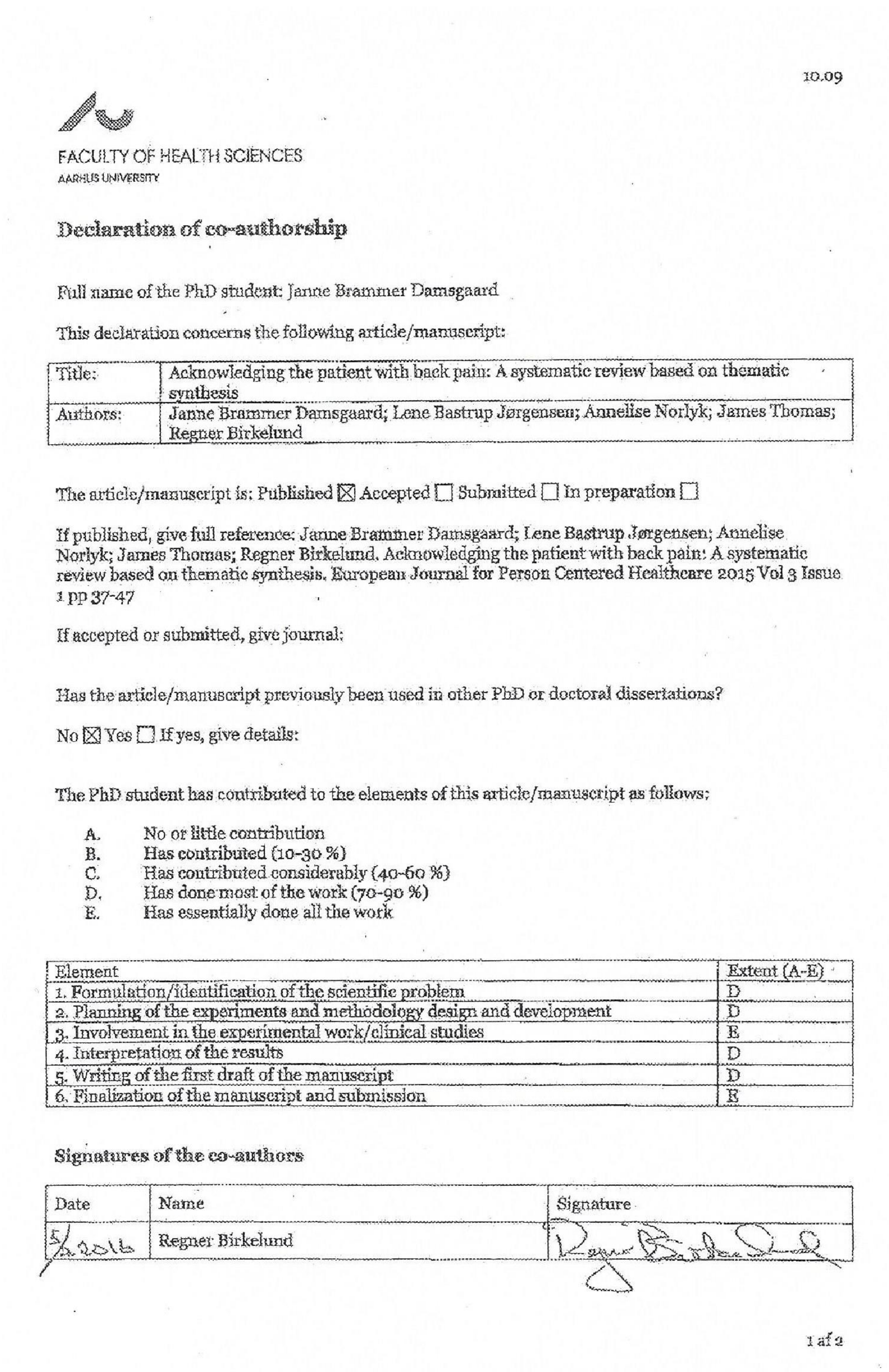
Appendix I: Sensitivity analysis, cf. James Thomas & Angela Harden

Sensitivity analysis	
	Comments
The quality of the reporting of	
Aim of the study	
Context	
Rationale	
Methods	
Findings	
Strategies employed to establish the reliability and validity	
Data collection tools	
Method of analysis	
The validity of the findings	
Criteria related to the assessment of the appropriateness of the study methods	
Are the findings rooted in the participants’ own perspectives (e.g. were data collection methods appropriate for helping the participants expressing their views?)	

Appendix J: Guidelines ENTREQ

Guidelines of ENTREQ - Enhancing transparency in reporting the synthesis of qualitative research	
	Comments
Aim	
Synthesis methodology	
Approach to searching	
Inclusion criteria	
Data sources	
Electronic search strategy	
Study screening methods	
Study characteristics	
Study selection results	
Rationale for appraisal	
Appraisal items	
Appraisal process	
Appraisal results	
Data extraction	
Software	
Number of reviewers	
Coding	
Study comparison	
Derivation of themes	
Quotations	
Synthesis output	

Appendix K: Declaration of co-authorship (Paper I, II & III)



10.09

FACULTY OF HEALTH SCIENCES
AARHUS UNIVERSITY

Declaration of co-authorship

Full name of the PhD student: Janne Brammer Damsgaard

This declaration concerns the following article/manuscript:

Title:	Acknowledging the patient with back pain: A systematic review based on thematic synthesis
Authors:	Janne Brammer Damsgaard; Lene Bastrup Jørgensen; Annelise Norlyk; James Thomas; Regner Birkelund

The article/manuscript is: Published ☒ Accepted ☐ Submitted ☐ In preparation ☐

If published, give full reference: Janne Brammer Damsgaard; Lene Bastrup Jørgensen; Annelise Norlyk; James Thomas; Regner Birkelund. Acknowledging the patient with back pain: A systematic review based on thematic synthesis. European Journal for Person Centered Healthcare 2015 Vol 3 Issue 1 pp 37-47

If accepted or submitted, give journal:

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No ☒ Yes ☐ If yes, give details:

The PhD student has contributed to the elements of this article/manuscript as follows:

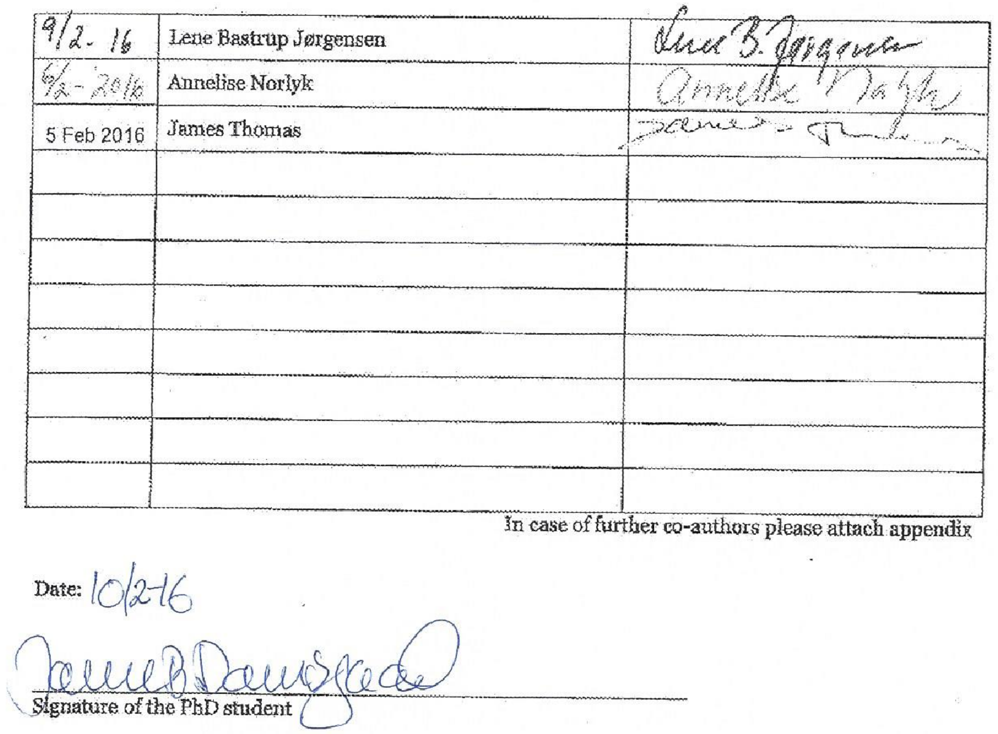
A.	No or little contribution
B.	Has contributed (10-30 %)
C.	Has contributed considerably (40-60 %)
D.	Has done most of the work (70-90 %)
E.	Has essentially done all the work

Element	Extent (A-E)
1. Formulation/identification of the scientific problem	D
2. Planning of the experiments and methodology design and development	D
3. Involvement in the experimental work/clinical studies	E
4. Interpretation of the results	D
5. Writing of the first draft of the manuscript	D
6. Finalization of the manuscript and submission	E

Signatures of the co-authors

Date	Name	Signature
5/2 2016	Regner Birkelund	

1 af 2



9/2-16	Lene Bastrup Jørgensen	Lene B. Jørgensen
6/2-2016	Annelise Norlyk	Annelise Norlyk
5 Feb 2016	James Thomas	

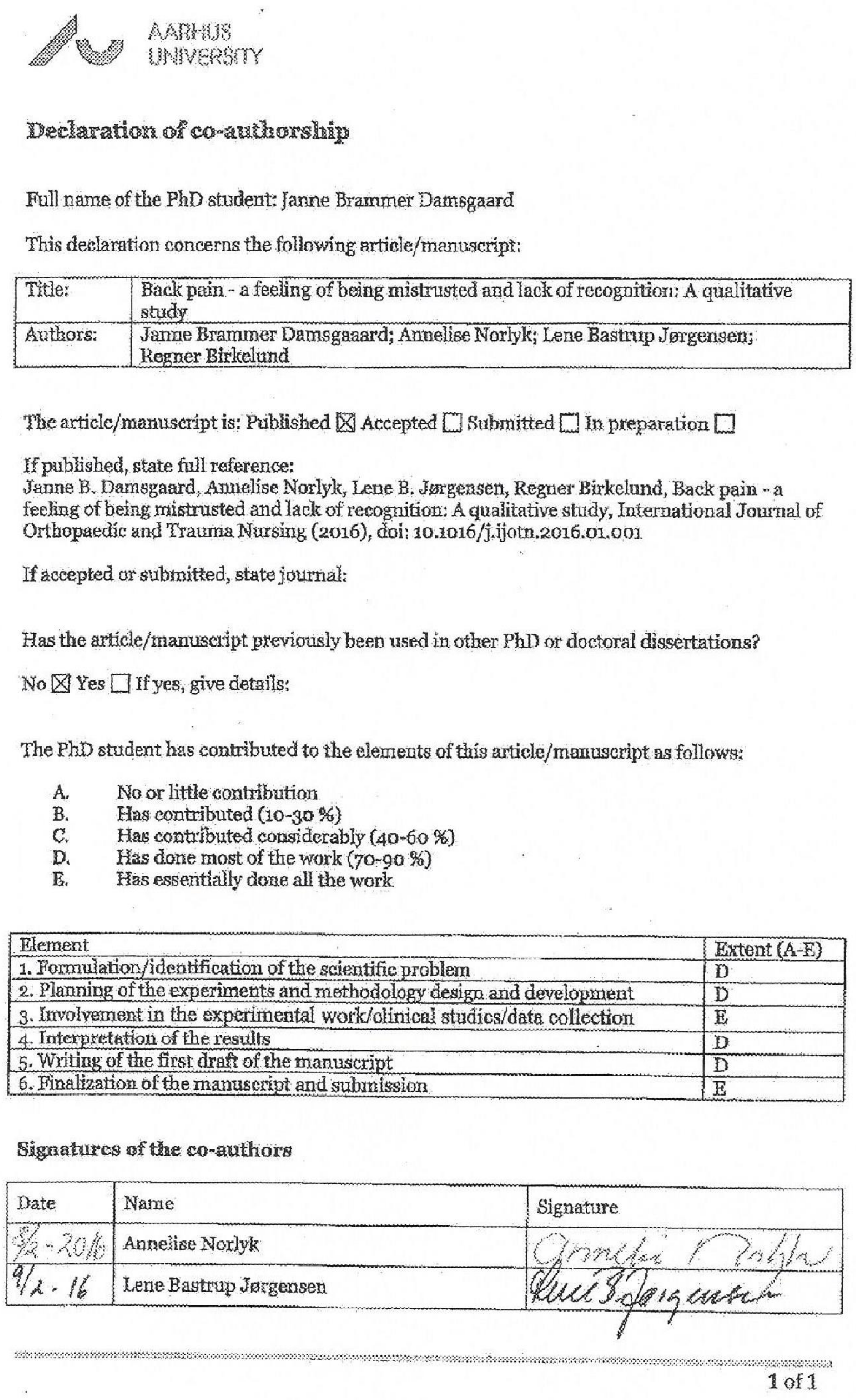
In case of further co-authors please attach appendix

Date: 10/2-16

Janne B. Damsgaard

Signature of the PhD student

2 af 2



AARHUS UNIVERSITY

Declaration of co-authorship

Full name of the PhD student: Janne Brammer Damsgaard

This declaration concerns the following article/manuscript:

Title:	Back pain - a feeling of being mistrusted and lack of recognition: A qualitative study
Authors:	Janne Brammer Damsgaard; Annelise Norlyk; Lene Bastrup Jørgensen; Regner Birkelund

The article/manuscript is: Published ☒ Accepted ☐ Submitted ☐ In preparation ☐

If published, state full reference:
Janne B. Damsgaard, Annelise Norlyk, Lene B. Jørgensen, Regner Birkelund, Back pain - a feeling of being mistrusted and lack of recognition: A qualitative study, International Journal of Orthopaedic and Trauma Nursing (2016), doi: 10.1016/j.ijotn.2016.01.001

If accepted or submitted, state journal:

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

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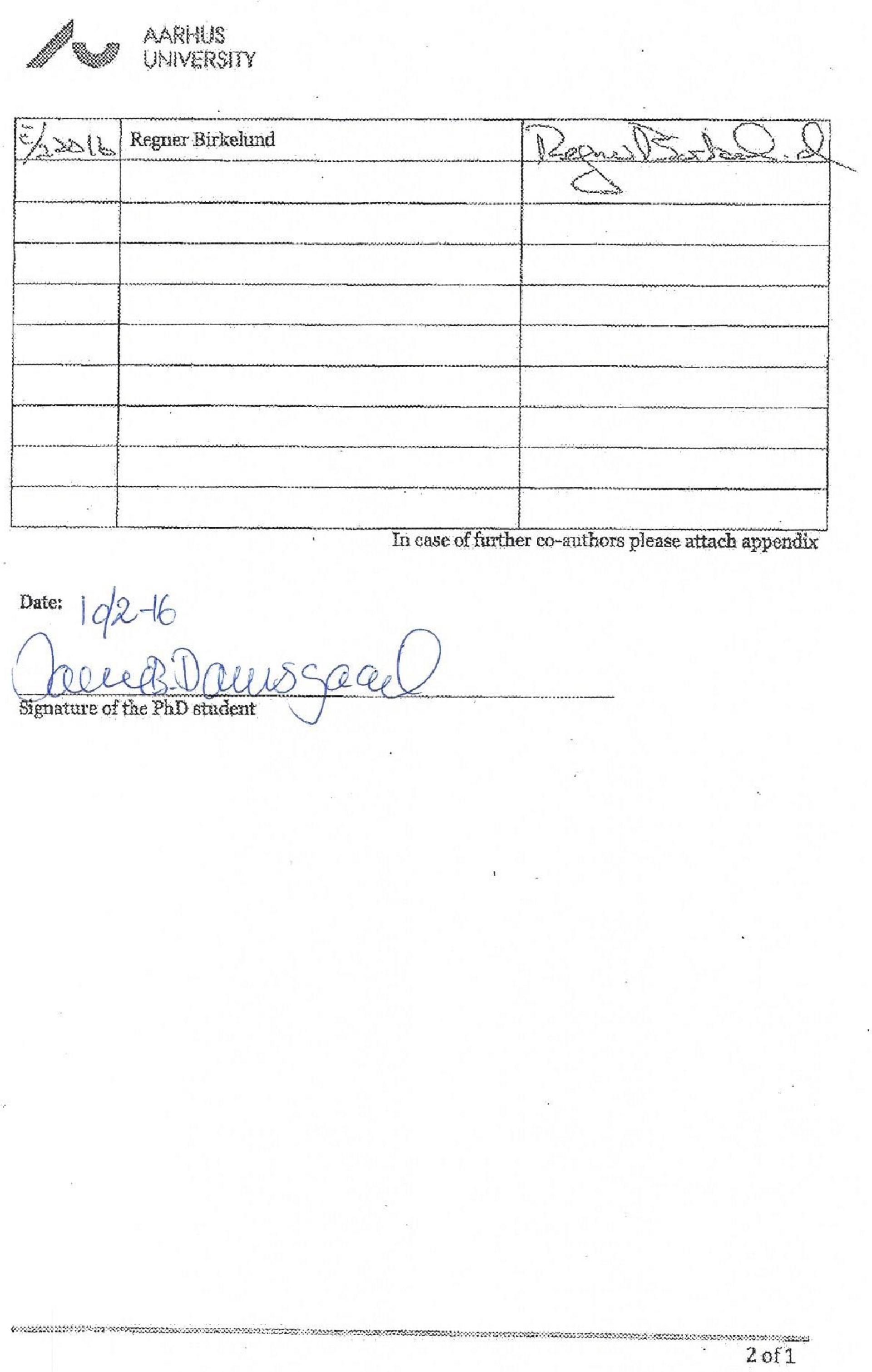
1. Formulation/identification of the scientific problem	D
2. Planning of the experiments and methodology design and development	D
3. Involvement in the experimental work/clinical studies/data collection	E
4. Interpretation of the results	D
5. Writing of the first draft of the manuscript	D
6. Finalization of the manuscript and submission	E

Signatures of the co-authors

Date	Name	Signature
8/2-2016	Annelise Norlyk	
9/2-16	Lene Bastrup Jørgensen	

1 of 1



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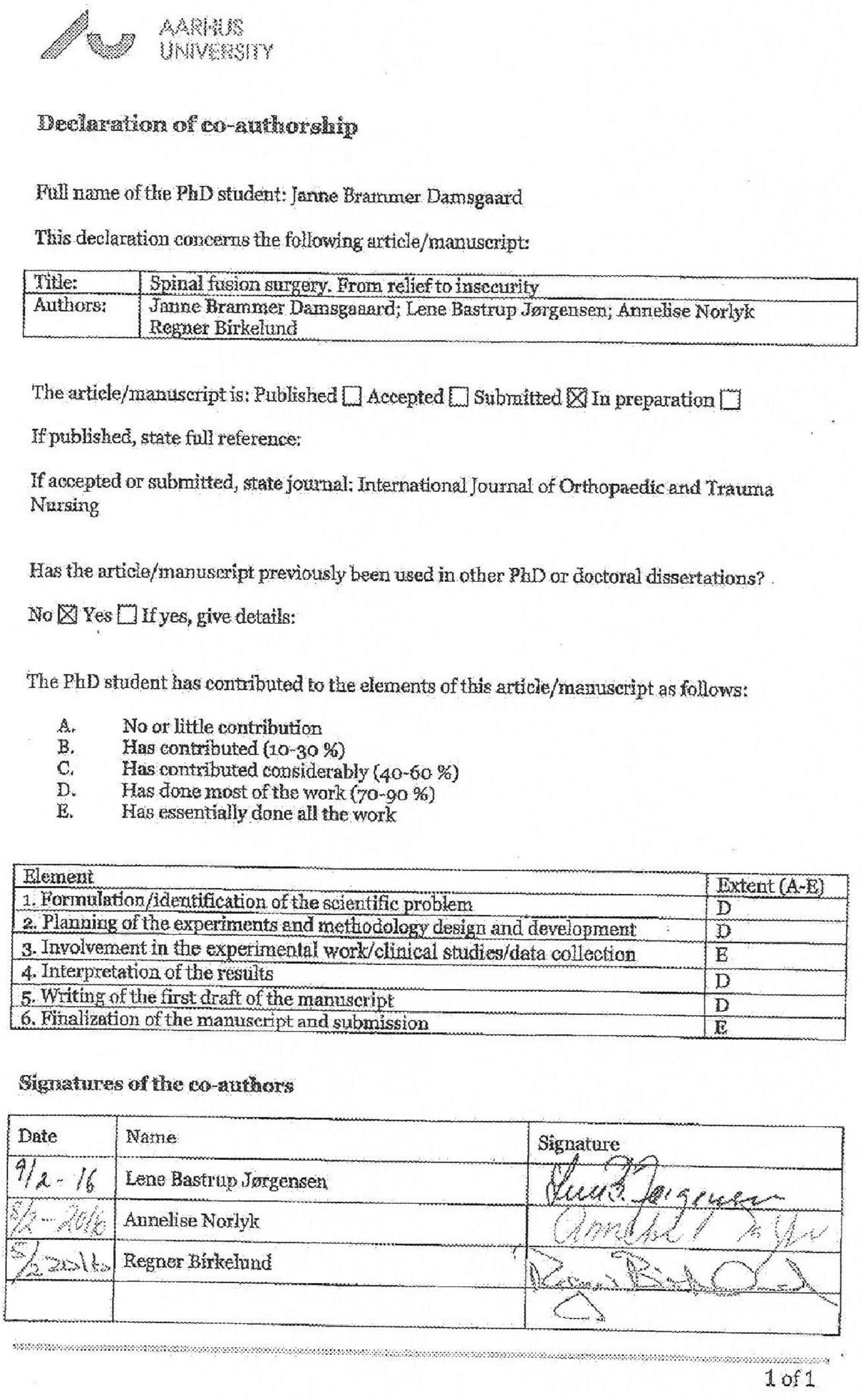
[illegible]/2 2016	Regner Birkelund	Regner Birkelund

In case of further co-authors please attach appendix

Date: 1/2-16

Janne B. Damsgaard
Signature of the PhD student

2 of 1



AARHUS UNIVERSITY

Declaration of co-authorship

Full name of the PhD student: Janne Brammer Damsgaard

This declaration concerns the following article/manuscript:

Title:	Spinal fusion surgery. From relief to insecurity
Authors:	Janne Brammer Damsgaaard; Lene Bastrup Jørgensen; Annelise Norlyk Regner Birkelund

The article/manuscript is: Published ☐ Accepted ☐ Submitted ☒ In preparation ☐

If published, state full reference:

If accepted or submitted, state journal: International Journal of Orthopaedic and Trauma Nursing

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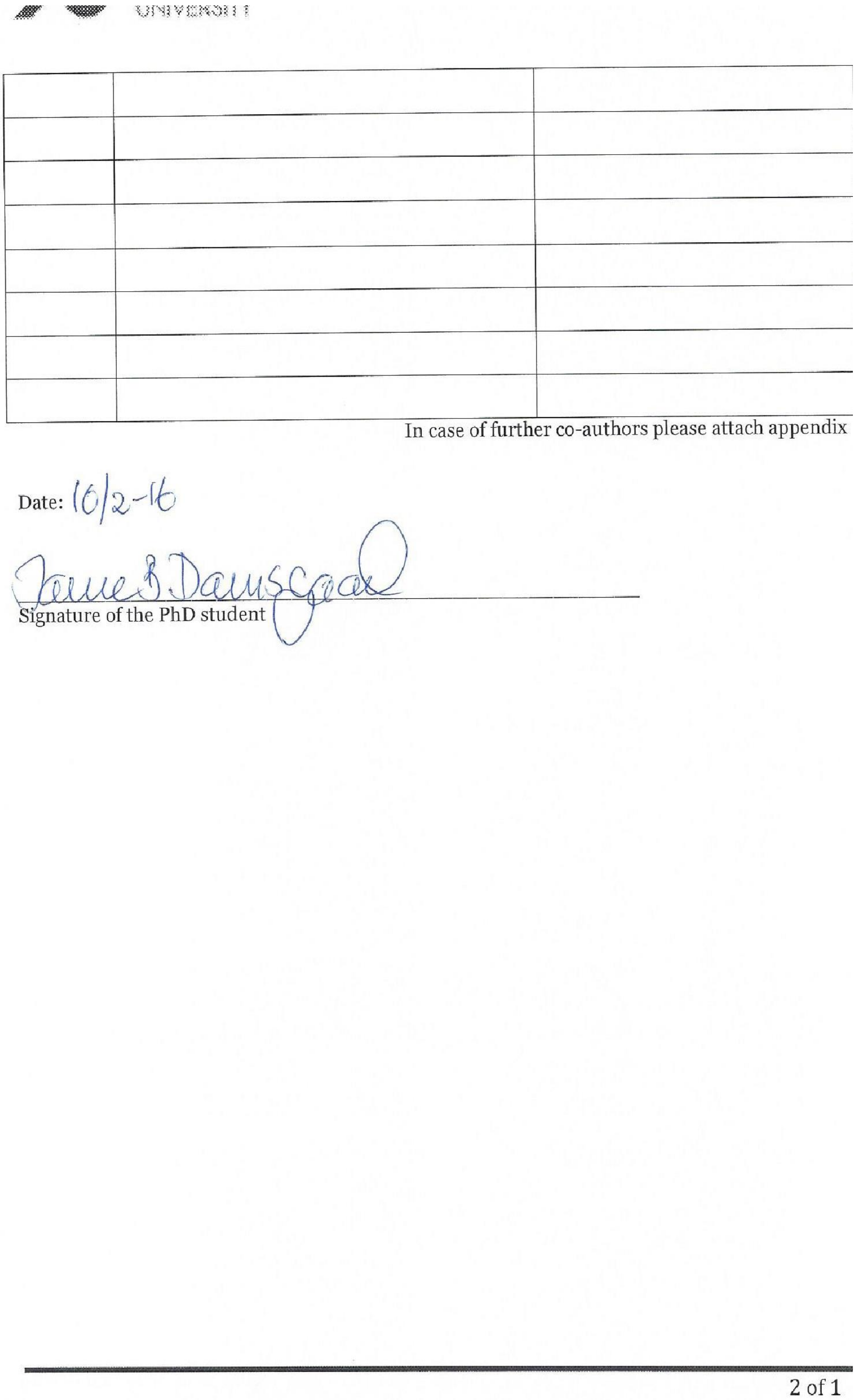
8/2-2016	Annelise Norlyk	
5/2 2016	Regner Birkelund	

1 of 1



In case of further co-authors please attach appendix

Date: 10/2-16

Janne B Damsgaard

Signature of the PhD student