

## 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   |
|---|--|
| <ul style="list-style-type: none"> <li>• Qualitative studies</li> <li>• English, German, Swedish, Norwegian, Danish literature</li> <li>• Back patients both hospitalised and not hospitalised</li> </ul> | <ul style="list-style-type: none"> <li>• Quantitative studies</li> <li>• Studies with focus on children or teenagers &lt; 18 years</li> <li>• Studies aimed at relatives</li> <li>• Other orthopaedic patient groups or specific physiotherapeutic rehabilitation</li> </ul> |

### 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 |
| <b>Phase 3. Main analytical theme including synthesis</b>  |   |
| <b>Acknowledging the back patient:</b><br>The divided view of the individual<br>Back patients' illness experience<br>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

|   |  |
|---|--|
| <p><b>Ulla Harriet Jensen [18]</b></p>                | <p>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.</p> <p>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.</p> |
| <p><b>Paul Ricoeur [20] &amp; Peter Kemp [45]</b></p> | <p>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.</p> <p>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.</p>   |
| <p><b>Hans-Georg Gadamer [35]</b></p>                 | <p>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.</p>   |
| <p><b>Todres et al.; Dahlberg et al. [37-39]</b></p>  | <p>Argues for a patient approach inspired by the philosophy <i>Lifeworld-led healthcare</i>, which in turn is based on a perspective that includes the individual's lifeworld.</p> <p>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.</p> <p>We cannot fully understand the quality of an illness as it is lived without also understanding what it means interpersonally and culturally.</p> <p>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.</p>   |

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<br>1. reading reduced the number to<br>2. reading reduced the number to<br>3. reading reduced the number to | 60 texts<br>32 texts<br>16 texts |
| 4    | <i>Berry Picking</i> resulted in a reduction to   | 8 texts                          |
|      | 8 texts assessed cf. <i>sensitivity analysis</i>  |                                  |

Table 5 Characteristics of included studies

| References                                 | Aim   | Methodology  | Participants   | Data collection   |
|--|---|--|--|---|
| Davis [9]<br>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]<br>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]<br>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]<br>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]<br>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]<br>Norway<br>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]<br>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]<br>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  $\frac{3}{4}$  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 reconnaissance*' [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 synthesised 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.

## References

- [1] The Pain Proposal Steering Committee. (2010). Pain proposal - Improving the current and future management of chronic pain - A European consensus report, September 2010.
- [2] Maniadakis N. & Gray A. (2000). The economic burden of back pain in the UK. *Pain* 84 (1) 95-103.
- [3] Jacobs P. & Golmohammadi K. (2003). The cost of low-back pain: a review of the literature. Prepared for the Health Services Utilization and Outcomes Commission of Alberta.
- [4] Marselisborg Centret RM. Hvordan går det folk med lænderygsmerte? "Hvordan fik du det" - En systematisk litteraturregning.
- [5] The British Pain Society. (2013). Available at: [http://www.britishpainsociety.org/media\\_faq.htm](http://www.britishpainsociety.org/media_faq.htm).
- [6] Holm G. (2003). Er du svindler, sindslidende eller hypokonder. *Sygeplejersken* (20).
- [7] Åbyholm, A.S. (1999). Å bli trodd er det viktigste. *Tidsskrift for den Norske Legeforening* 11 (119).
- [8] Slade, S.C., Mooloy, E. & Keating, J.L. (2009). Stigma Experienced by People with Nonspecific Chronic Low Back Pain: A Qualitative Study. *Pain Medicine* 10 (1) 143-154.
- [9] Davis, R.E., Vincent, C., Henley, A. & McGregor, A. (2011). Exploring the care experience of patients undergoing spinal surgery: a qualitative study. *Journal of Evaluation in Clinical Practice* 19 (1) 132-138.
- [10] Vroman, K., Warner, R. & Chamberlain, K. (2009). Now let me tell you in my own words: narratives of acute and chronic low back pain. *Disability and Rehabilitation* 31 (12) 976-987.
- [11] Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science & Medicine* 57 (6) 1045-1054.
- [12] Slade, S., Molloy, E. & Keating J.L. (2009). "Listen to me, tell me": a qualitative study of partnership in care for people with non-specific chronic low back pain. *Clinical Rehabilitation* 23 (3) 270-280.
- [13] Yee, A., Adjei, N., Do, J., Ford, M. & Finkelstein, J. (2008). Do patient expectations of spinal surgery relate to functional outcome? *Clinical Orthopaedics and Related Research* 466 (5) 1154-1161.
- [14] McGregor, A.H. & Hughes, S.P. (2002). The evaluation of the surgical management of nerve root compression in patients with low back pain: part I: the assessment of outcome. *Spine* 27 (13) 1465-1470.
- [15] Atlas, S.J., Keller, R.B., Wu Y.A., Deyo R.A. & Singer, D.E. (2005). Long-term outcomes of surgical and nonsurgical management of lumbar spinal stenosis: 8 to 10 year results from the main lumbar spine study. *Spine* 30 (8) 936-943.
- [16] Riiskjær, E., Ammentorp, J. & Kofoed, P.E. (2011). Er 96 procent af patienterne virkelig tilfredse med sundhedsvæsenet? *Information.dk*.
- [17] Abbott, A.D., Hedlund, R. & Tyni-Lenné, R. (2011). Patients' experience post-lumbar fusion regarding back problems, recovery and expectations in terms of the international classification of functioning, disability and health. *Disability and Rehabilitation* 33 (15-16) 1399-1408.
- [18] Jensen, U.H. & Paarup, B. (2006). Sociokulturelle aspekter i diagnose og behandling af rygpatienter i Danmark. *Tidsskrift for forskning i sygdom og samfund*.
- [19] Dalsgaard, T. (2006). Symptomers sociale betydning og sygdomsnarrativer i medicinsk uforklarede lidelser. In: Risør, M.B., ed. *Somativering? - sygdom uden forklaring*. nr. 5 ed. Afd. for Antropologi og Etnografi, Aarhus Universitet, Moesgaard, 8270 Højbjerg: Foreningen Medicinsk Antropologisk Forum. Afd. for Antropologi og Etnografi, Aarhus Universitet, Moesgaard; *Tidsskrift for Forskning i Sygdom og Samfund*, p. 127.
- [20] Ricoeur, P. (2004). *Parcours de la reconnaissance. Trois études*. Paris: Editions Stock.
- [21] Malterud, K. (2008). *Kvalitative metoder i medisinsk forskning*. 2<sup>nd</sup> edn. Oslo: Universitetsforlaget.
- [22] Thomas, J. & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 8, 45.
- [23] Carroll, C., Booth, A. & Lloyd-Jones, M. (2012). Should We Exclude Inadequately Reported Studies From Qualitative Systematic Reviews? An Evaluation of Sensitivity Analyses in Two Case Study Reviews. *Qualitative Health Research* 22 (10) 1425-1434.
- [24] Boulton, M., Fitzpatrick, R. & Swimburn, C.A. (1996). Qualitative research in healthcare II: a structured review and evaluation of studies. *Journal of Clinical Practice* 2 (3) 171-179.
- [25] Cobb, A. & Hagemaster, J. (1987). Ten criteria for evaluating qualitative research proposals. *Journal of Nursing Education* 26 (4) 138-143.
- [26] Mays, N. & Pope, C. (1995). Rigour and qualitative research. *British Medical Journal* 311 (6997) 109-112.

- [27] Medical Society Group.(1996). Criteria for the evaluation of qualitative research papers. *Medical Social News* 22, 68.
- [28] Thomas, J., Sutcliffe, K., Harden, A., Oakley, A., Oliver, S., Rees, R. *et al.* (2008). Children and Healthy Eating: A systematic review of barriers and facilitators 2003. Available at: <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=246>. London EPPI-Centre, Social Science Research Unit, Institute and Education, University of London. Accessed 4th July.
- [29] Thomas, J., Harden, A. & Newman, M. (2012). Synthesis: Combining results systematically and appropriately. In: An introduction to Systematic Reviews, Gough, D., Oliver, S. & Thomas, J., eds. p.179. London: SAGE.
- [30] Kavanagh, J., Campbell, F., Harden, A. & Thomas, J. (2012). Mixed methods synthesis: a worked example. In: Synthesising Qualitative Research: Choosing the Right Approach, first edn. Hannes, K. & Lockwood, C., eds. Oxford: John Wiley & Sons, Ltd.
- [31] Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G. & Oakley, A. (2004). Applying systematic review methods to studies of people's views: an example from public health. *Journal of Epidemiology and Community Health* 58 (9) 794-800.
- [32] Harden, A., Brunton, G., Fletcher, A. & Oakley, A. (2006). Young people, Pregnancy and Social Exclusion: A systematic synthesis of research evidence to identify effective, appropriate and promising approaches for prevention and support. 2006; Available at: <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=674> London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.
- [33] Thomas, J., Kavanagh, J., Tucker, H., Burchett, H., Tripney, J. & Oakley, A. (2007). Accidental injury. Risk-taking Behaviour and the Social Circumstances in which young people Live: A systematic review. Available at: <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=1910> London EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.
- [34] Barnett-Page, E. & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology* 9, 59.
- [35] Gadamer, H.G. (1993/1996). The enigma of health. Gaiger, J. & Walker, N., trans. eds. Stanford, CA: Stanford University Press.
- [36] Thorne, S., Jensen, L., Kearney, M.H., Noblit, G. & Sandelowsky, M. (2004). Qualitative meta-synthesis: reflections on methodological orientation and ideological agenda. *Qualitative Health Research* 14 (10) 1342-1365.
- [37] Todres, L., Galvin, K. & Dahlberg, K. (2007). Lifeworld-led healthcare: revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy* 10 (1) 53-63.
- [38] Dahlberg, K., Todres, L. & Galvin, K. (2009). Lifeworld-led healthcare is more than patient-led care: an existential view of well-being. *Medicine, Health Care and Philosophy* 12 (3) 265-271.
- [39] Dahlberg, K., Dahlberg, H. & Nyström, M. (2001/2008). Reflective Lifeworld Research. Lund: Studentlitteratur AB.
- [40] Tong, A., Flemming, K., McInnes, E., Oliver, S. & Carig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology* 12, 181.
- [41] Sandelowski, M. & Barroso, J. (2006). Handbook for Synthesizing Qualitative Research. London: Springer Publishing Company.
- [42] Sandelowski, M. & Barroso, J. (2002). Finding the findings in Qualitative Studies. *Journal of Nursing Scholarship* 34 (3) 213-219.
- [43] Bates, M.J. (1989). The Design of Browsing and Berrypicking Techniques for the online search interface. Graduate School of Library and Information Science, University of California at Los Angeles, Los Angeles, CA 90024-1520.
- [44] Carroll, C., Booth, A., Leaviss, J. & Rick, J. (2013). "Best fit" framework synthesis: refining the method. *BMC Medical Research Methodology* 13, 37.
- [45] Kemp, P. (2012). Anerkendelse af Ricoeur/Ricoeur og anerkendelsen (Reconnaissance à Ricoeur). In: Den menneskelige eksistens. Introduktion til den eksistentielle fænomenologi. 1stedn., Keller, K.D., ed. Aalborg: Aalborg universitetsforlag.