A systematic review of low back pain and sciatica patients’ expectations and experiences of health care

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Abstract

BACKGROUND CONTEXT: Previous systematic reviews of patients’ experience of health services have used mixed qualitative and quantitative studies. This review focused on qualitative studies, which are more suitable for capturing experience, using modern methods of synthesis of qualitative studies.

PURPOSE: To describe the experience of health care of low back pain and sciatica patients and the sources of satisfaction or dissatisfaction with special reference to patients who do not receive a diagnosis.

STUDY DESIGN: A systematic review of qualitative studies.

SAMPLE: Primary qualitative studies identified from Medline, Embase, CINAHL, and Psychinfo databases.

OUTCOME MEASURES: Conceptual themes of patients’ experiences.

METHOD: Data collection and analysis were through thematic content analysis. Two reviewers independently screened titles and collected and analyzed data. The authors were in receipt of a Primary Care Research Bursary from National Health Service Suffolk and Norfolk Research Departments, a not-for-profit organization.

RESULTS: Twenty-eight articles met the inclusion criteria. Most studies were of high quality. Nine themes emerged: the process and content of care, relationships and interpersonal skills, personalized care, information, the outcome of care, the importance of a diagnosis, delegitimation, recognizing the expert, and service matters. How care was given mattered greatly to patients, with importance given to receiving a perceived full assessment, consideration for the individual’s context, good relationships, empathy, and the sharing of information. These aspects of care facilitated the acceptance by some of the limitations of health care and were spread across disciplines. Not having a diagnosis made coping more difficult for some but for others led to delegitimation, a feeling of not being believed. Service matters such as cost and waiting time received little mention.

CONCLUSIONS: Although much research into the development of chronic low back pain (LBP) has focused on the patient, this review suggests that research into aspects of care also warrant research. The benefits of generic principles of care, such as personalization and communication, are important to patients with LBP and sciatica; so, practitioners may help their patients by paying as much attention to them as to specific interventions. When neither cure nor a diagnostic label is forthcoming, generic skills remain important for patient satisfaction.

Keywords: Back pain; Sciatica; Experience; Satisfaction; Delegitimation; Diagnosis; Personalized care; Communication

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Introduction

Patient experience

Previous systematic reviews of patients’ experience of health care for low back pain (LBP) have combined quantitative and qualitative studies [1]. A new review is needed for four reasons. First, more studies have appeared since earlier reviews [1]. Second, qualitative research is best suited for understanding experience; so, a review focused on qualitative studies is warranted [2]. Third, the methodology of synthesizing qualitative studies has progressed. Fourth, the most recent review [3] was directed at research methodology rather than practice. Thus, an updated review of qualitative studies using modern methods is warranted.

Theoretical approach

Grounded theory is the qualitative method most commonly used in medical research. Data items, such as each comment in an interview, are assigned brief descriptions, “codes.” Codes are compared to develop higher codes that link them. Previous data and codes may be reanalyzed and further data collected as analysis proceed, a process termed “iteration.” Iteration continues until no new information emerges, the point of “saturation” when “themes” have been developed that capture the varying experiences of the subjects, creating a “theoretical framework.”

The synthesis of qualitative research in medicine is less well established than the synthesis of quantitative research. Although both aim to distil the best available evidence, there are important differences (Table 1).

Sciatica patients

It could be hypothesized that sciatica patients have different experiences of health care, particularly its psychosocial aspects, because sciatica is associated with definable pathologies, most commonly disc herniation and lumbar spinal stenosis, whereas most cases of LBP are labeled nonspecific. However, some argue that a significant proportion of sciatica is not explained by those pathologies [4], and others dispute that LBP is nonspecific and argue that specific diagnoses can and should be made [5].

Aims

The principal aims were to describe the experience of health care of LBP and sciatica patients and the sources of satisfaction or dissatisfaction. A secondary aim was to describe the experience and satisfaction of patients who do not receive a diagnosis.

Methods

Search

The Medline, Embase, CINAHL and Psychinfo databases were searched for publications up to the period May 22, 2012. Both free-text and thesaurus terms were used to maximize yield [6]: (back pain.ti,ab OR sciatica*.ti,ab OR exp back pain OR exp sciatica) AND (expectation.ti,ab OR experience.ti,ab OR satisf*.ti,ab OR exp patient satisfaction OR exp client satisfaction OR qualitative.ti,ab OR exp qualitative research).

The gray literature was searched in The Health Management Information Consortium database and the System for Information on Gray Literature in Europe up to the period May 22, 2012 using the following terms: back pain, sciatica, satisfaction, expectation, experience, and qualitative.

Both reviewers independently screened titles and abstracts for eligibility. The references of all retrieved articles were screened. Disagreements were resolved by discussion.

Eligibility

Studies were included if

- Patients had LBP or sciatica of any duration.
- Patients had received health care directed at diagnosis or management.
- Health care was delivered by a practitioner who could be a primary care physician, physiotherapist,
chiropractor, osteopath, a secondary care specialist physician, or surgeon.

- The study used a recognized qualitative methodology [7] including solely qualitative studies, mixed method studies (patient experience reported both quantitatively and qualitatively), questionnaire surveys using open questions to collect and interpret data qualitatively, and qualitative studies that were parallel to or imbedded in trials or observational studies.
- Reported outcomes were patients’ experience of care provided by a practitioner or satisfaction with such care. Studies that reported patients’ expectations of care were included where they provided data relevant to experience or satisfaction.
- Reports were in English, Spanish, French, or Greek.

Studies were excluded if

- They reported on rehabilitation programs that had no element of diagnosis or management.
- They reported on self-care obtained from sources other than a health-care practitioner, such as self-help associations.

Method of synthesis

Thematic content analysis [8] is a method of synthesizing qualitative studies that is similar to grounded theory. It uses an iterative method of collating and analyzing data to create themes. Like synthesis of quantitative studies, the search strategy, inclusion criteria, and quality assessment are prespecified.

Quality assessment

The 12-item EPPI Center’s tool [8] to score the methodological quality of qualitative studies [9] is suitable for all qualitative study designs. It has been widely employed [10–18]. Scores were assigned as 1 if a criterion was met, 0 if not met, and 0.5 if partially met. Each study was assessed independently by the reviewers, and their mean score was taken as the final.

Data collection and analysis

Each article was analyzed independently by two reviewers. Each portion of text pertinent to the research questions was assigned an initial code, close to the original, thus avoiding premature interpretation. Codes were compared between the two reviewers and differences discussed. As coding progressed, initial codes were compared for connections to develop higher order codes. Iterative comparison between codes, earlier text, and emerging high-order codes continued to saturation. Data entry and analysis were performed with a customized database.

Results

Search

Twenty-eight studies out of 293 titles met the inclusion criteria (Fig. 1) in a variety of settings (Table 2). Eighteen studies were from the United Kingdom and four from the United States. Of 15 non-English titles, only 3 were excluded for language reasons alone.

Quality of studies

Most studies were of high quality: 23 scored 8 or more, median quality 9.6, and range 6.5 to 11. The intraclass correlation between reviewers was 0.86 indicating good agreement.

Themes

One hundred ninety-nine codes, 50 high-order codes, and 9 themes emerged (Fig. 2). Themes demonstrated both connectivity (overlap of high-order codes) and contradictions. Contradictions were seen between some high-order codes within each theme. Supporting quotes are identified by study number, S, and original page number, p.

Process and content of care

This theme was associated with the most codes and citations (Table 3) and the largest number of links to other themes (Fig. 2). Patients valued highly what they perceived to be a sufficient assessment:

- Many participants placed importance on a thorough assessment, feeling that it enabled their treatment to better relate to their needs. S4p247
- Primary care might be a target for such criticism because it lacks specialist knowledge and has shorter consultations, but such criticism was not universal:
- They praised general practitioners who took careful histories, carried out detailed examinations and ordered diagnostic investigations, and they appreciated being offered explanations of the rationale behind such investigation. S21p155
- Some studies reported that investigations, particularly radiography, are perceived as crucial to a thorough assessment, despite widely accepted guidelines, that plain radiographs have limited value:
- Radiography was sometimes considered more reliable than clinical investigation. S7p1360. ... patients had been given a clear explanation, but doubted its validity ... because they believed that it was based on inadequate investigations. S21p157
In contrast, other studies found that careful history taking and examination, particularly palpation of painful areas, may obviate the need for investigation:

Almost all (n 31) of the patients thought that the medical history taking and clinical examination had been thorough and satisfactory. S9p257

Most studies reported patients’ disquiet at any hint that their pain was not physically based, something closely linked with delegitimation:

[patients] expressed their concerns/frustrations that their back problem during the consultation was labeled as “just” being psychological or psychosomatic. S9p258

In contrast, some patients welcomed an exploration of the psychosocial aspects of their disease:

Through the interviews it occurred that the patients’ concept of psychosocial issues and that such issues had been discussed in most cases meant that the doctor had dealt with a possible correlation (in both directions) between daily life situation, including job, family, coping and quality of life aspects, role function and the patient’s LBP. In 25 of 35 consultations the patients felt that this was not focused on at all or to a small extent and that they missed it. S9p258

Another contrast was between patients whose attitudes can be termed passive, in the sense of seeking an intervention from practitioners to cure them, and active, in the sense that they were ready to take steps to improve the situation (that might fall short of cure):

Four patients said during the interview that they expected passive external treatment and Five patients were convinced that surgery was what they needed in order to get better. S9p258

In contrast:

Some believed that patients had to do their bit in the treatment process for it to work, otherwise the intervention is wasted. S14p131

The interplay between patient expectations and the content of care influenced satisfaction. Expectations frequently meant lack of faith in medication:

There was also a sense that drugs, which were considered to be the principal solution available from GPs, were inappropriate for back pain. S26p752
Table 2
Study characteristics and quality scores

<table>
<thead>
<tr>
<th>Study no.</th>
<th>Setting</th>
<th>Duration pain</th>
<th>Sampling method</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Spinal triage service, Canada</td>
<td>Uncertain</td>
<td>Convenience sample</td>
<td>Patients referred to primary/secondary care triage service</td>
<td>Questionnaire</td>
<td>Inductive thematic analysis approach</td>
<td>9.5</td>
</tr>
<tr>
<td>2</td>
<td>General practice, Israel</td>
<td>Uncertain</td>
<td>Identification from chart review and then purposeful sampling</td>
<td>Back pain in past year</td>
<td>Focus group, interview, and observation</td>
<td>Grounded theory</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>Pain clinic, UK</td>
<td>Chronic</td>
<td>Not stated</td>
<td>Pain management program graduates seeking further referral</td>
<td>Focus group</td>
<td>Thematic analysis</td>
<td>10.75</td>
</tr>
<tr>
<td>4</td>
<td>Back clinic (osteopath and acupuncturist), UK</td>
<td>Chronic</td>
<td>Diverse sample from those referred to new service</td>
<td>Patients registered at one primary care practice</td>
<td>Interview (semistructured)</td>
<td>Vague, “conventional qualitative method”</td>
<td>9.25</td>
</tr>
<tr>
<td>5</td>
<td>Physiotherapy, UK</td>
<td>Chronic</td>
<td>Purposive sampling from discharge files</td>
<td>Had received two or more physiotherapy sessions</td>
<td>Interview (semistructured)</td>
<td>Framework analysis</td>
<td>10.75</td>
</tr>
<tr>
<td>6</td>
<td>Physiotherapy, UK</td>
<td>Acute and subacute</td>
<td>Convenience sample from one community department</td>
<td>Recurring LBP referred to physiotherapist during current exacerbation</td>
<td>Interview (semistructured)</td>
<td>Interpretative phenomenological analysis</td>
<td>8.75</td>
</tr>
<tr>
<td>7</td>
<td>X-ray department, combined with quantitative study, Norway</td>
<td>Mixed 36 acute 63 chronic</td>
<td>Consecutive patients</td>
<td>Patients referred by GPs for lumbosacral spine X-rays</td>
<td>Questionnaire and semistructured interview</td>
<td>Template analysis</td>
<td>9.25</td>
</tr>
<tr>
<td>8</td>
<td>Chiropractic, alongside controlled trial, USA</td>
<td>Mixed but &gt;50% had pain for &gt;1 y</td>
<td>Volunteers for an RCT of spinal manipulation, epidural steroid, and home exercise</td>
<td>Sciatica patients with symptoms ≥4 wk, pain ≥3 on 0–10 scale</td>
<td>Interview (semistructured)</td>
<td>Content analysis</td>
<td>9.75</td>
</tr>
<tr>
<td>9</td>
<td>Variety of secondary care specialists, Norway</td>
<td>Mixed</td>
<td>Consecutive patients then maximum variation sample</td>
<td>Sciatica 12 plus 2 back pain, 2- to 7-y duration</td>
<td>Observation then interview (semistructured)</td>
<td>Grounded theory</td>
<td>10.75</td>
</tr>
<tr>
<td>10</td>
<td>Physiotherapy and acute pain services, combined with quantitative study, UK</td>
<td>Mixed</td>
<td>200 consecutive discharges from physiotherapy department and by advertisement from own pain services unit</td>
<td>Back pain</td>
<td>Questionnaire and focus group</td>
<td>Descriptive and grounded theory</td>
<td>6.5</td>
</tr>
<tr>
<td>11</td>
<td>University campus, Northern Ireland</td>
<td>Chronic</td>
<td>E-mail advertising then consecutive selection</td>
<td>Anyone with back pain ≥3 mo in past year</td>
<td>Focus group</td>
<td>Grounded theory</td>
<td>11</td>
</tr>
<tr>
<td>12</td>
<td>Community, Finland</td>
<td>Chronic</td>
<td>Entrants to a writing competition</td>
<td>Women with back pain</td>
<td>Free-text questionnaire</td>
<td>Phenomenological description and hermeneutic explanation (Ricoeur)</td>
<td>9.75</td>
</tr>
<tr>
<td>13</td>
<td>Back pain rehabilitation, UK</td>
<td>Chronic &gt;12 m</td>
<td>12 randomly selected from consecutive sample of 24</td>
<td>Patients referred from pain clinic to back pain rehabilitation unit pain</td>
<td>Interview (semistructured)</td>
<td>Content analysis</td>
<td>8.5</td>
</tr>
<tr>
<td>14</td>
<td>Physiotherapy, UK</td>
<td>Mixed</td>
<td>Systematic sampling, every fifth name on list from above</td>
<td>Patients who had received care in previous year</td>
<td>Interview (semistructured)</td>
<td>Framework analysis</td>
<td>8.5</td>
</tr>
</tbody>
</table>
Table 2 (Continued)

<table>
<thead>
<tr>
<th>Study no.</th>
<th>Setting</th>
<th>Duration pain</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>Physiotherapy, UK</td>
<td>Mixed</td>
<td>Random, every fifth name</td>
<td>Patients who had received care in previous year</td>
<td>Interview (semistructured)</td>
<td>Framework analysis, fully described</td>
</tr>
<tr>
<td>16</td>
<td>General practice, UK</td>
<td>Mixed</td>
<td>Patients invited by GPs who were part of an interview study</td>
<td>Patients who had consulted GP in previous 12 mo</td>
<td>Focus group</td>
<td>9.25</td>
</tr>
<tr>
<td>17</td>
<td>Organization with managed health program, combined with quantitative study, USA</td>
<td>Chronic</td>
<td>Random sample from records</td>
<td>CBLP defined as three or more visits to doctor over 3 y for back pain with episodes at least 90 d apart</td>
<td>Interview (semistructured) followed by Qaire</td>
<td>Content analysis</td>
</tr>
<tr>
<td>18</td>
<td>General practice, combined with quantitative study, UK</td>
<td>Mixed</td>
<td>Purposive sample nested within a large cohort study mostly observed by questionnaire</td>
<td>Sciatica sufferers</td>
<td>Interviews (not specified)</td>
<td>Constant comparative method</td>
</tr>
<tr>
<td>19</td>
<td>Organization with managed health program, USA</td>
<td>Chronic</td>
<td>Random from register of patients</td>
<td>CBLP defined as three or more visits to doctor over 3 y for back pain with episodes at least 90 d apart, this approximates to patients with CBLP</td>
<td>Interview (semistructured)</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>20</td>
<td>General practice, The Netherlands</td>
<td>Uncertain</td>
<td>Next patient seen during study period by participating GPs</td>
<td>Patients seeing GP for back pain, not specified other than &gt;18 y</td>
<td>Interview (semistructured)</td>
<td>“Categorized,” no further details</td>
</tr>
<tr>
<td>21</td>
<td>General practice, UK</td>
<td>Uncertain</td>
<td>Phasic, representative practices and then one GP selects seven consecutive patients</td>
<td>More than one episode LBP excluding sciatica</td>
<td>Interview (semistructured)</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>22</td>
<td>General practice, UK</td>
<td>Uncertain</td>
<td>Same sample as Skelton et al. 1995 [54], different set of results</td>
<td>Same sample as Skelton et al. 1995 [54], different set of results</td>
<td>Same interview Skelton et al., 1995 [54]</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>23</td>
<td>Back pain rehabilitation, Australia</td>
<td>Mixed</td>
<td>Advertising in community newspapers and university e-mail</td>
<td>Entering rehabilitation program and taken part in an exercise program</td>
<td>Focus group</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>24</td>
<td>Physiotherapy, nested in controlled trial, UK</td>
<td>Chronic</td>
<td>All patients who took part in active arms of RCT</td>
<td>Participation in spinal stabilization exercises</td>
<td>Focus group</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>25</td>
<td>Pain clinic, UK</td>
<td>Chronic</td>
<td>Invitation to all who had attended in a 3-mo period</td>
<td>Patients attending pain-management program</td>
<td>Interview (semistructured)</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>26</td>
<td>General practice, nested in controlled trial, UK</td>
<td>Mixed</td>
<td>All patients in large RCT recruited by GPs</td>
<td>LBP ≥4 wk and consulted GP</td>
<td>Free-text questionnaire</td>
<td>Modified framework approach</td>
</tr>
<tr>
<td>27</td>
<td>Variety of clinics, USA</td>
<td>56 acute 77 chronic</td>
<td>Not stated</td>
<td>Acute and CLBP</td>
<td>Free-text questionnaire</td>
<td>Thematic content analysis</td>
</tr>
<tr>
<td>28</td>
<td>Pain clinic, UK</td>
<td>Chronic</td>
<td>Initially consecutive then maximum variation</td>
<td>Chronic benign LBP</td>
<td>Open interview</td>
<td>“Inductive” phenomenology</td>
</tr>
</tbody>
</table>

CLBP, chronic low back pain; GP, general practitioner; LBP, low back pain; RCT, randomized controlled trial.
Expectations were not confined to drugs but extended to specific manual therapies:

Seven took into account the actual treatment experience itself (i.e., the approach to treatment, technique used). S8p504

Several of the findings linked with the theme of personalized care: the desire to be treated as an individual with individual needs and problems requiring individual solutions.

**Personalized care**

Closely linked to the process of care, patients wanted involvement in decisions:

All participants expressed the need for mutual enquiry, problem-solving, negotiation and renegotiation between care-provider and care-seeker to establish mutual therapeutic goals. S23p273

Personalized care encompasses many things: taking account of patient preferences, tailoring treatments for the individual, and understanding the patient’s specific context. A study, conducted in the outpatient departments of a variety of disciplines, of what constitutes a good back consultation discovered that:

A constant finding (observation and interviews) from the discussions/negotiations between the physician and the patient about treatment options was the importance of meeting the patient’s expectations and preferences (i.e. being patient-centred) in the decision-making process. S9p258

This finding recurred in several studies. Patients wanted their circumstances assessed believing that the treatment ought to be customized for them as an individual:

... participants wanted care-providers to develop a comprehensive picture of the individual’s values, preferences and lifestyle in order to develop individualized programmes. S23p273

Practitioners with good skills who appeared to understand the individual’s context were valued in several studies:

Patients described how it was important to know that the GP understood them as an individual and the impact the pain was having on their lives. S25p78
Patient-practitioner relationship and interpersonal skills

The practitioner’s interpersonal skills and the relationship with the patient were rated as important across several disciplines and settings. A study of physiotherapy patients reported:

They particularly valued behaviours such as listening and responding to their questions, consulting with them about the effectiveness of the therapy and relating the intervention to their individual self help needs. S24p183

Empathy and understanding were essential components of practitioners’ interaction:

Appreciation by clinicians of how sciatica affected people’s lives and self-image was mentioned as key to an effective therapeutic relationship. S25p78

Showing an interest in patients and treating them as individuals helped the development of good relationships that in turn improved patients’ cooperation in self-care:

Consideration of life circumstances and preferences was important to all participants in developing therapeutic partnerships and optimizing exercise outcomes. S23p273

Good communication skills and the sharing of information may partly explain why some patients come to accept the rationale of therapy, whereas others do not:

The importance of clear information and explanation emerged from many of the accounts, and they felt that this would help them cope with the diagnosis and prognosis. S15p132

Outcome of care

Patients with acute pain start with notions of cure, but when pain becomes chronic, expectations may shift to achieving strategies for adaptation:

Although many patients had come to accept that the problem was not curable they frequently expressed satisfaction with strategies for self-help that they had learnt through physiotherapy. S15p15

Some adapted to the situation and were satisfied with the care they received, accepting that information and coping strategies were all that could be offered:

… many expressed overall satisfaction with care, suggesting that this did not relate simply to the outcome of pain. S15p15. Although many patients had come to accept that the problem was not curable they frequently expressed satisfaction with strategies for self-help that they had learnt through physiotherapy. S15p15

Yet in contrast, some patients with chronic LBP never relinquished the goal of achieving cure and translated failure of treatment to lack of practitioners’ commitment:

What is evident from these narratives is that despite their continuing frustration and anger [with services] participants clearly felt that a cure was not only possible but should be readily available. S3p34

In chronic pain, other outcomes become important, such as functional ability, quality of life, and reassurance:

Approximately half of the respondents in this study rated a change in their ability to perform certain activities to be a factor they considered when evaluating their overall improvement, and just over half considered quality of life to be one of the most important outcomes to them. S8p506.

Recognizing the expert

Patients have ideas about which discipline, if any, is the expert in their condition. Some patients thought that GPs lack necessary knowledge and skills compared with other practitioners:

Patients described how GPs lacked specialist knowledge that would allow them to effectively treat back pain …. S27p79.

However, this was not a universal finding. Patients with recurrent low back pain were reported to be satisfied with GP care:

… [patients] believed that it was appropriate to visit their general practitioner routinely for episodes of low back pain. S21p257

The importance of interpersonal skills and empathy arose again, affecting the perception of who is the expert:

Non-orthodox and folk healers are often perceived as being more empathetic, more knowledgeable, having better diagnostic skills and providing more effective therapies. S2p983

However, another study found that patients attended a nonorthodox practitioner only because conventional services had been exhausted:

Most of these patients [who tried CAM] … as a desperate measure when their pain became intolerable and an immediate general practitioner consultation was unavailable or likely to be ineffective. S21p280

Recognition of expertise was tied in with expectations of the content of care. Medication was seen by many as ineffective compared with other forms of treatment:

… patients saw medication as just treating symptoms rather than “dealing with the actual problem.” S25p753

Necessity of diagnosis

Even when no cure is possible, and perhaps even more so, having a diagnosis was important to many patients. A study of chiropractic patients noted:
A main and general finding of this study was the importance to the patient of receiving an understandable explanation of the back pain or, if possible, getting a diagnosis. S8p257

Receiving a diagnosis had other benefits, such as reassurance that the cause is not sinister:

- An explanation of the problem provided reassurance to some and also encouraged self-management. S15p13

A diagnosis did not always necessitate imaging. An examination perceived as adequate may explain why clinical diagnosis alone satisfies some patients:

- These alternative healers frequently discern the exact site of the pain and often touch it, something many conventional practitioners fail to do. S2p983

In contrast, conventional practitioners sharing the diagnostic uncertainty inherent in medicine may fail to reassure:

- There is frustration with the uncertainty present in the usual diagnostic categorization. S2p983

A powerful driver for wanting a precise diagnosis was to have proof that there was something truly wrong, to legitimate the pain.

**Delegitimation**

A theme that recurred through many of the studies of chronic LBP was the need for legitimation: the feeling of “being seen, heard and believed, i.e. being taken seriously” (S9). The opposite, delegitimation, added further pain to sufferers:

- An element of others questioning the authenticity of their LBP was articulated in the distress and frustration experienced in interactions with medical professionals. S27p980

Why this happens in back pain and sciatica may be linked to the absence of external signs of disease:

- A theme across the narratives was that other people failed to appreciate their suffering and because they appeared outwardly normal, did not take their pain (i.e. them) seriously. S27p980

The link between legitimation and a physical diagnosis may explain why imaging was sought by some patients:

- One method of legitimization is through attempts to make “visible” the invisible by seeking diagnostic validation of the cause of the pain. S3p641

**Information**

Several studies found a desire for information and dissatisfaction when it was inadequate. Information needs were summarized as follows:

- ...four key areas in which patients generally appreciated information giving: the problem itself, the patients’ role in back care, the treatment process, the prognosis of the condition. S15p13

These key areas recurred across studies. The quality of communication was as important as the information:

- ...good communication involved: taking time over explanations; using appropriate terminology: listening, understanding and getting to know the patient; and encouraging the patient’s participation in the communication process. S5p247

**Service matters**

Aspects of services that patients found unsatisfactory were access, appointments, and cost. In socialized services, these included the perception that generalists are a barrier to specialist services, the length of waiting times, and difficulty of access to physiotherapists. In the private sector, cost was an important matter. There was little linkage between service matters and the other themes.

**Subgroup analysis: sciatica patients**

Analysis of the three studies that reported sciatica patients produced 30 high-order codes that mapped to the same nine themes from the overall analysis. These included such experiences as wanting hospital specialists to consider their views, taking their perspective and preferences into account, the importance of being believed, and the importance of empathy.

**Sensitivity analysis**

Two sensitivity analyses were performed. Removing all studies of lower quality (score less than the median) and removing all studies from Great Britain did not alter the themes or high-order codes.

**Discussion**

**Limitations and strengths**

This review’s main limitation is the concentration of studies in English-speaking countries, mostly Great Britain. This might reduce transferability to other countries. However, the sensitivity analysis excluding the British studies did not alter the results.

Some argue against synthesizing qualitative data because it removes the data from their context, which is crucial to qualitative research. In contrast, we see comprehensive synthesis as a strength. Some themes cut across the boundaries of primary/secondary care and across all disciplines. The ubiquity of the findings increases their transferability. We also found contrasting themes between studies that revealed a richer description of the spectrum.
of patient experiences than any individual study achieved. The main strength in relation to previous reviews is its systematic methods of qualitative research synthesis with rigorous data collection, quality appraisal, and analysis [8]. A further strength was the high quality of the studies.

**Implications for practice**

A mixed picture of patients’ experiences emerges from these studies. It is a truism that patients’ expectation of care is cure. However, when the prospect of cure fades, they adapt broadly in one of two ways. Some come to accept that the limits of intervention have been reached and that they must take responsibility for further care. Others continue to believe that cure is possible and that practitioners have failed. Personal psychological features have been proposed as explanations for these contrasting responses [19–21]. The principal finding of this review is that aspects of health care may also play a part. The extent to which patients perceived care to be good influenced both their degree of satisfaction and their willingness to accept professionals’ advice. The mixed picture was mirrored in the process and content of care. Whereas some patients welcomed questions on how psychosocial circumstances related to pain, others interpreted them as doubting a physical basis for their pain. It cannot be known from these studies whether it was the questions themselves or the manner of asking that made the difference. The findings on communication skills suggest the latter is important.

The importance of receiving a full assessment was shown by the contrast between satisfied patients who perceived having a good clinical assessment and dissatisfied patients who perceived an inadequate one. Satisfaction was reported with all types of practitioner, but the studies of patients of alternative practitioners were illuminating. These patients not only valued the examination, including touching the site of pain, but also appreciated receiving a diagnosis. In contrast, patients of conventional practitioners were frustrated by the ruling-out process of diagnosis, a frustration that could be compounded when no diagnosis is forthcoming, a common situation for 90% of LBP patients [22]. For some, a lack of a diagnosis led to a state in which they felt their suffering was denied. This state of delegitimation has been well described in many other chronic painful conditions [23] and where pathology is unproven [24].

Thus, having a diagnosis can be of supreme importance to patients who do not recover. Some form of explanation for pain may be better than none, although attempts to describe subgroups of patients who currently have no diagnosis [25,26] continue.

Practitioners can help such patients by giving them information about the condition, what they could do to help themselves and their prognosis. This finding accords with the folk model of illness in which patients seek answers to the questions what has happened, why, what will happen, and what should I do [27] and confirms the conclusions of the review by Verbeek et al. [1]. Our review additionally shows the importance of personalized care. Although all practitioners aspire to provide it, this review suggests that attention is not always paid to recognizing the specific circumstances of the individuals and involving them in decisions. Personalized care was closely linked with the interpersonal skills of the practitioner. Good communication skills, empathy, and a close relationship were greatly valued and reported to make patients feel involved in decisions and to improve adherence. This is concord with studies of physician consultation styles in other conditions, where it has been shown to improve patient outcomes [28,29]. One reason patients chose alternative practitioners was that they found them more empathic, a finding not confined to LBP and sciatica [30,31]. Taken together, it seems that patients who do not recover want not only an explanation for their pain and advice on what to do but also to be given these with empathy and consideration of their individual circumstances. These suggestions apply also to sciatica patients because the hypothesis that they have different experiences was not supported by the subgroup analysis.

**Implications for research**

Patient satisfaction was found for each discipline, but this could be because of selection bias because most studies drew samples from attendees to a department. Nevertheless, no discipline was without the confidence of some patients, including nonspecialist general practitioners, so that future research should be directed at clarifying the generic aspects of good care, namely, forming relationships, personalizing care, and information sharing. Research into the impact of the process and content of care in general, rather than the characteristics of patients, may offer new insights into the “revolving door” [32] of repeated consultations and investigations in the significant minority of LBP patients with chronic pain or disability [33].

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**References**


