



## The intangible costs of living with low back pain from a patient perspective: a scoping review

Nicola L. Saywell, Katherine Thomson, Thomas Adams & Julia Hill

**To cite this article:** Nicola L. Saywell, Katherine Thomson, Thomas Adams & Julia Hill (2025) The intangible costs of living with low back pain from a patient perspective: a scoping review, *Disability and Rehabilitation*, 47:14, 3548-3560, DOI: [10.1080/09638288.2024.2423776](https://doi.org/10.1080/09638288.2024.2423776)

**To link to this article:** <https://doi.org/10.1080/09638288.2024.2423776>



© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 08 Nov 2024.



[Submit your article to this journal](#)



Article views: 1103



[View related articles](#)



[View Crossmark data](#)

REVIEW



# The intangible costs of living with low back pain from a patient perspective: a scoping review

Nicola L. Saywell<sup>a,b</sup> , Katherine Thomson<sup>c</sup>, Thomas Adams<sup>a,d</sup>  and Julia Hill<sup>a,d</sup> 

<sup>a</sup>Physiotherapy Department, School of Clinical Sciences, Auckland University of Technology, Auckland, New Zealand; <sup>b</sup>Research Innovation Centre, Auckland University of Technology, Auckland, New Zealand; <sup>c</sup>Clinical Physiotherapist, Auckland, New Zealand; <sup>d</sup>Active Living and Rehabilitation: Aotearoa New Zealand, School of Clinical Sciences, Auckland University of Technology, Auckland, New Zealand

## ABSTRACT

**Purpose:** Health-related low back pain costs can be direct monetary, indirect monetary, or intangible, non-monetary. The purpose of this review was to identify the intangible, non-monetary costs of low back pain from the perspective of the individual.

**Materials and methods:** A scoping review of literature was undertaken. Four databases were searched up to 6<sup>th</sup> August 2024. Data were charted and coded using deductively derived categories in line with our purpose; additional categories were developed for text that did not fit these categories. Data were analysed using directed content analysis.

**Results:** Forty-six studies met the inclusion criteria. Six categories were derived from the data, which express the experience of the person with low back pain: *Perceptions of pain*, *Experience of healthcare*, *Becoming defined by low back pain*, *Life on hold*, *My social self*, and *Disrupted work life*. Each category explored an aspect of life affected by low back pain.

**Conclusion:** This review highlights that low back pain profoundly affects many areas, with implications for peoples' personal, social, and work lives. Our findings suggest that suffering can be reduced when healthcare practitioners show empathy and legitimise the lived experience of low back pain, acknowledging the restrictions it imposes on peoples' lives.

## ARTICLE HISTORY

Received 25 April 2024  
Revised 21 October 2024  
Accepted 24 October 2024

## KEYWORDS

Low back pain; patient experience; perceptions; intangible costs; scoping review

## > IMPLICATIONS FOR REHABILITATION

- Intangible costs of low back pain are less frequently reported than direct or indirect monetary costs, so may be under-recognised in service planning.
- There needs to be recognition of, and empathy for, the impact low back pain has on all areas of life.
- The search for a definitive diagnosis from a person with low back pain is frequently caused by a need for legitimisation.
- Healthcare practitioners need to identify people with low back pain at risk of a poor outcome early in treatment to minimise the risk of chronicity and the concomitant intangible costs.



## Introduction


Low back pain (LBP) is the leading musculoskeletal cause of increasing global health loss [1]. For most people, episodes of acute LBP will resolve quickly; however, recurrence is common, and for some the pain will become chronic with recurrent episodes [2,3]. Low back pain is associated with high healthcare utilisation and generates a significant cost burden for health and social care systems, and the individual [4,5]. These health-related costs are differentiated into three categories: direct monetary costs related to health resource use, indirect monetary costs related to productivity loss, and intangible, non-monetary costs related to pain and suffering [6].

Direct costs are typically reported and represent a health sector or societal perspective. They include medical costs, such as hospital services, treatment from healthcare practitioners (HCPs) and

medication costs [7]. Indirect costs are primarily described using quantitative outcomes such as days lost from work, the cost of return-to-work interventions, and the estimated cost of work productivity loss.

Direct and indirect costs focus on the financial burden of LBP from a societal perspective. Intangible costs are those that can be identified but cannot be quantified or easily estimated [8]. In health, intangible costs relate to an individual's lived experience and are less clear-cut than monetary costs [9]. Cost-of-illness studies frequently exclude the intangible costs of LBP; researchers cite difficulty assigning monetary measures to pain and long-term suffering [10] and insurance companies use conceptual (or abstract) costs to compensate an individual for an adverse life event [6]. Bunzli et al. [11] and Froud et al. [12] conducted systematic reviews with meta-syntheses of qualitative studies describing patients' experiences of LBP. The aim of this review is to provide a comprehensive

**CONTACT** Nicola L. Saywell  [nicola.saywell@aut.ac.nz](mailto:nicola.saywell@aut.ac.nz)  Physiotherapy Department, School of Clinical Sciences, Faculty of Health and Environmental Sciences, Auckland University of Technology, Akoranga Campus, 90 Akoranga Drive, Northcote, Auckland 0627, New Zealand

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2024.2423776>.

© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

update of published qualitative literature, adding quantitative data where appropriate, to explore the intangible costs of LBP.

## Methods

This scoping review followed the Arksey and O'Malley [13] five-stage framework and the extensions of this framework proposed by Levac et al. [14] and Peters et al. [15]. The methodological framework includes identifying the research question, identifying relevant literature, selecting literature, charting the data, collating, summarising, and reporting the results. The review was completed using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews checklist (PRISMA-ScR) [16].

This review aligns with post positivism described by Grant and Giddings [17], which recognises that our knowledge of reality is influenced by our values. NS and JH have extensive clinical experience as physiotherapists and regularly use qualitative and quantitative research methodologies. KT is a new graduate physiotherapist and has concerns about barriers to accessing and navigating health services in New Zealand informed by her roles as a rural community member, and healthcare consumer.

### Search strategy

We conducted a search of online databases CINAHL Complete, MEDLINE, and SPORTDiscus via EBSCO Health Databases, AMED Allied and Complementary Medicine via Ovid, Scopus, and Business Source Complete (BuSC) via EBSCO between January and 6<sup>th</sup> August 2024 using the key concepts of "Low back Pain," "Activity Limitation" and "Lived experience." The full search is shown in Appendix 1. All retrieved articles were exported to EndNote X9.3.3, and duplicates removed. KT independently screened the original titles, and abstracts in consultation with JH. The reference list of relevant studies was hand-searched and full texts were screened.

### Inclusion criteria

Eligibility was guided by population, concept, and context [18]. Studies were included if they were published in English from January 2000, were primary quantitative, qualitative, or mixed methods studies, represented acute or chronic non-specific LBP in a population over 16 years, and had defined intangible costs. In studies with quantitative designs, the perspective of LBP included the completion of a patient-reported outcome measure, e.g., the Roland-Morris Disability Questionnaire. Studies including a LBP population as part of the cohort were eligible if their data was reported separately. Literature reviews were excluded, as were studies including people with a neurological disorder, serious pathology, pregnancy, or recent surgical intervention.

### Charting the data

Data from the results section of included studies were tabulated. A data extraction tool was adapted from previous publications [18,19] and refined to align with the aim of the scoping review. A descriptive summary of source details and characteristics was tabulated.

### Mapping the data

Following data charting, the results were mapped using directed content analysis [20]. (1) We coded the results using deductively derived categories informed by previous reviews [11,12] and from

the clinical experience of the team. We ensured they related to the aim of the review, to identify the intangible costs of low back pain. Operational definitions were developed for each category to support the coding process. We then read full texts, highlighting and charting concepts of relevance. (2) All charted text was then coded using the predetermined categories. Text that could not be coded using the initial coding scheme was assigned a new code. The process of highlighting and charting text before coding was performed to increase trustworthiness by capturing all occurrences of a concept [20]. (3) The formation of subcategories was based on the codes and were formed inductively [21]. The Joanna Briggs Institute (JBI) scoping review guidance supports the use of content analysis of any study design [18,19,21]. Results from qualitative studies were coded first followed by the results from quantitative studies. The results from the quantitative studies were assigned to relevant categories, giving additional data to support the interpretation of qualitative content. KT reviewed and revised categories and subcategories, which were refined and then finalised in consultation with JH and NS.

## Results

The results of the search strategy and study selection process are presented using an adaptation of the PRISMA flow diagram (see Figure 1).

Forty-six studies met the inclusion criteria, see Table 1 for study characteristics. The following pairs of publications used the same participant sample, so data were only extracted from the more relevant of the two for each category, (1) [22] and [23]; (2) [24] and [25], (3) [26] and [27].

The content mapping formed six categories and 18 subcategories. Table 2 shows the categories, their definitions, and subcategories. The studies that referred to each category can be found in Appendix 2.

In the section below, each subcategory is explored and illustrated using participant quotes.

## Perceptions of pain

### Nature of pain

Participants in 27 studies discussed the nature of their pain, describing it as invisible and unpredictable. They struggled to have their pain recognised, creating a dissonance between their suffering and measurable pathology. For some the lack of understanding of their pain led to frustration:

They've seen me in pain for so long... I think "if they could know how much pain I feel' but they see me every day in the same situation, and they've become used to seeing me in pain." (39,p.1122, 52-year-old male on sick leave)

The unpredictable nature and course of LBP created challenges with day-to-day coping and planning for the future and shaped how some participants lived their lives. Participants sensed that they were not in control of their pain and that pain could increase or diminish regardless of their actions:

Even when I wasn't doing something I'd end up in agony and it would be very frustrating because it would be like "I don't understand, I haven't done anything." (36,p.589)

Another characteristic of unpredictable pain was the sometimes-unbearable severity; six studies included participants who disclosed suicidal thoughts induced by the experience of pain.

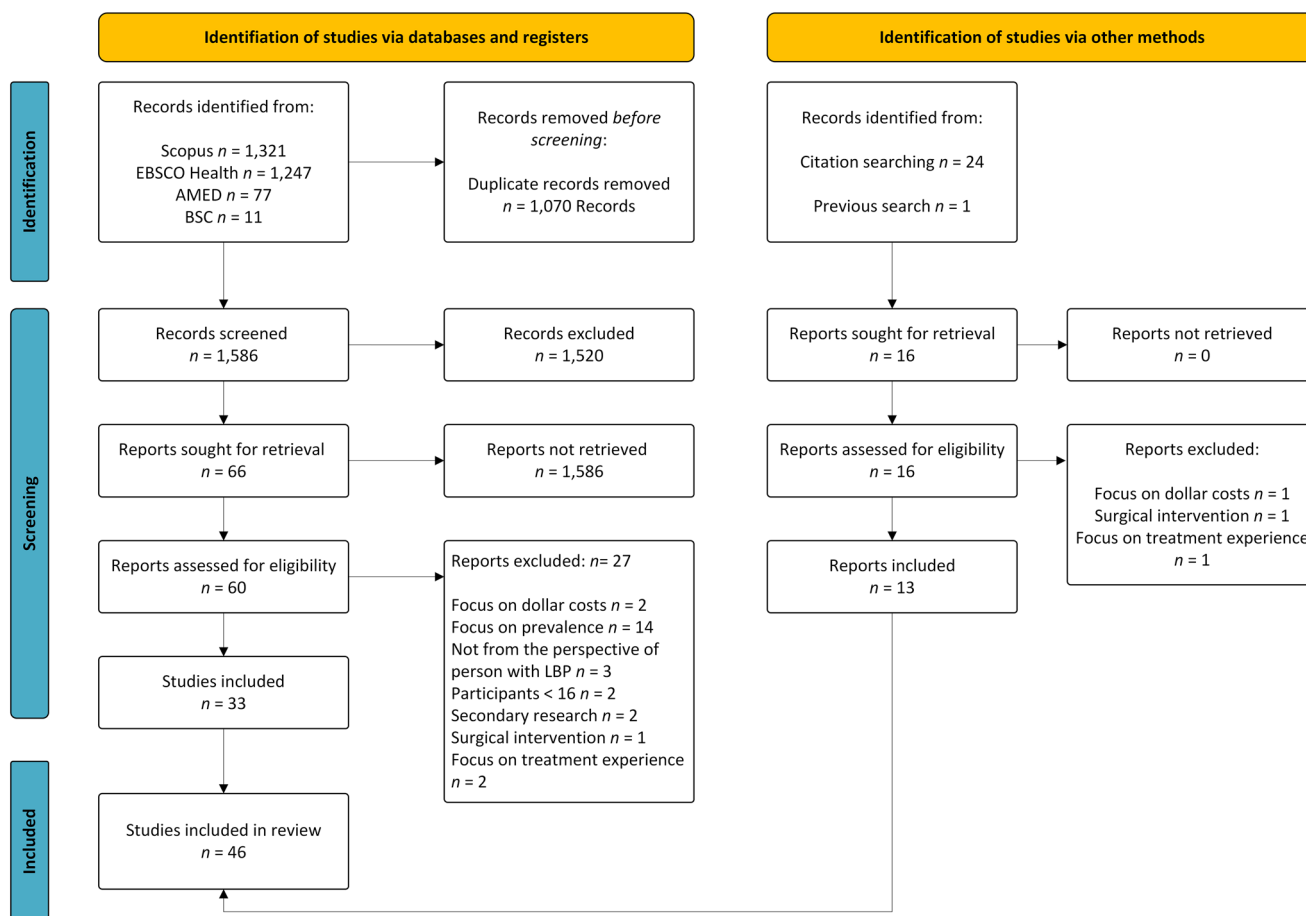


Figure 1. PRISMA flow chart.  
Note. Adapted from Page et al. [75]. CC BY 4.0.

### Pain under scrutiny

In 20 studies, participants discussed feeling stigmatised and having the legitimacy of their pain questioned; they shared concerns about how others perceived their pain. They feared social judgement, particularly around the use of opioid medication, time off work and the receipt of financial compensation or social benefits. The invisible nature of LBP led participants to encounter or anticipate suspicion from others that they were a malingerer or a hypochondriac:

...because it's not a visible thing, so many people use it as an excuse, because it's an easy excuse, that whenever a person says they've got a back problem it's "yeh, yeh, yeh." I remember at my sickness interview – you can see the disbelief in the manager's eyes, and I'm thinking OK well... (22,p.474, 37-year-old male)

Participants perceived that their pain experience was misunderstood, distrusted, and delegitimised by family members, friends, colleagues, and HCPs. To prove their pain, participants made efforts to justify their symptoms and to demonstrate consistent behaviours in social and private settings.

### Living with pain

Twenty-three studies included discussion of participants' attitudes towards managing life with LBP. Participants in five studies expressed resignation to living with pain and being without hope for symptom resolution. Other participants described a process

of becoming familiar with and accepting LBP as part of life, which led to better control of their pain. Rural workers in New Zealand [38] credited love of the land and way of life, for their ability to accept pain and continue farm work:

No, I like doing it, and yeah, like there's certain things that do cause you pain, but there's other things you just get great pleasure out of, you know... (38,p.402)

In ten studies, participants identified coping strategies such as remaining stoical, ignoring pain symptoms, and putting on a brave face. Five studies discussed the role of formal and informal support networks in managing LBP. Meeting others with unexplained pain helped to validate their pain experience. Eleven studies discussed self-management strategies including learned ways to ease pain:

Before I start cooking, I take rest for about an hour: to build up new energy and to relax...then I start and it works, I can enjoy cooking again! (61,p.148, 45-year-old male and former road builder)

In Makris et al. [52], 74% of participants used a combination of non-pharmacological strategies, including physical therapy and exercise, and 58% used hot and cold modalities to relieve pain symptoms. Herbal remedies were trusted by participants in a study conducted in Ghana [28]:

... I decided that, though with the efficacy of the herbal drugs, the local medicine, [...] I believe that they are natural herbs (28,p.7).

Table 1. Characteristics of included studies.

Reference	Country	Participants	Study design	Reported methodology	Research discipline	Primary data collection
[28]	Ghana	Adults with chronic LBP Age range 27-87 years n=30	Qualitative	Straussian grounded theory principles.	Physiotherapy, Chiropractic and sports rehabilitation	Individual semi-structured interviews
[29]	Australia	Unemployed participants with chronic LBP Age range 23-59 years n=11	Qualitative	Thematic analysis embedded in ethnographic study	Occupational therapy	Individual semi-structured interviews and participant observation
[30]	Morocco	Sexually active patients with cLBP M=43 years n=100	Cross-sectional	NR	Rheumatology	Face-to-face interview with a descriptive and explanatory structured questionnaire using specific and closed questions
[31]	France	Adults with chronic mechanical LBP Age range 25-81 years n=25	Monocentric qualitative study	Epistemological, thematic content analysis	Rheumatology	Semi-structured interviews conducted during four focus groups
[32]	UK	Working and non-working patients with non-specific LBP and their significant others Age range 25-68 years n=18	Qualitative	Common Sense model of self-regulation	Applied psychological research	Individual semi-structured interviews structured around the Illness Perception Questionnaire (chronic pain version)
[33]	Australia	People with LBP Age NR n=8 Clinicians and policymakers n=10 International multidisciplinary experts n=31	Qualitative	Grounded conceptualisation	Epidemiology	Two face-to-face concept mapping workshops. A third concept mapping exercise was conducted via email and a face-to-face workshop at the 10th International Forum for Primary Care Research on LBP (USA)
[34]	UK	Individuals with cLBP Age range 22-63 years n=7	Qualitative	Interpretive, Phenomenology	Physiotherapy	Semi-structured in-depth interviews, field notes
[22]	UK	Employed patients with LBP Age range 22-58 years n=25	Qualitative	Thematic analysis within an essentialist methodology	Rehabilitation and ageing, health sciences, clinical practice research	Individual semi-structured interviews
[23]	UK	Employed patients with LBP Age range 22-58 years n=25	Qualitative	Thematic analysis	Rehabilitation and ageing	Individual semi-structured interviews
[35]	UK	Patients with cLBP Age range 19-59 years n=6	Mixed methods	Thematic analysis	Psychological, sociological, and clinical backgrounds	RMDQ, interviews
[36]	New Zealand	Individuals with cLBP Age range 25-80 years n=64	Qualitative	Inductive thematic analysis	Nursing and physiotherapy	Face-to-face semi-structured interviews
[37]	UK	NHS staff with back pain Aged > 18 years n=30	Sequential explanatory mixed methods design	Interpretative description approach, inductive analytical method	Physiotherapy	Back-PAQ and semi-structured interviews
[38]	New Zealand	Rural workers with non-specific LBP Age range 27-61 years n=33	Mixed methods	Interpretative Phenomenological Analysis	Physiotherapy, occupational rehabilitation	BIPO, GSES and one-to-one in-depth interview
[39]	Spain	Adults with chronic non-malignant LBP Age range 40-88 years n=15	Qualitative	Constructionist perspective	Preventative medicine and public health	Individual semi-structured interviews
[40]	Netherlands	Patients with LBP and/or leg pain Age range 18-65 years n=1502	Cross-sectional	NR	Rehabilitation	Impact Stratification, PDI, EQ5D, WAS, iPCQ and health insurance claims
[41]	Canada	Adults with LBP Mean age 54 (SD ± 14.7) n=26	Mixed methods	Triangulation mixed method design	Physical and Occupational therapy	Individual semi-structured interviews and a card sorting activity.

(Continued)

Table 1. Continued.

Reference	Country	Participants	Study design	Reported methodology	Research discipline	Primary data collection
[24]	England	Patients with sciatica Age range 28-86 years <i>n</i> = 20	Qualitative study within UK-based SCOPIc RCT	Normalisation process theory, Allen's conceptualisation of care pathways as "boundary objects"	Medical sociology, social gerontology, academic general practice, clinical academic physiotherapy, and spinal expertise	Individual semi-structured interviews
[42]	Denmark	Manual workers with back pain <i>M</i> = 53.5 years <i>n</i> = 20	Explorative qualitative study	Open explorative approach, qualitative descriptive method	Rheumatology and spine diseases	Three focus group interviews, field notes
[43]	Norway	Back pain sufferers Age range 24-65 years <i>n</i> = 19	Qualitative	Content analysis	Social science	Discussion list data, open, in-depth interviews
[44]	UK	People with chronic back pain Age range 28-80 years <i>n</i> = 20	Qualitative	Thematic analysis	Health and social care	In-depth, unstructured interviews
[45]	UK	Patients with chronic benign back pain Age range 28-62 years <i>n</i> = 18	Qualitative	Interpretative Phenomenological Analysis	Health and Community Studies	In-depth, narrative interviews, field notes
[46]	Denmark	Turkish immigrants with chronic back pain Age range 38-60 years <i>n</i> = 11	Qualitative, descriptive, and cross-cultural design	Phenomenological approach	Rheumatology and clinical medicine	Interviews
[47]	Canada	NA	Patient-authored article	Reflective interpretive	Dentistry	Patient-authored
[48]	Australia	Patients with LBP Age range 31-59 years <i>n</i> = 36	Qualitative	Framework analysis approach	Physiotherapy	Focus group interviews
[49]	Australia	Adults with persistent LBP Aged $\geq$ 18 years Quantitative study <i>n</i> = 96 Qualitative study <i>n</i> = 10	Mixed-methods parallel convergent study design with quantitative and qualitative components	Interpretive (qualitative study)	Clinical background in SCI and LBP rehabilitation, research background in neurological rehabilitation and LBP	Online surveys and semi-structured qualitative interviews
[50]	UK	Patients with back pain (Group A) Age NR <i>n</i> = 200 Volunteers with a back problem (Group B) Age NR <i>n</i> = 8	Mixed methods	Combined methodological approach	Nursing	Group A: Satisfaction Questionnaire, Back Belief Questionnaire Group B: Focus group
[51]	Taiwan	Care workers with LBP Working age <i>n</i> = 677	Survey	Statistical analysis, multiple linear regression method	Public health	Wong-Baker FACES Pain Rating Scale, BPI-SF
[52]	USA	Community-living older adults with restricting back pain Median age 83 years <i>n</i> = 93	Qualitative	Inductive thematic analysis	Clinical sciences and rheumatology	Semi-structured interviews and focus groups
[53]	France	Patients with cLBP Aged > 18 years <i>n</i> = 101 Controls Aged > 18 years <i>n</i> = 97	Cross-sectional case-control study	Exploratory, epidemiological	Rheumatology	PSQI (French version), DPQ (French version), VAS
[54]	UK	Physiotherapy patients with LBP Age range 29-77 years <i>n</i> = 34	Qualitative	Explorative approach	Physiotherapy	Semi-structured interviews
[55]	New Zealand	Birth cohort Aged 26 years <i>n</i> = 980	Birth cohort study	NR	Occupational and environmental medicine	Interviewer-administered questionnaire, VAS, modified Oswestry questionnaire
[56]	Japan	Respondents reporting cLBP Aged $\geq$ 18 years <i>n</i> = 392	Large cross-sectional patient survey	Logistic regression	NR	Japan National Health and Wellness Survey (internet-based)

(Continued)

Table 1. Continued.

Reference	Country	Participants	Study design	Reported methodology	Research discipline	Primary data collection
[57]	UK	Patients with LBP Age range 19-76 <i>n</i> = 34	Exploratory study	Thematic analysis and comparative case analysis	Psychology	Semi-structured interviews
[58]	UK	Adults with LBP Age range 30-59 <i>n</i> = 6 General Practitioners <i>n</i> = 3 Health professionals <i>n</i> = 4	Qualitative	NR	Health services research	Three focus groups (structured format), detailed notes
[26]	UK	Patients with chronic benign LBP Age range 36-52 years <i>n</i> = 6	Qualitative	Interpretative Phenomenological Analysis	Psychology and pain	Semi-structured interviews
[59]	UK	Patients with cLBP Age range 17-65 years <i>n</i> = 50	Qualitative	Interviews were analysed qualitatively and quantitatively. Problem statements were analysed using manifest content	Psychology and psychotherapy	Interviews and use of a Problem Board
[60]	UK	Individuals returning to work after sickness absence due to LBP Working age <i>n</i> = 5	Qualitative	Interpretative Phenomenological Analysis	Physiotherapy, one non-clinician author	Semi-structured interviews
[61]	Netherlands	Clients with cLBP Age range 42-70 years <i>n</i> = 7	Explorative study	Narrative approach	Occupational therapy	Narrative semi-structured interviews
[25]	England	Patients with sciatica Age range 28-86 years <i>n</i> = 20	Qualitative study within UK-based SCOPIC RCT	Social-constructionist perspective, reflexive approach	Medical sociology, social gerontology, academic general practice, clinical academic physiotherapy, and spinal expertise	Individual semi-structured interviews
[27]	UK	Patients with chronic benign LBP Age range 36-52 years <i>n</i> = 6	Qualitative	Interpretative Phenomenological Analysis	Psychology and pain	Semi-structured interviews
[62]	USA	Patients with cLBP Aged ≥ 18 years Concept elicitation interviews <i>n</i> = 22 Cognitive interviews <i>n</i> = 21	Qualitative	Grounded theory approach	NR	Face-to-face focus groups and semi-structured individual interviews
[63]	USA	Workers with work-related back pain Aged > 20 years Wisconsin workers <i>n</i> = 198 Florida workers <i>n</i> = 216	Qualitative	Anthropological	Social and Behavioural Science, Environmental Health	Ethnographic interviews
[64]	UK	Patients with persistent, unexplained back pain Age range 29-67 years <i>n</i> = 20	Qualitative	Grounded theory	Physiotherapy, musculoskeletal science	Semi-structured interviews
[65]	USA	Workers with episodic or recurrent LBP Age range 23-66 years <i>n</i> = 38	Qualitative	Grounded theory approach	Public and environmental health, disability research	Focus groups
[66]	UK	Patients with chronic benign back pain Age range 28-79 years <i>n</i> = 20	Qualitative	Interpretative phenomenological approach	Medicine, health, and life sciences	Single narrative interviews, field notes
[67]	Switzerland	Survey respondents Aged > 20 years <i>n</i> = 2,507	Cost of illness study	Prevalence-based bottom-up approach	Health economics	Large survey using self-administered questionnaires

Back-PAQ, Back-Pain Attitudes Questionnaire; BIPQ, Brief Illness Perception Questionnaire; BPI-SF, Brief Pain Inventory-Short Form; cLBP, chronic low back pain; DPQ, Dallas Pain Questionnaire; EQ5D, EuroQol-5D questionnaire; GSES, General Self Efficacy Scale; iPCQ, Institute for Medical Technology Assessment Productivity Cost Questionnaire; LBP, low back pain; NA, not applicable; NHS, National Health Service; NR, not reported; PDI, Pain Disability Index; PSQI, Pittsburgh Sleep Quality Index; RMDQ, Roland-Morris Disability Questionnaire; SCI, spinal cord injury; SCOPIC RCT, Sciatica Outcomes in Primary Care randomised control trial; UK, United Kingdom; USA, United States of America; VAS, visual analogue scale; WAS, Work Ability Score.

**Table 2.** Name, definition and subcategories of each category.

Category name	Definition	Subcategories
Perceptions of pain	The intersection between how individuals perceive their pain and how they perceive others view their pain, and how these perceptions influence the ways they navigate everyday life.	Nature of pain Pain under scrutiny Living with pain
Experience of healthcare	Understanding motivations for engaging with health services and reactions to unfulfilled treatment expectations.	Search for causality Care-seeking Dissatisfaction with care
Becoming defined by low back pain	The psychological processes that indicate a transition from a healthy person with LBP to a person suffering from LBP.	Impact on mood and emotion Hypervigilance Altered sense of self
Life on hold	The consequences of LBP leading to activity limitations and participation restrictions that suspend the individual in a life constrained by pain.	Waiting for previous self Limitation in activity and restriction in participation Loss of independence
My social self	The influence of LBP on the restructuring of social environments and changing the dynamics of interpersonal relationships.	Social isolation and withdrawal Restructured social roles
Disrupted work life	A continuum of the effects of LBP on work capacity, and the influence of financial consequences of workplace change on their wellbeing.	Presenteeism Absenteeism Return to work Unemployment

## Experience of healthcare

### Search for causality

Eleven studies addressed the search for causality. Participants who sought health services were often motivated by a desire to attribute a cause to their LBP and have their pain validated professionally. A diagnosis was considered valuable in social and medical domains to legitimise pain and suffering, support applications for financial benefits and compensation, and document fitness to work or sickness certification. In their search for causality, participants hoped to encounter effective treatment and a linear recovery pathway; the lack of an adequate explanation, limited their ability to accept the pain:

So, if you have a cause, and something to read about it and understand, then it does make you cope better, definitely (58,p.338).

Inconsistent and variable pain caused tension between the expectation of a diagnosis-treatment-cure pathway and the non-linear reality of LBP. Uncertainty around causality triggered doubt as to whether the diagnosis was complete and contributed to negative beliefs about LBP and functional loss:

It's important to get a proper diagnosis otherwise you can do more harm than good (37,p.171, 42-year-old female nurse).

### Care-seeking

Participants in 18 studies discussed engagement with health services with over half related to medication maintenance. Some participants worried that a lack of treatment could encourage accusations of malingering, and others accessed health services as proof of suffering:

I suppose I use my doctor to tell me that it's ok that you're here. Because (...) what you find when you have a bad back is that people can't see that you're sick (43,p.2248, 31-year-old female).

A mixed-method study by Layzell [50] found 71% of participants believed there was a medical treatment to help with back pain. Montgomery et al. [56] reported that participants with chronic LBP reported approximately seven more HCP visits in a six-month period than those without back pain. Additionally, engaging with multiple HCPs and using many treatment modalities were common behaviours; 79% of respondents to an internet survey, reported consulting two or more HCPs for LBP treatment [68].

### Dissatisfaction with care

Participants in 16 studies discussed dissatisfaction with care. Participants expressed dissatisfaction with medical management, particularly when their treatment expectations were unfulfilled. Inaccessible and unaffordable health care were also identified as barriers to effective treatment; some participants struggled to afford prescription charges for pain relief [49]. A lack of information created uncertainty about the effectiveness and safety of medication and its potential impact on work. For some participants being prescribed sick leave and pain medication was perceived as an act of dismissal by doctors. A poor therapeutic alliance led to tension between evidence-based practice guidelines and person-centred care and left participants feeling frustrated with a health system they thought was failing them:

He [the doctor] doesn't really seem to understand your problem and you feel like bursting into tears, you have wasted such a lot of time and energy... You don't feel that you're being treated as a person at all (45,p.1458, 58-year-old female).

Participants felt they were not listened to, and that doctors condemned treatments they found beneficial, such as massage; participants were unconvinced that many of the HCPs they consulted understood their pain, or them as individuals. This created feelings of disempowerment and low self-efficacy, contributing to low agency among participants.

### Becoming defined by low back pain

#### Impact on mood and emotion

Participants in 34 studies discussed the significant impact of LBP on their emotional state, including mood changes and feeling irritated and frustrated with symptoms and physical limitations:

The physical pain itself is not nice but I can live with that. A bigger problem is the kind of pain caused by all the things that I cannot do or that are changing (61,p.147, 47-year-old female and former office worker).

Participants in four studies expressed sadness when pain excluded them from participating in enjoyed activities. The emotional impacts were quantified by Stokes et al. [62], with participants reporting feeling depressed (73%), lacking motivation (36%), angry (32%), sad (23%) and irritated and short-tempered (41%). For others, worrying about the future with LBP caused anxiety

and reduced their ability to plan or anticipate the fulfilment of goals.

Sometimes I fear that I'm not that old, that if I start having this now then I don't know how it would be in a few years' time [28].

### **Hypervigilance**

Participants in nine studies discussed hypervigilance. The negative perception that back pain will worsen encouraged hypervigilance and body consciousness about daily activities. Participants became fearful of re-injury or reoccurrences of pain. This increased the need to be cautious, mindful of the consequences of movement and nervous about physical challenges:

I want to aim higher, but I am also frightened of what that might cause (29,p.237, 59-year-old male and self-employed roof tiler).

Participants also developed a sense of a right or wrong way to do things. This often led to fear avoidance, pain catastrophising and poor expectations for recovery:

I wouldn't put myself into physically challenging situations where it may impact adversely on my spine (37,p.173, 57-year-old male).

### **Altered sense of self**

Participants in 16 studies discussed an altered sense of self. For some participants, the experience of pain separated them from their former selves and reframed their identity as a pain-affected person. Changes to cognitive function were mentioned in four studies, and 36% of participants in the study by Stokes and colleagues [62] reported difficulty concentrating or focusing due to chronic LBP.

The impact of LBP on social roles led to a questioning of self-worth, low self-efficacy and altered self-perception:

I'm just useless, I can't help out my mother, can't kick a ball in the garden with the kids. I'm just a burden (27,p.525, 51-year-old male).

In contrast, some participants viewed the changes positively. Approximately 10% of participants in a study by Reid [59] described the benefits of living with chronic LBP, including spending more time with the family, learning to cope with difficult challenges and changing life priorities. Others come to accept and embrace pain as being indistinguishable from who they are.

The pain has become a part of me...I almost love the pain (61,p.148, male, 48-year-old, 27 years of LBP, single, living with mother, former office work).

### **Life on hold**

#### **Waiting for previous self**

Participants in nine studies discussed waiting for previous self. Some participants were unwilling to accept LBP as long-term or to adapt their self-perception in response to pain. This could result in an experience of dualism, where the dysfunctional or painful part of the body is considered separate from the self:

Now it's me with this bit that doesn't fit, but its but it's not me, it's a part of my body which doesn't belong (26,p.219, 36-year-old male).

Expectations for a cure and a comparison with their former self had negative consequences for emotional well-being. Participants expressed hope of returning to a life before LBP, describing a fight to cling to important aspects of the self.

This included a wish to be normal and meet social and personal expectations. Others believed and hoped that fighting to suppress their pain would help to overcome the pain:

I know I probably shouldn't do the camping as much as I do because of the effects it has, but that is part of my life, and I don't want to stop doing that (64,p.1728, 35-year-old female).

#### **Limitation in activity and restriction in participation**

These were a frequently reported intangible cost; participants in 30 studies discussed physical limitations to activities requiring bending and lifting. A recent mixed methods study reported that half of the participants with LBP reported physical restrictions as the most important domain affecting health related quality of life [41]. This is supported by a study by Holloway et al. [44] who found reduced tolerance for prolonged periods of standing or sitting, limited participants' ability to commute to work and maintain certain postures, resulting in a need to rest throughout the day, making the participant housebound in some cases:

Pain has become a severe obstacle to any type of performance (44,p.380, male media studies lecturer).

For some, continued physical limitations developed into permanent disability with associated general physical impacts such as fatigue, reduced physical fitness, and increased risk of falls. Interference from LBP when performing everyday activities caused tension between desire and ability, and participants had to navigate feeling unable to perform sports or hobbies. Feeling forced to modify or relinquish activities was experienced as a loss central to their sense of self, and restored participation became synonymous with recovery:

If I could do all the things I value... running around the backyard with my kids...I would say I was fully recovered (48,p.129, 34-year-old male with recurrent LBP).

#### **Loss of independence**

Participants in 18 studies reported a loss of independence. The impact of LBP on domestic activities and self-care had a negative effect on independence. A study by Stokes et al. [62] revealed that chronic LBP affected the ability of individuals to perform domestic activities and self-care, which in turn reduced their independence. The participants reported that indoor (82%) and outdoor (55%) household activities were affected by LBP, along with self-care activities such as dressing (50%), bathing (27%), and grooming (18%). Participants described an improved capacity for housework and self-care as important components of recovery. They talked about being able to complete domestic activities in response to the proposed "miracle" of having no back pain. In most studies, dependence on others led participants to feel inadequate, helpless, and burdensome:

I always feel conscious that I'm overloading other people, you know, just like making a cup of tea, I'll say, "Are you alright, be careful," I say, "Can I help?" and I know I can't help at all, I can't (32,p.5, female participant in non-working sample).

However, for some participants, the relationship with a supportive spouse was positive, as they actively defended the person with LBP against any criticism.

I think she herself manages remarkably. I think she does what she can, and I think she's managed it really well (32,p.7, David, significant other of working participant with LBP)

## My social self

### Social isolation and withdrawal

Participants in 21 studies reported social isolation and withdrawal. Reduced social activities and social isolation were common. Some participants felt they were excluded from family activities, or self-isolated to control or cope with pain:

I've kinda given up on the social aspect of my life...I just go to work, that's it (65,p.2039, 61-year-old female hairdresser).

Others avoided crowded places for fear of being jostled, or felt too exhausted by pain to socialise. Participants also recognised changes in their social behaviour, such as concealing pain symptoms or feeling unable to sympathise with the pain experience of others:

Well, I'm not as open as I used to be. I'm not. I don't get out there and talk with everybody. I usually stay in my house; I don't go out that much (52,p.1229).

Participants identified the social consequences of pain as being responsible for strained relationships and difficulty with developing and maintaining a range of different relationships. Eight studies discussed intimacy between partners and marital and relationship breakdown. In four studies, participants referred to the impact of LBP on sex. A cross-sectional study found that 81% of patients experienced sexual difficulties related to chronic LBP [30]

It totally has stopped our sex life. It's hard to be intimate when you're feeling so yucky (62,p.301)

There was also a link between the financial consequences of chronic LBP and peoples' social life. The person with back pain frequently did not want to socialise if they were unable to contribute financially:

I can't afford any grog you see, you can't go over to someone else's place with no beer or food (29,p.236).

Equally, there was a sense that friends were less keen on involving those with LBP in activities if they weren't able to contribute in any way, which led to further reluctance to socialise, and more isolation.

They don't want me when I've got no money, don't have anything (29,p.237, 35 year old male)

### Restructured social roles

Eighteen studies explored the impact of LBP on social roles and responsibilities in participants' private life, which were often renegotiated or lost. Participants were concerned about their reduced capacity to fulfil parental roles and the stress on children to assume responsibility for domestic tasks. Some felt burdensome, and worried about the consequences:

They help me, everything that needs to be done now it's done by my sons-in-law, poor them, because I can't. But you often feel useless; it bothers you that someone is working hard on your behalf, but they are very nice (39,p.1124, retired 72-year-old male).

Participants also struggled with losing the "breadwinner" role and the economic consequences of being financially dependent on partners or social benefits. Stress on spouses due to additional roles, limitation in joint leisure activities and navigating their

partner's emotional state challenged spousal relationships. Over time, this resulted in participants feeling uncertain of their role within the relationship, and reduced sympathy from their partners.

## Disrupted work life

### Presenteeism

Challenges while at work were discussed in 23 studies. Low back pain flare-ups were described as disruptive and caused variability in the level of functioning at work. In an Australian survey 70% of respondents reported moderate to complete interference of back pain with work [68]. Occupational demands were difficult to maintain, and job strain forced people to ignore symptoms to avoid becoming a burden, leading to negative health consequences and distress:

I was "on my knees" still contributing when I wasn't fit for work (60,p.437, female participant).

Participants also expressed guilt about letting colleagues down and the perceived increase in job strain for managers and co-workers if they were unable to fulfil usual roles within the team:

If we're very busy and my back hurts, then I'll get a bad conscience if I'm not able to keep up [...] If there are major projects going on, then you'll drag yourself to work, even though it hurts (42,p.713, male gardener).

A survey of adults in Japan found that presenteeism among people with chronic LBP was approximately 1.5 times that of matched controls [56]. Some participants questioned their ability to continue their current jobs and either chose to change work duties or continued usual work, which increased the risk of back pain and created tension between physical health and economic health.

### Absenteeism

Absenteeism was addressed in 18 of the studies. When LBP restricted the ability to work, participants often grappled with decision-making around work absence. Pain intensity and worrying about time off work were influential in the decision to report sick. Participants felt torn between family pressure to take time off and financial stress caused by exhausting their leave entitlements:

At home the only income is my salary. I have to pay the mortgage, for my children's studies... well, our income is reduced as I'm on sick leave...so I cannot stop working and this situation has led me to a state of anxiety (39,p.1125, 52-year-old male on sick leave).

The workplace environment, job strain and effects on company bonus schemes also influenced absence. Some participants expressed concern about sickness records and disciplinary measures that could affect job security.

### Return to work

Participants in 12 studies discussed the topic of their return to work. Personal work ethic, perceived coercion from employers, and socio-economic factors caused participants to feel pressure to return to work. Consequently, some participants ignored the limitations from their LBP or used annual leave entitlements resulting in a loss of future flexibility:

...at the moment, like I say, I'm having every Wednesday off as annual leave until Christmas, but eventually, I've got no annual leave left, I've got to do full-time... I'm finding it very hard and I'm frightened that I'm going to do it because I have to, but then I end up getting worse and I just can't cope...I can't go off sick. I can't afford to go on half pay (35,p.1590, female participant).

Following periods of unemployment, some participants experienced challenges returning to paid work and concealed pain symptoms to obtain employment and maintain independence. Participants who returned to work too early reported significant limitation in their ability to do their job, following their return:

I probably suffered more as a result of being back (60,p.437, female participant).

Participants in three studies expressed a desire to return to work and recognised the positive psychological advantages of continued employment:

I've found the best treatment for the back pain is me getting on with work, getting on with life (32,p.6, male participant in working sample).

Managing LBP in the workplace was easier for participants who were flexible with work practices and confident about employee rights, employer responsibilities, and their worth as an employee. Employed participants discussed the advantages of good working relationships with line managers, team-based work structures, and a positive work safety climate in negotiating and maintaining formal and informal work concessions. Behavioural strategies at work included segmenting and pacing the workday, asking for help, and considering the order and variety of work tasks. Participants also discussed individual work modifications and initiatives such as wearing a lumbar corset and minimising postures and tasks that exacerbate pain. If these conditions weren't available participants frequently struggled to cope:

Some days, due to the pain, I just cannot get out of bed though I want to. Getting my employer to understand this appears to be an impossible task (31,p.439).

Job strain, inappropriate equipment, small workspaces, and absent, over-cautious, or unhelpful advice from occupational health services or line managers were common barriers to managing LBP in the workplace.

## Unemployment

Unemployment was covered in 18 studies and represented a range of perspectives. For some participants LBP presented an opportunity for a career or job change; others saw LBP as incompatible with employment and felt forced to resign:

I'd have felt inadequate, I'd have felt that they were saying "She's come back, and she can't even do this and can't even do that," so I didn't even go down there (32,p.6, female participant in non-working sample and former school cleaner).

A loss of occupational status because of early retirement, unemployment, and permanent work disability all significantly impacted economic well-being and made obtaining health insurance difficult.

## Discussion

This study explored the intangible, non-monetary costs for a person with LBP from their perspective. The main findings

demonstrate how LBP affects perceptions of pain, experiences with health services, self-identity, activities of daily living, and social and work capacities. They have extended the understanding of LBP's intangible costs. At an individual level the effects of low back pain are less clearly defined. There is some overlap between themes, for example when your life is on hold, this often has negative effects on both your social and work life.

In our review, participants searched for causality and expressed a desire for professional validation of their pain. The current review has parallels with literature from other chronic invisible conditions. Barker and Moseley [69] suggested that disbelief from family, friends, employers, colleagues, insurers, and HCPs of the reality of chronic pain from any condition, contributes to stigmatisation. This may explain the increase in depression, anxiety, low self-esteem, social isolation, and relationship breakdown in those with chronic pain. Sezier and colleagues [70] investigated the experiences of people with chronic dizziness and found that participants shared similar concerns such as a need for a diagnosis and the search for legitimacy. This is starkly demonstrated by Fruhstorfer and colleagues [71], who found participants with chronic invisible conditions such as chronic pain, fatigue, and depression sought medical assistance in dying (MAID) and reported that "the process of requesting MAID can acknowledge and legitimise the suffering participants described" (71,p.46)

Our review found the emotional impacts of LBP were mood changes, hypervigilance, and changes to sense of self. In a qualitative study by Ryan and Roberts [72], patients with radicular symptoms experienced low mood and anxiety, and felt like their life was on hold, experiencing suicidal thoughts due to the recurrent exacerbation of their pain. The study found that participants had varied approaches to accepting and living with pain, including putting on a brave face and remaining stoical. This aligns with our study, which highlights a range of approaches that participants used to adapt to living with LBP.

An additional finding of our review was that people with LBP had difficulty performing functional tasks and experienced limitations in their social and leisure activities. They restricted their physical activity and social lives due to pain and fear of further injury. However, a significant factor contributing to their activity limitation was their desire to avoid activities that might cause others to doubt the authenticity of their pain. This review highlighted that prolonged LBP has a progressive effect on reducing work capacity. In a system that requires the sufferer to prove their pain with a visible injury or observable and measurable disability, it is not surprising that people feel compelled to maintain the sick role [69].

Healthcare practitioners have a range of surgical, medical, and non-pharmacological strategies but may undervalue the powerful management strategy of empathy. A recent cohort study [73] investigated the impact of physician empathy on a range of outcomes in people with chronic LBP. The study clearly demonstrated that patients of physicians with high levels of empathy had lower levels of pain, better health-related quality of life and lower back-related disability. This was reported over a 12-month period and accounted for time and many relevant covariates. Empathy from a physician was found to be more effective than spinal surgery, opioid use and non-pharmacological treatment in reducing pain.

## Clinical and research implications

The findings of this review illustrate the impact on the individual with LBP. Healthcare practitioners need to legitimise the lived

experience and impact of LBP. In clinical practice, patients with LBP should be reassured that invisible pain does not suggest that their pain is imagined; they should experience empathy for the impact of LBP on their lives. This review emphasises the need for healthcare practitioners to identify those who may develop chronic LBP to reduce the suffering and other personal cost. Clinical practice guidelines for the management of LBP increasingly recommend using validated prognostic screening tools such as STarT Back [74] to identify those at risk of poor outcomes.

### Strengths and limitations

The guidance of the structured five-stage framework by Refs. [13–15], and the PRISMA-ScR [16] ensured the robustness of this review. Rigour in directed content analysis was guided by Hsieh and Shannon [20] and Joanna Briggs Institute (JBI) scoping review guidance [19]. A strength of directed content analysis is that it expands previous research; however, researchers may be inclined to identify evidence which supports rather than challenges their beliefs. Rigour was maintained through discussion, revision, and presentation of categories and subcategories to all authors, to ensure the original context was acknowledged. The transferability of some of these findings is dependent on context, for example a disrupted work life has fewer negative consequences for people with LBP in countries where prolonged paid sick leave is available. In addition, when participants were referring to the care they received from healthcare practitioners, many studies failed to note which discipline of healthcare practitioner was being referred to; we were specific only when it was clearly stated.

### Conclusion

This review highlights the impact of LBP on peoples' lives. The findings reveal the perceptions of pain, experiences with health services, interference in daily living, and psychological, social, and work implications of LBP. Acknowledging the distress of individuals and showing empathy for those whose lives have been affected by LBP can help validate their experience and reduce suffering.

### Disclosure statement

No potential conflict of interest was reported by the author(s).

### Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### ORCID

Nicola L. Saywell  <http://orcid.org/0000-0003-4676-3444>

Thomas Adams  <http://orcid.org/0000-0001-9359-6189>

Julia Hill  <http://orcid.org/0000-0002-6216-3329>

### References

- [1] GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020;396(10258):1204–1222. doi:10.1016/S0140-6736(20)30925-9.
- [2] Da Silva T, Mills K, Kongsted A, et al. What is the personal impact of recurrences of low back pain? Subanalysis of an inception cohort study. *J Orthop Sports Phys Ther*. 2020;50(6):294–300. doi:10.2519/jospt.2020.9345.
- [3] Perrot S, Doane MJ, Jaffe DH, et al. Burden of chronic low back pain: association with pain severity and prescription medication use in five large European countries. *Pain Pract*. 2022;22(3):359–371. doi:10.1111/papr.13093.
- [4] Chou L, Ranger TA, Peiris W, et al. Patients' perceived needs of health care providers for low back pain management: a systematic scoping review. *Spine J*. 2018;18(4):691–711. doi:10.1016/j.spinee.2018.01.006.
- [5] Lo J, Chan L, Flynn S. A systematic review of the incidence, prevalence, costs, and activity and work limitations of amputation, osteoarthritis, rheumatoid arthritis, back pain, multiple sclerosis, spinal cord injury, stroke, and traumatic brain injury in the United States: a 2019 update. *Arch Phys Med Rehabil*. 2021;102(1):115–131. doi:10.1016/j.apmr.2020.04.001.
- [6] Fautrel B, Boonen A, de Wit M, et al. Cost assessment of health interventions and diseases. *RMD Open*. 2020;6(3):1–6. doi:10.1136/rmdopen-2020-001287.
- [7] Tymecka-Woszczerowicz A, Wrona W, Kowalski PM, et al. Indirect costs of back pain - review. *Polish Ann Med*. 2015;22(2):143–148. doi:10.1016/j.poamed.2015.07.003.
- [8] Center for Disease Control. ; 2021, 20/10/2021). *Program cost analysis*. Office of Policy, Performance, and Evaluation. Retrieved 23/09/2024 from <https://www.cdc.gov/policy/polaris/economics/program-cost/index.html#:~:text=Intangible%20costs%20are%20non%20%E%AC%81nancial,than%20direct%20and%20productivity%20costs>.
- [9] Hunter DJ, Schofield D, Callander E. Science and society: the individual and socioeconomic impact of osteoarthritis. *Nat Rev Rheumatol*. 2014;10(7):437–441. doi:10.1038/nrrheum.2014.4.
- [10] Dagenais S, Caro J, Haldeman S. A systematic review of low back pain cost of illness studies in the United States and internationally. *Spine J*. 2008;8(1):8–20. doi:10.1016/j.spinee.2007.10.005.
- [11] Bunzli S, Watkins R, Smith A, et al. Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *Clin J Pain*. 2013;29(10):907–916. doi:10.1097/AJP.0b013e31827a6dd8.
- [12] Froud R, Patterson S, Eldridge S, et al. A systematic review and meta-synthesis of the impact of low back pain on people's lives. *BMC Musculoskelet Disord*. 2014;15(1):50. doi:10.1186/1471-2474-15-50.
- [13] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19–32. doi:10.1080/1364557032000119616.
- [14] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5(1):69–77. doi:10.1186/1748-5908-5-69.
- [15] Peters MDJ, Godfrey CM, Khalil H, et al. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc*. 2015;13(3):141–146. doi:10.1097/XEB.0000000000000050.
- [16] Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169(7):467–473. doi:10.7326/M18-0850.
- [17] Grant BM, Giddings LS. Making sense of methodologies: a paradigm framework for the novice researcher. *Contemp Nurse*. 2002;13(1):10–28. doi:10.5172/conu.13.1.10.
- [18] Peters MDJ, Marnie C, Tricco AC, et al. Updated methodological guidance for the conduct of scoping reviews. *JBI Evid Synth*. 2020;18(10):2119–2126. doi:10.11124/JBIES-20-00167.

- [19] Pollock D, Peters MDJ, Khalil H, et al. Recommendations for the extraction, analysis, and presentation of results in scoping reviews. *JBI Evid Synth.* 2023;21(3):520–532. doi:10.11124/JBIES-22-00123.
- [20] Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277–1288. doi:10.1177/1049732305276687.
- [21] Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* 2008;62(1):107–115. doi:10.1111/j.1365-2648.2007.04569.x.
- [22] Coole C, Drummond A, Watson PJ, et al. What concerns workers with low back pain? Findings of a qualitative study of patients referred for rehabilitation. *J Occup Rehabil.* 2010;20(4):472–480. doi:10.1007/s10926-010-9237-5.
- [23] Coole C, Watson PJ, Drummond A. Low back pain patients' experiences of work modifications; a qualitative study. *BMC Musculoskelet Disord.* 2010;11(1):277. doi:10.1186/1471-2474-11-277.
- [24] Foster NE, Konstantinou K, Lewis M, et al. Stratified versus usual care for the management of primary care patients with sciatica: the scopic RCT. *Health Technol Assess.* 2020;24(49):1–130. doi:10.3310/hta24490.
- [25] Saunders B, Bartlam B, Artus M, et al. Biographical suspension and liminality of Self in accounts of severe sciatica. *Soc Sci Med.* 2018;218:28–36. doi:10.1016/j.socscimed.2018.10.001.
- [26] Osborn M, Smith JA. Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis. *Scand J Caring Sci.* 2006;20(2):216–222. doi:10.1111/j.1471-6712.2006.00399.x.
- [27] Smith JA, Osborn M. Pain as an assault on the self: an interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychol Health.* 2007;22(5):517–534. doi:10.1080/14768320600941756.
- [28] Ampiah JA, Moffatt F, Diver C, et al. A qualitative investigation of the psychosocial impact of chronic low back pain in Ghana [Article]. *BMJ Open.* 2023;13(7):e073538. doi:10.1136/bmjopen-2023-073538.
- [29] Ashby S, Richards K, James C, et al. The effect of fear of movement on the lives of people with chronic low back pain. *Int J Ther Rehabil.* 2010;17(5):232–243. including commentary by. doi:10.12968/ijtr.2010.17.5.47842.
- [30] Bahouq H, Fadoua A, Hanan R, et al. Profile of sexuality in Moroccan chronic low back pain patients. *BMC Musculoskelet Disord.* 2013;14(1):63. doi:10.1186/1471-2474-14-63.
- [31] Bailly F, Foltz V, Rozenberg S, et al. The impact of chronic low back pain is partly related to loss of social role: a qualitative study. *Joint Bone Spine.* 2015;82(6):437–441. doi:10.1016/j.jbspin.2015.02.019.
- [32] Brooks J, McCluskey S, King N, et al. Illness perceptions in the context of differing work participation outcomes: exploring the influence of significant others in persistent back pain. *BMC Musculoskelet Disord.* 2013;14(1):48. doi:10.1186/1471-2474-14-48.
- [33] Buchbinder R, Batterham R, Elsworth G, et al. A validity-driven approach to the understanding of the personal and societal burden of low back pain: development of a conceptual and measurement model. *Arthritis Res Ther.* 2011;13(5): R152. doi:10.1186/ar3468.
- [34] Cook FM, Hassenkamp AM. Active rehabilitation for chronic low back pain: the patient's perspective. *Physiotherapy.* 2000;86(2):61–68. doi:10.1016/S0031-9406(05)61207-2.
- [35] Corbett M, Foster NE, Ong BN. Living with low back pain: Stories of hope and despair. *Soc Sci Med.* 2007;65(8):1584–1594. doi:10.1016/j.socscimed.2007.06.008.
- [36] Crowe M, Whitehead L, Gagan MJ, et al. Listening to the body and talking to myself - the impact of chronic lower back pain: a qualitative study. *Int J Nurs Stud.* 2010;47(5):586–592. doi:10.1016/j.ijnurstu.2009.09.012.
- [37] Davis J, Newton C, Singh G, et al. 'Keep moving, but carefully': back pain beliefs among NHS staff. *Eur J Physiother.* 2023;25(3):168–176. doi:10.1080/21679169.2022.2047781.
- [38] Dean S, Hudson S, Hay-Smith E, et al. Rural workers' experience of low back pain: exploring why they continue to work. *J Occup Rehabil.* 2011;21(3):395–409. doi:10.1007/s10926-010-9275-z.
- [39] De Sola H, Maquibar A, Failde I, et al. Living with opioids: a qualitative study with patients with chronic low back pain. *Health Expect.* 2020;23(5):1118–1128. doi:10.1111/hex.13089.
- [40] Dutmer AL, Schiphorst Preuper HR, Soer R, et al. Personal and societal impact of low back pain: the Groningen spine cohort. *Spine (Phila Pa 1976).* 2019;44(24):E1443–E1451. doi:10.1097/BRS.0000000000003174.
- [41] Eilayyan O, Gogovor A, Zidarov D, et al. Identifying domains of health-related quality of life: the perspective of individuals with low back pain [Article]. *J Patient Rep Outcomes.* 2023;7(1):79. doi:10.1186/s41687-023-00597-5.
- [42] Frederiksen P, Karsten MMV, Indahl A, et al. What challenges manual workers' ability to cope with back pain at work, and what influences their decision to call in sick? *J Occup Rehabil.* 2015;25(4):707–716. doi:10.1007/s10926-015-9578-1.
- [43] Glenton C. Chronic back pain sufferers - striving for the sick role. *Soc Sci Med.* 2003;57(11):2243–2252. doi:10.1016/S0277-9536(03)00130-8.
- [44] Holloway I, Sofaer B, Walker J. The transition from well person to "pain afflicted" patient: the career of people with chronic back pain. *Illness Crisis Loss* 2000;8(4):373–387. doi:10.1177/10541373000800403.
- [45] Holloway I, Sofaer-Bennett B, Walker J. The stigmatisation of people with chronic back pain. *Disabil Rehabil.* 2007;29(18):1456–1464. doi:10.1080/09638280601107260.
- [46] Honoré Grauslund AM, Solmunde Michelsen J, Esbensen BA. Everyday life with chronic back pain: a qualitative study among Turkish immigrants in Denmark. *Disabil Rehabil.* 2021;43(8):1162–1170. doi:10.1080/09638288.2019.1661034.
- [47] Hovey RB. Cathartic narratives for chaotic thinking. *CMAJ.* 2016;188(17-18):E543–E544. doi:10.1503/cmaj.160831.
- [48] Hush JM, Refshauge K, Sullivan G, et al. Recovery: what does this mean to patients with low back pain? *Arthritis Rheum.* 2009;61(1):124–131. doi:10.1002/art.24162.
- [49] Karran EL, Fryer CE, Middleton JW, et al. Exploring the social determinants of health outcomes for adults with low back pain or spinal cord injury and persistent pain: a mixed methods study. *J Pain.* 2022;23(9):1461–1479. doi:10.1016/j.jpain.2022.04.001.
- [50] Layzell M. Back pain management: a patient satisfaction study of services. *Br J Nurs.* 2001;10(12):800–807. doi:10.12968/bjon.2001.10.12.12337.
- [51] Lin JD, Lin LP, Su SF, et al. The interference of low back pain on everyday functions of life in care workers for persons with intellectual, autistic, and associated multiple disabilities: the Brief Pain Inventory short form (BPI-SF) survey. *Res Autism Spectr Disord.* 2014;8(6):692–700. doi:10.1016/j.rasd.2014.03.011.
- [52] Makris UE, Higashi RT, Marks EG, et al. Physical, emotional, and social impacts of restricting back pain in older adults: a qualitative study. *Pain Med.* 2017;18(7):1225–1235. doi:10.1093/pm/pnw196.
- [53] Marty M, Rozenberg S, Duplan B, et al. Quality of sleep in patients with chronic low back pain: a case-control study. *Eur Spine J.* 2008;17(6):839–844. doi:10.1007/s00586-008-0660-7.

- [54] May S. Patients' attitudes and beliefs about back pain and its management after physiotherapy for low back pain. *Physiother Res Int*. 2007;12(3):126–135. doi:10.1002/pri.367.
- [55] McBride D, Begg D, Herbison P, et al. Low back pain in young New Zealanders. *N Z Med J*. 2004;117(1203):U1099. <https://pubmed.ncbi.nlm.nih.gov/15477923>
- [56] Montgomery W, Sato M, Nagasaka Y, et al. The economic and humanistic costs of chronic lower back pain in Japan. *Clinicoecon Outcomes Res*. 2017;9:361–371. doi:10.2147/CEOR.S134130.
- [57] Nichols VP, Griffiths FE, McCarthy CJ, et al. Exploring the use of the 'Adapted Miracle Question' in the assessment of low back pain. *Physiotherapy*. 2011;97(3):203–208. doi:10.1016/j.physio.2010.11.003.
- [58] Ong BN, Hooper H. Involving users in low back pain research. *Health Expect*. 2003;6(4):332–341. doi:10.1046/j.1369-7625.2003.00230.x.
- [59] Reid M. An assessment of health needs of chronic low back pain patients from general practice. *J Health Psychol*. 2004;9(3):451–462. doi:10.1177/1359105304042353.
- [60] Ryan C, Lauchlan D, Rooney L, et al. Returning to work after long term sickness absence due to low back pain - the struggle within: a qualitative study of the patient's experience. *Work*. 2014;49(3):433–444. doi:10.3233/wor-131646.
- [61] Satink T, Winding K, Jonsson H. Daily occupations with or without pain: dilemmas in occupational performance. *OTJR Occup Participat Health*. 2004;24(4):144–150. doi:10.1177/153944920402400404.
- [62] Stokes J, Evans CJ, Pompilus F, et al. Development of a questionnaire to assess the impact of chronic low back pain for use in regulated clinical trials. *Patient*. 2013;6(4):291–305. doi:10.1007/s40271-013-0026-z.
- [63] Strunin L, Boden LI. Family consequences of chronic back pain. *Soc Sci Med*. 2004;58(7):1385–1393. doi:10.1016/S0277-9536(03)00333-2.
- [64] Toye F, Barker K. Could I be imagining this? - The dialectic struggles of people with persistent unexplained back pain. *Disabil Rehabil*. 2010;32(21):1722–1732. doi:10.3109/09638281003657857.
- [65] Tveito TH, Shaw WS, Huang YH, et al. Managing pain in the workplace: a focus group study of challenges, strategies and what matters most to workers with low back pain. *Disabil Rehabil*. 2010;32(24):2035–2045. doi:10.3109/09638281003797398.
- [66] Walker J, Sofaer B, Holloway I. The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. *Eur J Pain*. 2006;10(3):199–207. doi:10.1016/j.ejpain.2005.03.007.
- [67] Wieser S, Horisberger B, Schmidhauser S, et al. Cost of low back pain in Switzerland in 2005. *Eur J Health Econ*. 2011;12(5):455–467. doi:10.1007/s10198-010-0258-y.
- [68] Ahern M, Dean CM, Dear BF, et al. The experiences and needs of people seeking primary care for low-back pain in Australia. *Pain Rep*. 2019;4(4):e756. doi:10.1097/PR9.0000000000000756.
- [69] Barker S, Moseley GL. The difficult problem: chronic pain and the politics of care. *AQ Austr Q*. 2016;87(3):8–17. <https://www.jstor.org/stable/24877696>
- [70] Sezier AEI, Saywell N, Terry G, et al. Working-age adults' perspectives on living with persistent postural-perceptual dizziness: a qualitative exploratory study. *BMJ Open*. 2019;9(4):e024326. doi:10.1136/bmjopen-2018-024326.
- [71] Fruhstorfer C, Kelly M, Spiegel L, et al. Patient experiences with requests for medical assistance in dying. *Can Fam Phys*. 2024;70(1):41–47. doi:10.46747/cfp.700141.
- [72] Ryan C, Roberts L. 'Life on hold': the lived experience of radicular symptoms. A qualitative, interpretative inquiry. *Musculoskelet Sci Pract*. 2019;39:51–57. doi:10.1016/j.msksp.2018.11.005.
- [73] Licciardone JC, Tran Y, Ngo K, et al. Physician empathy and chronic pain outcomes. *JAMA Netw Open*. 2024;7(4):e246026. doi:10.1001/jamanetworkopen.2024.6026.
- [74] Oliveira CB, Maher CG, Pinto RZ, et al. Clinical practice guidelines for the management of non-specific low back pain in primary care: an updated overview. *Eur Spine J*. 2018;27(11):2791–2803. doi:10.1007/s00586-018-5673-2.
- [75] Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372(8286):n71. doi:10.1136/bmj.n71.