

Francine Toye, Kate Seers, Nick Allcock, Michelle Briggs, Eloise Carr, JoyAnn Andrews and Karen Barker

Patients' experiences of chronic non-malignant musculoskeletal pain:

a qualitative systematic review

Abstract

Background

Musculoskeletal (MSK) pain is one of the most predominant types of pain and accounts for a large portion of the primary care workload.

Aim

To systematically review and integrate the findings of qualitative research to increase understanding of patients' experiences of chronic non-malignant MSK pain.

Design and setting

Synthesis of qualitative research using meta-ethnography using six electronic databases up until February 2012 (Medline, Embase, Cinahl, Psychinfo, Amed and HMIC).

Method

Databases were searched from their inception until February 2012, supplemented by hand-searching contents lists of specific journals for 2001–2011 and citation tracking. Full published reports of qualitative studies exploring adults' own experience of chronic non-malignant MSK pain were eligible for inclusion.

Results

Out of 24 992 titles, 676 abstracts, and 321 full texts were screened, 77 papers reporting 60 individual studies were included. A new concept of pain as an adversarial struggle emerged. This adversarial struggle was to: 1) affirm self; 2) reconstruct self in time; 3) construct an explanation for suffering; 4) negotiate the healthcare system; and 5) prove legitimacy. However, despite this struggle there is also a sense for some patients of 6) moving forward alongside pain.

Conclusions

This review provides a theoretical underpinning for improving patient experience and facilitating a therapeutic collaborative partnership. A conceptual model is presented, which offers opportunities for improvement by involving patients, showing them their pain is understood, and forming the basis to help patients move forward alongside their pain.

Keywords

chronic pain; meta-ethnography; patient experience; qualitative research; qualitative synthesis.

INTRODUCTION

Alleviation of pain is a key aim of healthcare,¹ yet pain can remain a puzzle² as it is not always related to a specific pathology.² Around 25% of adults suffer with moderate or severe pain,^{3–7} and for 6–14% of these the pain is severe and disabling.^{2,8} Musculoskeletal (MSK) pain is one of the most predominant types of pain and accounts for a large portion of the primary care workload.^{2,9} Chronic pain is one of the Royal College of General Practitioners' clinical priorities for 2011–2014. Although insights from several qualitative syntheses have contributed to a greater understanding of the processes of health care,^{10–12} in other areas the proliferation of qualitative studies mean that these studies are 'doomed never to be visited'.¹³ The aim of this review was to synthesise existing qualitative research to improve understanding and thus best practice for people with chronic non-malignant MSK pain. There are various methods for synthesising qualitative research.^{13–16} Studies range from those aiming at describing qualitative findings, to studies aiming at being more interpretive and generating theory. Meta-ethnography is an interpretive form of knowledge synthesis, proposed by Noblit and Hare,¹⁷ which aims to develop new conceptual understandings.

METHOD

Reports of qualitative studies were included that explored adults' own experience of chronic non-malignant MSK pain. Chronic was defined as ≥ 3 months. Exclusion criteria were cancer, neurological, phantom, facial, head, dental and/or mouth, abdominal and/or visceral, menstrual and/or gynaecological, pelvic, duration or site of pain not specified, other chronic pain conditions, auto-ethnography, and individual case studies. Six electronic bibliographic databases were searched from inception until February 2012: Medline, Embase, Cinahl, Psychinfo, Amed, HMIC. As meta-ethnography relies on identifying and defining concepts within each study, the search was limited to English language. A combination of free text terms and thesaurus or subject headings was used. Search terms were used specific to qualitative research available from the InterTASC Information Specialists' Sub-Group (ISSG) Search Filter Resource (www.york.ac.uk/inst/crd/intertasc/). These terms were combined with other relevant subject headings and thesaurus terms (for example, research, qualitative/; attitude to health/; interviews as topic/; focus groups/; nursing methodology research/; life experiences/; pain/; arthritis/; fibromyalgia/; osteoarthritis/; musculoskeletal diseases/). Details of search syntax are available on

F Toye, PhD, qualitative research lead;
JA Andrews, PhD, qualitative researcher;
K Barker, PhD, clinical director (musculoskeletal), Nuffield Orthopaedic Centre, Oxford University Hospitals NHS Trust, Oxford, UK. **K Seers**, DSc, professor and director, Royal College of Nursing Research Institute, School of Health and Social Studies, University of Warwick, Coventry, UK. **N Allcock**, PhD, clinical academic professor of nursing, School of Health and Life Sciences, Glasgow Caledonian University, Glasgow, UK. **M Briggs**, PhD, professor of nursing, Institute of Health and Wellbeing, Leeds Metropolitan University, Leeds, UK. **E Carr**, PhD, professor, Faculty of Nursing, University of

Calgary, Calgary, Alberta, Canada.

Address for correspondence

Francine Toye, Nuffield Orthopaedic Centre, Oxford University Hospitals NHS Trust, Windmill Road, Oxford OX3 8ER, UK.
Email: Francine.toye@ouh.nhs.uk

Submitted: 20 June 2013; **Editor's response:** 14 August 2013; **final acceptance:** 6 September 2013.

©British Journal of General Practice

This is the full-length article (published online 25 Nov 2013) of an abridged version published in print. Cite this article as: **Br J Gen Pract** 2013; DOI: 10.3399/bjgp13X675412

How this fits in

Chronic musculoskeletal (MSK) pain accounts for a large portion of the workload in primary care. There is a growing body of qualitative research exploring patients' experience of chronic MSK pain, but no study that brings together or synthesises this large body of knowledge to make it accessible for clinical practice. Chronic MSK pain is experienced as an adversarial struggle on multiple levels (self, time, relationships, health care). The model in the present study suggests possibilities for helping patients to move forward with chronic pain.

request from the authors. Contents list of particular journals agreed by the team were hand-searched for 2001–2011. The list of journals is also available on request. Reference lists were searched for further potential studies. Titles, abstracts, or full texts were screened to exclude articles that did not meet the inclusion criteria.

The use of quality criteria for qualitative research is mooted^{14,18–22} and it is known that quality appraisal does not produce consistent judgements.²¹ To be utilised within a meta-ethnography, studies must provide adequate description of their concepts.^{14,17} It was also agreed that papers should provide an adequate methodological report. Checklists were used to provide a focus for team discussion on quality. It was not intended to use these checklists to 'score' papers for the purposes of inclusion or exclusion. A full description of the teams' approach to appraisal for qualitative synthesis has been published elsewhere.²² Three appraisal tools were used: Critical Appraisal Skills Programme (CASP) for appraising qualitative research;²³ Qualitative Assessment and Review Instrument (JBI-QARI);²⁴ and finally papers were categorised as key papers (KP) ('conceptually rich and could potentially make an important contribution to the synthesis'), satisfactory papers (SAT), irrelevant papers, or fatally flawed (FF) papers.²¹ The concepts fatally FF, SAT, and KP have not been defined, but are global judgements made by a particular appraiser which comprise several unspecified factors. Two team members appraised all papers, and if they did not reach an agreement the paper was sent to two other team members for a decision.

The methods of meta-ethnography¹⁷ were used to synthesise the data.^{14,25,26} Central to meta-ethnography is identification of key ideas or 'concepts', and comparison

of these concepts across studies.¹⁷ A full copy of all papers was uploaded onto QSR International's NVivo 9 software to help organise the qualitative analysis. NVivo 9 allows for collection, organisation, and analysis of a large body of knowledge by 'coding' data under 'nodes'. It also helps to keep track of developing ideas and theories via 'memos'. Three members of the team read each paper to identify and describe the concepts in each paper. These independent descriptions were compared and combined descriptions of each concept were constructed. The aim was not to reach consensus but to develop ideas through discussion. These concepts formed the primary data for the meta-ethnography. If team members agreed that there was no clear concept articulated in the original study, then it was labelled 'untranslatable'. In short, if the original study was more descriptive with no clear ideas, there were no 'data' to analyse. Concepts were then collaboratively organised into categories with shared meaning through constant comparison,²⁷ and a conceptual model was developed.¹⁷

RESULTS

In total, 24 992 titles, 676 abstracts, and 321 full texts of potentially relevant studies were screened (Figure 1). Of the 321 potential studies, 228 were excluded that did not meet the study aims. Details of reasons for excluding studies are available from the authors. Two team members appraised 93 papers. The ranges of agreement for CASP and JBIQ rank were 52–75% and 29–82% respectively. The team members agreed that five studies were key,^{28–32} one team member graded a further five as key,^{33–37} and the other graded a further seven as key.^{38–44} Full details of the appraisal scoring are also available from the authors. The team members did not agree over 24 papers and sent these to two other team members for a decision. Sixteen studies were excluded after quality appraisal,^{44–59} hence 77 papers were included reporting 60 studies. These studies explored the experiences of 1168 adults ranging from 18 to 91 years of age. Forty-nine papers (37 studies) explored chronic MSK pain.^{29–37,39,40,43,48,60–95} Twenty-eight papers (23 studies) focused primarily on fibromyalgia (FM).^{28,38,41,42,96–119} Studies were included from a range of countries: Iceland (1); Northern Ireland (1); Switzerland (1); Finland (2); the Netherlands (2); New Zealand (2); Australia (3); Canada (4); Norway (8); the US (8); Sweden (19); and the UK (26). Appendix 1 describes the study characteristics.

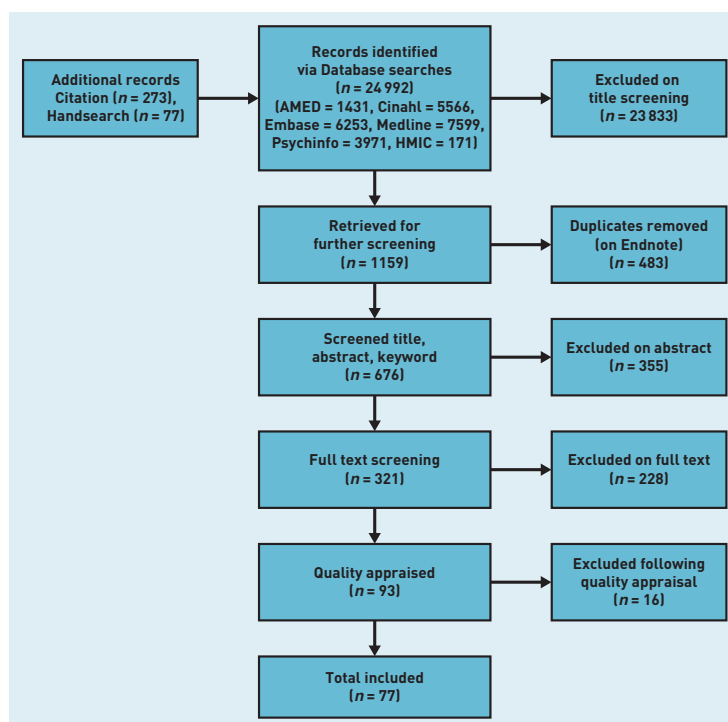


Figure 1. Number of studies identified, screened, excluded, and included.

Conceptual categories

The overriding theme emerging was an adversarial struggle, giving a sense of being guilty until proven innocent. Patients struggled to with the following.

1. Affirm self. This category incorporates a struggle to affirm my self: Firstly, my body has become alienated from me, and has become a malevolent it.^{33, 82} I no longer am a body but have a body.^{120,121} Secondly, although I struggle to prevent the erosion of my old 'real self' and not 'give in' to my painful body, I face the fact that I am irreparably altered.⁹⁴ Finally, loss of roles that made me what I am has undermined my self-worth, and I feel guilty because I cannot meet other people's expectations. Fear of overburdening others, and the desire to appear like my old self, encourage me to hide pain. However, this can be a double-edged sword because people do not necessarily believe what they cannot see.

2. Reconstruct self in time [construction of time altered – unpredictable now and future]. This category shows how the construct of self now and in the future is altered. The day-to-day unpredictability of my pain creates an endless timeless present where my life has become dominated by caution and spontaneity is lost. Plans, expectations, and dreams of the future are irreparably altered and life focuses inwards.

3. Construct an explanation for suffering.

This concept describes the struggle to explain pain that does not fit an objective biomedical category.^{122,124} Diagnosis remains highly valued and is integral to a sense of credibility.^{123–125} Disbelief by others threatens my personal integrity.¹¹⁷ The discrepancy between culturally accepted explanations and personal experience creates powerful emotions. I feel worthless, afraid, agitated, ashamed, and guilty. Overwhelming doubt permeates my experience at work, my social life, health care, and family.

4. Negotiate the healthcare system.

This category describes the struggle to negotiate the healthcare system. I feel 'like a shuttlecock' referred back and forth to various health professionals. It describes an ambivalent stance, although reticent to engage in a system that is not meeting my expectations, at the same time I am compelled or 'trapped in the system'. I continue in health care in hope of a future cure. I need to feel valued as a person within the system. Paradoxically, although I want my body problem to be diagnosed and treated, I also need to be treated as more than just a body. This is central to the therapeutic relationship, not an adjunct.

5. Prove legitimacy. This category describes an etiquette, or 'right way', of being in pain to appear credible. It does not imply that pain is not real. I struggle to find the right balance between hiding and showing pain. The pull to hide pain and to appear 'normal' is increased by my sense of shame at having medically unexplained pain.³¹ Paradoxically, hiding pain can further threaten my credibility. I strive to present a picture of myself as a 'good' person who is not to blame for my pain.

However despite this struggle, there was a sense of moving forward.

6. Moving forward alongside my pain. Despite the adversarial struggle, our model describes six ways of moving forward alongside pain:

- Listening to and integrating my painful body shows a developing relationship of trust and cooperation with the body. The alienated body becomes integrated through listening to, and respecting it. I am no longer at the mercy of the body but a co-expert.
- Redefining normal describes a way of

Table 1. Conceptual categories and source studies with example of narrative from primary studies

Conceptual category	Thematic sentence to describe conceptual category (primary studies supporting this category)	Example of narrative from primary study chosen to illustrate conceptual category
1. Struggling to affirm a sense of my self	My body is now against me [30, 32, 33, 40–42, 60, 61, 68, 72, 73, 83, 95–97, 99–104, 106, 107, 109, 112, 117, 118]	<i>I mean ... a normal person isn't aware of their legs because they just say 'right walk', you know their brain tells them to walk and they walk, whereas when you're in pain you're aware of them all the time [62].</i>
	The old me is my real self [28, 29, 31–33, 37–39, 41, 68, 69, 76, 78, 83, 93–97, 99, 103, 106, 107, 113, 117]	<i>It's like living with this [person] who follows you around all the time ... You're cursed with him and he gets in the way, he embarrasses me, he's unsociable and sometimes downright rude ... I know there is no 'person' ... but it's not me, that's not me [31].</i>
	I am becoming isolated from others [29, 31, 32, 34, 35, 38, 41, 42, 48, 61, 62, 65, 69, 73, 76, 78, 86, 91, 95, 96, 97–99, 101, 102, 104–107, 109, 112, 113, 117, 118]	<i>I have two small children, and I don't want them to say when they're older, we couldn't do this or that because my mum was sick. They're entitled to better than that [42].</i>
2. Altered construction of time	My days are unpredictable [28, 29, 32, 41, 42, 60, 66, 83, 89, 97–99, 101, 103, 105, 107, 110, 112]	<i>One day you feel like doing something. Then, all of a sudden, bang! The illness is so fickle, so capricious [106].</i>
	My future will not be what I thought [29, 32, 41, 69, 72, 78, 89, 92, 95, 96, 101, 108, 111, 118]	<i>I worked all my life and now I can't enjoy my life ... it's (the pain) taken over ... this is my future [78].</i>
3. Struggling to explain why I am suffering	It doesn't make sense there is no medical reason [28, 30, 32, 43, 69, 70, 77, 78, 86, 92, 96, 99, 101, 103, 108, 111, 113–115, 117, 119]	<i>When I had a broken arm, it was wonderful, they all rushed towards me to help me in the supermarket and I didn't feel a bit guilty because it was in a plaster and it was OK. But now you ... look perfectly alright and you do feel a bit of a fool [91].</i>
	No one believes me because I have nothing to show for it [29, 32, 35, 36, 42, 43, 64, 73, 78, 85, 91, 92, 94, 96, 99, 101, 103, 104, 111, 113, 115, 117]	<i>People think that you're swinging the lead, because it's not a visible thing, so many people use it as an excuse ... whenever a person says they've got a back problem it's 'yeah, yeah'. I remember at my sickness interview — you can see the disbelief in the manager's eyes [89].</i>
	There must be some other reason [28, 29, 32, 34, 39, 70, 73, 89, 93, 94, 103, 108, 113, 115]	<i>I feel that, all these rigid things that you try and put in place to protect yourself, quite often are actually a problem that you have in your mind rather than your back. So I think your mind and your back are quite closely linked [93].</i>
4. Struggling to negotiate the healthcare system	I can't see the point of going to the doctor again but I must [32, 35, 36, 38, 39, 40, 42, 43, 66, 69, 78, 79, 80, 85, 87, 92, 101, 105, 101, 105, 111, 119]	<i>I just get passed [around] ... I don't have any faith really, what I want to find out is what is causing this pain all through my body and I seem to meet a blank wall [43].</i>
	I need someone to listen to me and understand what pain has done to me [38–40, 42, 43, 66, 67, 69, 80, 85, 86, 87, 92, 99, 104, 111]	<i>You're feeling like you are unimportant and insignificant, feeling as though you're taking up their time, their time is more valuable than yours ... I think quite often they don't take into the equation that maybe you do understand ... and you have got a few brains [85].</i>
5. Struggling to prove that I am credible	Should I hide or show my pain? [28, 29, 31, 36, 39, 41, 42, 60, 62, 69, 70, 73, 89, 94, 96, 99, 101, 102, 105, 111, 113, 114, 116]	<i>Someone says to me: 'Well you look so good, it is impossible to see that you are suffering'. Perhaps the reason is that the more I suffered, when going somewhere, the more make-up I put on, so no-one would notice [69].</i>
	I need to show that I am not like other people with pain [32, 37, 38, 64, 86, 94, 114]	<i>I think there is an essential difference between my pain and theirs, but as long as I've a somewhat doubtful diagnosis, the only difference is that I complain more: I become the person who has pain because I need or want to have pain [37].</i>
6. Moving forward with chronic pain	I now cooperate with my body and work with it [28, 35, 41, 63, 67, 68, 71, 72, 76, 85, 99, 100, 101, 103, 104, 106, 109, 112, 115, 116, 118]	<i>Increase awareness and accept yourself as you are, just setting limits is something I worked with a lot. It's not the boundaries of the world around that matter, it's my body and the signals from it that have to give me advice [100].</i>
	I am still me and can enjoy my life [28, 35, 42, 61, 70, 71, 68, 69, 96, 99, 104, 107]	<i>When I finally did accept the fact that, okay, I wasn't going to be able to work and that I was going to have to do things differently ... I shifted my energies ... to the stuff that gives me pleasure [96].</i>
	There are other people like me that believe and value my experience [35, 67, 70, 80, 100, 103, 104, 114]	<i>You know, it is so hard to have this illness ... but it kind of grew smaller when I noticed that others have it too and that I may talk about it ... earlier when I had severe pains I just kind of shrank in to myself ... you were finally allowed to talk about it aloud [114].</i>

... continued

Table 1 continued. Conceptual categories and source studies with example of narrative from primary studies

Conceptual category	Thematic sentence to describe conceptual category (primary studies supporting this category)	Example of narrative from primary study chosen to illustrate conceptual category
6. Moving forward with chronic pain (continued)	I don't have to hide my pain and can let people know my limitations (35, 69, 100, 104, 112)	<i>Before when people asked how I felt, how it was, then I said okay, but now I dare to say more, straight out (100).</i>
	I realise that I have changed but don't need to continue searching for a medical answer (39, 41, 62, 75, 96, 99, 111, 115)	<i>I came home with a diagnosis and [my brothers] said, 'there is no cure, deal with it.' They say, 'you either live with it or you sit at home and mope about it. There is no cure, get on with your life.' I'm like, 'okay, guess I'll move on then (96).</i>
	I am confident to give things a go and make changes (67, 69, 75, 82, 85, 87, 96, 100, 104, 107, 113, 114, 117, 119)	<i>You just keep experimenting. That's all you do. You know, you hear of this, you try that, this works, that doesn't work. This person suggests this, someone else suggests something else (87).</i>

moving forward that no longer focuses on losses but on reconstructing an acceptable new self. It describes an acceptance of change and a sense of repairing existence; I have changed but I am still me and can enjoy life. This can be felt alongside grief for the old 'real self'. This concept supports studies showing that ability to redefine self, or psychological flexibility, might help people move forward with pain and reduce its impact.^{126,127}

- c) Being part of a community of others describes a sense of sharing, being valued and becoming credible. However, despite the benefits of being part of group of others with pain, there is a sense of ambivalence; although I am like the others,^{28,94,96,113,114} at the same time I am not like them and need to be valued as an individual.
- d) Telling others about my pain describes the release that comes with no longer having to hide pain from others, and the benefits of letting others know about my limitations. I am learning to limit demands from others and manage my resources. There is a sense that I no longer need to gain the approval of others.
- e) Realising that there is no cure for my pain describes the liberation from the ceaseless search for a cure which has hitherto limited possibilities for moving forward. There is a sense that recovery is about becoming someone rather than being what you once were.
- f) Becoming an expert describes becoming less reliant on a healthcare professional to know and meet my needs. I am coming to know my own body, and gain the confidence to experiment and make my own choices.

Table 1 describes these conceptual categories and source studies with a narrative exemplar of each category. Figure 2 shows the conceptual model drawn from conceptual categories 1–5. Figure 3 shows the conceptual model drawn from conceptual category 6 'moving forward alongside pain'.

DISCUSSION

Summary

This research presents a significant advance over previous studies in that it provides a unique and extensive conceptual synthesis of qualitative research exploring chronic MSK pain using meta-ethnography. The present model presents a line of argument that highlights the adversarial experience of people with chronic MSK pain, but also offers an understanding of how some aspects can be surmounted. The innovation is to show that struggle pervades multiple levels of the person's experience, sense of body and self, biographical trajectory, reciprocal relationships, and experience of healthcare services. The struggle to keep hold of a sense of self while feeling misunderstood and not believed was described. Despite this adversarial struggle, the present model offers an understanding of how a person with chronic MSK pain can move forward alongside their pain. This adversarial experience is central to the present model, and more research exploring similarities and differences between the experience of MSK and other types of chronic pain (such as cancer pain, headache, or visceral pain) would help to understand the experience of chronic pain.

Strengths and limitations

The findings of qualitative research are an interpretation of data. This centrality of

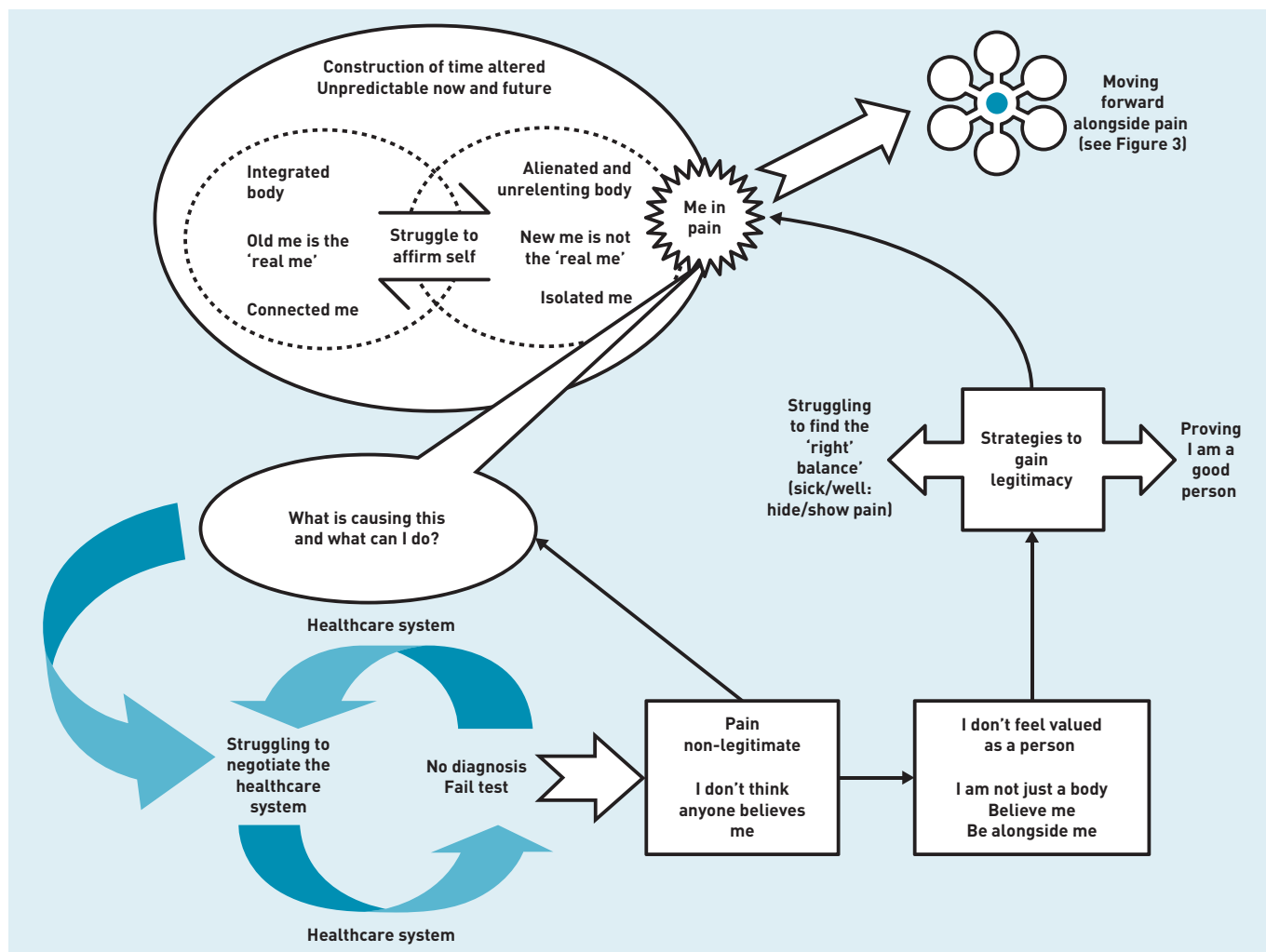


Figure 2. Conceptual model: a constant adversarial struggle.

interpretation is the strength of qualitative research that aims at challenging and developing ideas. The present model is based on a rigorous collaborative process over 2 years. The delay between final search and publication is not a limitation

Figure 3. Conceptual model: moving forward alongside pain.



of this study. As qualitative syntheses do not aim to summarise the entire body of available knowledge, meta-ethnographers do not advocate an exhaustive literature search.^{14,17} Some argue that including too many studies makes conceptual analysis 'unwieldy' or makes it difficult to maintain insight or 'sufficient familiarity'.¹⁴

There are very few meta-ethnographic syntheses that include such a large number of studies;^{14,26} some suggest that meta-ethnography is more suited for smaller syntheses.¹⁴ The present study specifically focused on the experience of MSK pain, which might mean that papers were excluded in which the study sample included chronic pain from other sites (such as visceral pain or headache). However, the present model may be transferable to other chronic pain conditions, and further research comparing this model with other experiences of pain would be useful.

Qualitative syntheses do not tend to use checklists and cut-off scores to determine study inclusion,¹⁴ and the present results

support the finding that there is limited agreement about what makes a good qualitative study.²¹ This raises issues about how to decide what to usefully include in qualitative systematic reviews.²² The authors remain convinced that checklists will continue to produce inconsistent judgements regarding quality. One of the issues is that although both methodological and conceptual rigour contribute to the quality of research, checklists tend to focus on methods rather than conceptual insight.²²

Comparisons with existing literature

This study's findings resonate with other qualitative syntheses. For example, in rheumatoid arthritis, the need to explain symptoms, the unpredictability of symptoms, the disruption to self, fear of the future, and the negative effects on social participation.¹⁴ In low back pain, the impact of pain on self and relationships with family and health professionals.¹²⁸ In fibromyalgia,¹²⁹ the unrelenting quality of pain, isolation, lost legitimacy, and the search for an explanation. However, these studies report very few successful strategies. The present innovation is to present a new and internationally relevant model that highlights the all-pervading adversarial experience of people with chronic MSK pain, and offers an understanding of how some aspects can be surmounted.

Implications for research and practice

The present model provides a theoretical underpinning for improving the patient experience and enhancing the relationship between patient and healthcare professional as a 'collaborative partnership' to empower self-management. Discussion of this model with patients has the potential to show them that their pain is understood and believed, forming a basis for considering ways of moving forward. People with chronic MSK pain do not feel believed and this has clear implications for clinical practice and education. The present study highlights the

need for educational strategies to improve patients' and clinicians' experience of care.¹³⁰ The model suggests that central to the relationship between patient and practitioner is the recognition of the patient as a person whose life has been deeply changed. Affirming a person's experience and allowing an empathetic interpretation of their story is not an adjunct, but integral to care. The model also suggests possibilities for helping patients to move forward. Importantly, the line of argument supports a model of health care where the healthcare professional sits alongside the person as a collaborative partner. This collaborative focus is recognised as important in commissioning appropriate health care; 'good commissioning places patients at the heart of the process'.¹³⁰ The present study thus illustrates the potential value of qualitative research in articulating the patient voice for both clinical practice and policy.

The model supports an embodied, non-dualistic approach that may be useful for other chronic conditions. It also suggests possibilities that might help patients to move forward alongside their pain, namely an integrated relationship with the painful body; redefining a positive sense of self now and in the future; communicating, rather than hiding, pain; knowing that I am not the only one with chronic pain; regaining a sense of reciprocity and social participation; recognising the limitations of the medical model; and being empowered to experiment and change the way I do things. Further research comparing the experience of chronic MSK pain with other chronic conditions might help to more fully understand and improve patients' experience of chronic illness. In addition to this, studies were not identified that specifically considered the impact of age or gender on the experience of pain. Finally, research to explore the impact of qualitative research on practitioners and policy makers would help to maximise its usefulness for improving health care.

Funding

This project was funded by the National Institute for Health Research Health Services and Delivery Research (NIHR HS&DR) Programme (09/2001/09). Visit the HS&DR website for more information. The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR programme, NIHR, NHS or the Department of Health.

Ethical approval

No ethics review was required for this study.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

We thank the authors of the primary qualitative studies included and the patients who told their stories. The full report of the study from which this paper is drawn is available online at <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-1/issue-12>

Discuss this article

Contribute and read comments about this article on the Discussion Forum: <http://www.rcgp.org.uk/bjgp-discuss>

REFERENCES

- Price C, Ellis B, Taylor A, Group motPSS. *Putting pain on the agenda: the report of the first English pain summit*. <http://www.painsummit.org.uk> [accessed 22 September 2013].
- Croft P, Peat G, van-der-Windt D. Primary care research and musculoskeletal medicine. *Prim Health Care Res Dev* 2010; **11**: 4–16.
- Breivika H, Collett B, Ventafridda V, et al. Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. *Eur J Pain* 2006; **10**(4): 287–333.
- Elliott AM, Smith BH, Penny KI, et al. The epidemiology of chronic pain in the community *Lancet* 1999; **354**: 1248–1252.
- König HH, Bernert S, Angermeyer MC, et al. Comparison of population health status in six European countries: results of a representative survey using the EQ-5D questionnaire. *Medical Care* 2009; **47**: 255–261.
- Croft P, Blyth FM, Windt Dvd, eds. *Chronic pain as a topic for epidemiology and public health*. In: *Chronic pain epidemiology from aetiology to public health*. Oxford: Oxford University Press, 2010: 1–8.
- Covinsky KE, Lindquist K, Dunlop DD, Yelin E. Pain, functional limitations, and aging. *J Am Geriatr Soc* 2009; **57**: 1556–1561.
- Smith B, Elliott A, Chambers W, et al. The impact of chronic pain in the community. *Fam Pract* 2001; **18**: 292–299.
- McBeth J, Jones K. Epidemiology of chronic musculoskeletal pain. *Best Pract Res Clin Rheumatol* 2007; **21**(3): 403–425.
- Britten N, Campbell R, Pope C, et al. Using meta ethnography to synthesise qualitative research: a worked example. *J Health Serv Res Policy* 2002; **7**(4): 209–215.
- Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experience of diabetes and diabetes care. *Soc Sci Med* 2003; **56**: 671–684.
- Malpass A, Shaw A, Sharp D, et al. 'Medication career' or 'Moral career'? The two sides of managing anti-depressants: A meta-ethnography of patients experience of antidepressants. *Soc Sci Med* 2009; **68**: 154–168.
- Sandelowski M, Barroso J. *Handbook for synthesising qualitative research*. New York, NY: Springer Publishing Company, 2007.
- Campbell R, Pound P, Morgan M, et al. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technol Assess* 2011; **15**(43): 1–164.
- Dixon-Woods M, Agarwal S, Jones D, et al. Synthesising qualitative and quantitative research evidence: a review of possible methods. *J Health Serv Res Policy* 2005; **10**(1): 45–53.
- Barnett-Page E, Thomas J. *Methods for synthesis of qualitative research: a critical review*. Economic and Social Research Council Research Methods. National Centre for Research Methods Working Paper Series [01/09]. Southampton: National Centre for Research Methods, 2009.
- Noblit G, Hare R. *Meta-ethnography: synthesising qualitative studies*. Thousand Oaks, CA: Sage Publications, 1988.
- Eakin J, Mykhalovskiy E. Reframing the evaluation of qualitative health: reflections on a review of appraisal guidelines in the health sciences. *J Eval Clin Pract* 2003; **9**(2): 187–194.
- Barbour R. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; **322**: 1115–1117.
- Centre for Reviews and Dissemination. *Systematic Reviews — CRD's guidance for undertaking reviews in healthcare*. York: York Publishing Services Limited, 2009.
- Dixon-Woods M, Sutton A, Shaw R, et al. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *J Health Serv Res Policy* 2007; **12**(1): 42–47.
- Toye F, Seers K, Allcock N, et al. 'Trying to pin down jelly' — exploring intuitive processes in quality assessment for meta-ethnography. *BMC Med Res Methodol* 2013; **13**: 46.
- CASP. Critical Appraisal Skills Programme: making sense of evidence about clinical effectiveness: 10 questions to help you make sense of qualitative research. http://www.casp-uk.net/wp-content/uploads/2011/11/CASP_Qualitative_Appraisal_Checklist_14oct10.pdf. 2010 [accessed 29 Oct 2013].
- The Joanna Briggs Institute. *The Joanna Briggs Institute Reviewers Manual*. <http://joannabriggs.org/assets/docs/sumari/ReviewersManual-2011.pdf> [accessed 4 Nov 2013].
- Hannes K, Macaitis K. A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qual Res* 2012; **12**(4): 402–442.
- Dixon-Woods M, Booth A, Sutton A. Synthesising qualitative research: a review of published reports. *Qual Res* 2007; **7**: 375–422.
- Charmaz K. *Constructing grounded theory*. Thousand Oaks, CA: Sage Publications, 2006.
- Mengshoel AM, Heggen K. Recovery from fibromyalgia — previous patients' own experiences. *Disabil Rehabil* 2004; **26**(1): 46–53.
- Osborn M, Smith J. The personal experience of chronic benign lower back pain: an interpretative phenomenological analysis. *Br J Health Psychol* 1998; **3**: 65–83.
- Rhodes LA, McPhillips-Tangum CA, Markham C, Klenk R. The power of the visible: the meaning of diagnostic tests in chronic back pain. *Soc Sci Med* 1999; **48**(9): 1189–1203.
- 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): 517–535.
- Snelgrove S, Lioffi C. An interpretative phenomenological analysis of living with chronic low back pain. *Br J Health Psychol* 2009; **14**(Pt 4): 735–749.
- 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**: 216–222.
- Sanders C, Donovan J, Dieppe P. The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Sociol Health Illness* 2002; **24**(2): 227–254.
- Werner A, Steihaug S, Malterud K. Encountering the continuing challenges for women with chronic pain: recovery through recognition. *Qual Health Res* 2003; **13**(4): 491–509.
- Werner A, Malterud K. It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Soc Sci Med* 2003; **57**(8): 1409–1419.
- Werner A, Isaksen LW, Materud K. I am not the kind of woman who complains of everything: illness stories on self and shame in women with chronic pain. *Soc Sci Med* 2004; **59**: 1035–1045.
- de Vries H, Brouwer S, Groothoff JW, et al. Staying at work with chronic nonspecific musculoskeletal pain: a qualitative study of workers' experiences. *BMC Musculoskelet Disord* 2011; **12**: 126.
- Harding G, Parsons S, Rahman A, Underwood M. 'It struck me that they didn't understand pain': the specialist pain clinic experience of patients with chronic musculoskeletal pain. *Arth Rheum* 2005; **53**(5): 691–696.
- Osborn M, Smith A. The fearfulness of chronic pain and the centrality of the therapeutic relationship in containing it: an interpretative phenomenological analysis. *Qual Res Psychol* 2008; **5**(4): 276–288.
- Paulson M, Danielson E, Soderberg S. Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qual Health Res* 2002; **12**(2): 238–249.
- Sturge-Jacobs M. The experience of living with fibromyalgia: confronting an invisible disability. *Res Theory Nurs Pract* 2002; **16**(1): 19–31.
- Walker J, Holloway I, Sofaer B. In the system: the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain* 1999; **80**(3): 621–628.
- Reid J, Ewan C, Lowy E. Pilgrimage of pain: the illness experiences of women with repetition strain injury and the search for credibility. *Soc Sci Med* 1991; **32**(5): 601–612.
- Busch H. Appraisal and coping processes among chronic low back pain patients. *Scand J Caring Sci* 2005; **19**(4): 396–402.
- Chew CA, May CR. The benefits of back pain. *Fam Pract* 1997; **14**(6): 461–465.
- Cudney SA, Butler MR, Weinert C, Sullivan T. Ten rural women living with fibromyalgia tell it like it is. *Holistic Nurs Pract* 2002; **16**(3): 35–45.
- De Souza LHL, Frank AO. Experiences of living with chronic back pain: the physical disabilities. *Disabil Rehabil* 2007; **29**(7): 587–596.
- Liedberg GM, Burckhardt CS, Henriksson CM. Young women with fibromyalgia in the United States and Sweden: Perceived difficulties during the first year after diagnosis. *Disabil Rehabil* 2006; **28**(19): 1177–1184.
- Morone NE, Lynch CS, Greco CM, et al. 'I felt like a new person' the effects of mindfulness meditation on older adults with chronic pain: qualitative narrative analysis of diary entries. *J Pain* 2008; **9**(9): 841–848.
- Raak R, Wahren LK. Health experiences and employment status in subjects

- with chronic back pain: a long-term perspective. *Pain Manage Nurs* 2006; **7**(2): 64–70.
52. Schaefer KM. Struggling to maintain balance: a study of women living with fibromyalgia. *J Adv Nurs* 1995; **21**(1): 95–102.
 53. Silva FC, Sampaio RF, Mancini MC, *et al*. A qualitative study of workers with chronic pain in Brazil and its social consequences. *Occup Ther Int* 2011; **18**(2): 85–95.
 54. Sokunbi O, Cross V, Watt P, Moore A. Experiences of individuals with chronic low back pain during and after their participation in a spinal stabilisation exercise programme — a pilot qualitative study. *Manual Ther* 2010; **15**(2): 179–185.
 55. Tavafian SS, Gregory D, Montazeri A. The experience of low back pain in Iranian women: a focus group study. *Health Care Women Int* 2008; **29**(4): 339–348.
 56. Wade BL, Shantall HM. The meaning of chronic pain: a phenomenological analysis. *S Afr J Physiother* 2003; **59**(1): 10–9.
 57. May CR, Rose MJ, Johnstone FC. Dealing with doubt. How patients account for non-specific chronic low back pain. *J Psychosomatic Res* 2000; **49**(4): 223–225.
 58. 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.
 59. Schaefer KM. Health patterns of women with fibromyalgia. *J Adv Nurs* 1997; **26**(3): 565–572.
 60. Hunhammar C, Nilsson-Wikmar L, Lofgren M. Striving to master variable pain: An interview study in primary care patients with non-specific long-term neck/shoulder pain. *J Rehabil Med* 2009; **41**(9): 768–74.
 61. Bair MJ, Matthias MS, Nyland KA, *et al*. Barriers and facilitators to chronic pain self-management: a qualitative study of primary care patients with comorbid musculoskeletal pain and depression. *Pain Med* 2009; **10**(7): 1280–1290.
 62. Campbell C, Cramb G. 'Nobody likes a back bore'—exploring lay perspectives of chronic pain: revealing the hidden voices of nonservice users. *Scand J Caring Sci* 2008; **22**(3): 383–390.
 63. Dragesund T, Råheim M. Norwegian psychomotor physiotherapy and patients with chronic pain: Patients' perspective on body awareness. *Physiother Theory Pract* 2008; **24**(4): 243–255.
 64. Johansson E, Hamberg K, Lindgren G, Westman G. 'I've been crying my way' — Qualitative analysis of a group of female patients' consultation experiences. *Fam Pract* 1996; **13**(6): 498–503.
 65. Johansson EE, Hamberg K, Lindgren G, Westman G. 'How could I even think of a job?' — Ambiguities in working life in a group of female patients with undefined musculoskeletal pain. *Scand J Primary Health Care* 1997; **15**(4): 169–174.
 66. Patel S, Greasley K, Watson PJ. Barriers to rehabilitation and return to work for unemployed chronic pain patients: a qualitative study. *Eur J Pain* 2007; **11**(8): 831–840.
 67. Steen E, Haugli L. From pain to self-awareness—a qualitative analysis of the significance of group participation for persons with chronic musculoskeletal pain. *Patient Educ Couns* 2001; **42**(1): 35–46.
 68. Lundberg M, Styf J, Bullington J. Experiences of moving with persistent pain—a qualitative study from a patient perspective. *Physiother Theory Pract* 2007; **23**(4): 199–209.
 69. Skuladottir H, Halldorsdottir S. The quest for well-being: self-identified needs of women in chronic pain. *Scand J Caring Sci* 2011; **25**(1): 81–91.
 70. Dickson GL, Kim JI. Reconstructing a meaning of pain: older Korean American women's experiences with the pain of osteoarthritis. *Qual Health Res* 2003; **13**(5): 675–688.
 71. Aegler B, Satink T. Performing occupations under pain: the experience of persons with chronic pain. *Scand J Occup Ther* 2009; **16**(1): 49–56.
 72. Afrell M, Biguet G, Rudebeck CE. Living with a body in pain — between acceptance and denial. *Scand J Caring Sci* 2007; **21**(3): 291–296.
 73. Johansson EE, Hamberg K, Westman G, Lindgren G. The meanings of pain: an exploration of women's descriptions of symptoms. *Soc Sci Med* 1999; **48**(12): 1791–1802.
 74. Strong J, Ashton R, Chant D, Cramond T. An investigation of the dimensions of chronic low back pain: the patients' perspectives. *Br J Occup Ther* 1994; **57**(6): 204–209.
 75. Strong J, Large RG. Coping with chronic low back pain: an idiographic exploration through focus groups. *Int J Psychiatry Med* 1995; **25**(4): 371–387.
 76. Satink T, Winding K, Jonsson H. Daily Occupations With or Without Pain: Dilemmas in Occupational Performance. *OTJR: Occup Participation Health* 2004; **24**(4): 144–150.
 77. Allegretti A, Borkan J, Reis S, Griffiths F. Paired interviews of shared experiences around chronic low back pain: classic mismatch between patients and their doctors. *Fam Pract* 2010; **27**(6): 676–683.
 78. Campbell C, Guy A. 'Why can't they do anything for a simple back problem?' A qualitative examination of expectations for low back pain treatment and outcome. *J Health Psychol* 2007; **12**(4): 641–652.
 79. Cook FM, Hassenkamp AM. Active rehabilitation for chronic low back pain: The patients' perspective. *Physiotherapy (London)* 2000; **86**(2): 61–68.
 80. Cooper K, Smith BH, Hancock E. Patients' perceptions of self-management of chronic low back pain: evidence for enhancing patient education and support. *Physiotherapy* 2009; **95**(1): 43–50.
 81. Cooper K, Smith BH, Hancock E. Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient. *Physiotherapy (London)* 2008; **94**(3): 244–52.
 82. 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 Studies* 2010; **47**(5): 586–592.
 83. Crowe M, Whitehead L, Jo M, *et al*. Self-management and chronic low back pain: a qualitative study. *J Adv Nurs* 2010; **66**(7): 1478–1486.
 84. Liddle SD, Baxter GD, Gracey JH. Chronic low back pain: patients' experiences, opinions and expectations for clinical management. *Disabil Rehabil* 2007; **29**(24): 1899–1909.
 85. Slade SC, Molloy E, Keating JL. Stigma experienced by people with nonspecific chronic low back pain: a qualitative study. *Pain Med* 2009; **10**(1): 143–154.
 86. Slade SC, Molloy E, Keating JL. 'Listen to me, tell me': a qualitative study of partnership in care for people with non-specific chronic low back pain. *Clin Rehabil* 2009; **23**(3): 270–280.
 87. Teh CF, Karp JF, Kleinman A, *et al*. Older people's experiences of patient-centered treatment for chronic pain: a qualitative study. *Pain Med* 2009; **10**(3): 521–530.
 88. Coole C, Drummond A, Watson PJ, Radford K. 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.
 89. Coole C, Watson PJ, Drummond A. Low back pain patients' experiences of work modifications; a qualitative study. *BMC Musculoskelet Disord* 2010; **11**: 277.
 90. Coole C, Watson PJ, Drummond A. Staying at work with back pain: patients' experiences of work-related help received from GPs and other clinicians. A qualitative study. *BMC Musculoskelet Disord* 2010; **11**: 190.
 91. Holloway I, Sofaer-Bennett B, Walker J. The stigmatisation of people with chronic back pain. *Disabil Rehabil* 2007; **29**(18): 1456–1464.
 92. Tøye F, Barker K. Persistent non-specific low back pain and patients' experience of general practice: a qualitative study. *Prim Health Care Res Dev* 2012; **13**: 72–84.
 93. Tøye F, Barker K. 'I can't see any reason for stopping doing anything, but I might have to do it differently' — restoring hope to patients with persistent non-specific low back pain — a qualitative study. *Disabil Rehabil* 2012; **34**(11): 894–903.
 94. Tøye 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.
 95. 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.
 96. Lachapelle DL, Lavoie S, Boudreau A. The meaning and process of pain acceptance. Perceptions of women living with arthritis and fibromyalgia. *Pain Res Manage* 2008; **13**(3): 201–210.
 97. Arnold LM, Crofford LJ, Mease PJ, *et al*. Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns* 2008; **73**(1): 114–120.
 98. Cunningham MM, Jillings C. Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res* 2006; **15**(4): 258–273.
 99. Gullacksen AC, Lidbeck J. The life adjustment process in chronic pain: psychosocial assessment and clinical implications. *Pain Res Manage* 2004; **9**(3): 145–153.
 100. Gustafsson M, Ekholm J, Ohman A. From shame to respect: musculoskeletal pain patients' experience of a rehabilitation programme, a qualitative study. *J Rehabil Med* 2004; **36**(3): 97–103.

101. Hallberg LR, Carlsson SG. Coping with fibromyalgia. A qualitative study. *Scand J Caring Sci* 2000; **14**(1): 29–36.
102. Hallberg LR, Carlsson SG. Psychosocial vulnerability and maintaining forces related to fibromyalgia: in-depth interviews with twenty-two female patients. *Scand J Caring Sci* 1998; **12**(2): 95–104.
103. Hellstrom O, Bullington J, Karlsson G, *et al*. A phenomenological study of fibromyalgia. Patient perspectives. *Scand J Prim Health Care* 1999; **17**(1): 11–16.
104. Kelley P, Clifford P. Coping with chronic pain: assessing narrative approaches. *Soc Work* 1997; **42**(3): 266–277.
105. Lempp HK, Hatch SL, Carville SF, Choy EH. Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study. *BMC Musculoskelet Disord* 2009; **10**: 124.
106. Liedberg GM, Henriksson CM. Factors of importance for work disability in women with fibromyalgia: an interview study. *Arth Rheum* 2002; **47**(3): 266–275.
107. Lofgren M, Ekholm J, Ohman A. 'A constant struggle': successful strategies of women in work despite fibromyalgia. *Disabil Rehabil* 2006; **28**(7): 447–455.
108. Madden S, Sim J. Creating meaning in fibromyalgia syndrome. *Soc Sci Med* 2006; **63**(11): 2962–2973.
109. Mannerkorpi K, Kroksmark T, Ekdahl C. How patients with fibromyalgia experience their symptoms in everyday life. *Physiother Res Int* 1999; **4**(2): 110–122.
110. Paulson M, Danielson E, Larsson K, Norberg A. Men's descriptions of their experience of nonmalignant pain of fibromyalgia type. *Scand J Caring Sci* 2001; **15**(1): 54–59.
111. Paulson M, Norberg A, Danielson E. Men living with fibromyalgia-type pain: experiences as patients in the Swedish health care system. *J Adv Nurs* 2002; **40**(1): 87–95.
112. Raheim M, Haland W. Lived Experience of Chronic Pain and Fibromyalgia: Women's Stories From Daily Life. *Qual Health Res* 2006; **16**(6): 741–761.
113. Raymond MC, Brown JB. Experience of fibromyalgia. Qualitative study. *Can Fam Phys* 2000; **46**: 1100–1106.
114. Sallinen M, Kukkurainen ML, Peltokallio L. Finally heard, believed and accepted – Peer support in the narratives of women with fibromyalgia. *Patient Educ Couns* 2011; **85**(2): e126–e130.
115. Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsen M. Women's narratives on experiences of work ability and functioning in fibromyalgia. *Musculoskelet Care* 2010; **8**(1): 18–26.
116. Schaefer KM. The Lived Experience of Fibromyalgia in African American Women. *Hol Nurs Pract* 2005; **19**(1): 17–25.
117. Soderberg S, Lundman B, Norberg A. Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qual Health Res* 1999; **9**(5): 575–587.
118. Soderberg S, Lundman B. Transitions experienced by women with fibromyalgia. *Health Care Women Int* 2001; **22**(7): 617–631.
119. Undeland M, Malterud K. The fibromyalgia diagnosis: hardly helpful for the patients? A qualitative focus group study. *Scand J Primary Health Care* 2007; **25**(4): 250–255.
120. Leder D. *The absent body*. Chicago, IL: University of Chicago Press, 1990.
121. Wall P. *Pain the science of suffering*. London: Phoenix, 1999.
122. Engel G. The need for a new medical model: a challenge for biomedicine. *Science* 1977; **196**: 129–136.
123. Helman C. *Culture health and illness*. 5th edn. London: Hodder Arnold, 2007.
124. Lupton D. *Medicine as culture*. London: Sage Publications, 1994.
125. Annandale E. *The sociology of health medicine. A critical introduction*. Cambridge: Polity Press, 1998.
126. McCracken L, Velleman S. Psychological flexibility in adults with chronic pain: a study of acceptance, mindfulness, and values-based action in primary care. *Pain* 2009; **148**(1): 141–147.
127. Vowles KE, McCracken LM. Comparing the role of psychological flexibility and traditional pain management coping strategies in chronic pain treatment outcomes. *Behav Res Ther* 2010; **48**: 141–6.
128. Snelgrove S, Liossi C. Living with chronic low back pain: a metasynthesis of qualitative research. *Chronic Illness* 2013; **14** June: <http://chi.sagepub.com/content/early/2013/04/10/1742395313476901> (accessed 4 Nov 2013).
129. Sim J, Madden S. Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. *Soc Sci Med* 2008; **67**(1): 57–67.
130. Royal College of General Practitioners. Principles of Commissioning Summary. <http://www.rcgp.org.uk/revalidation-and-cpd/-/media/6C164D7796EA49A3AC25AD5383AEC653.ashx> (accessed 4 Nov 2013).

Appendix 1. Characteristics of included studies

Author and year	Age range, years	Condition	Source of participants	Country	Number included	Males	Data collection	Methodology ^a
Aegler 2009, ⁷¹	29–61	MSK	PMP	Switzerland	8	3	Semi-structured interview	Thematic analysis
Afrell 2007, ⁷²	30–72	MSK	PC, PMP, pain clinic	Sweden	20	7	Semi-structured interview	Phenomenology
Allegretti 2010, ⁷⁷	28–72	MSK (CBP)	PC	US	23	12	Semi-structured interview	Thematic analysis
Arnold 2008, ⁹⁷	31–72	FM	Rheumatology	US	48	0	FG	Grounded theory
Bair 2009, ⁶¹	27–84	MSK	RCT	US	18	7	FG	Thematic analysis
Campbell 2007, ⁷⁸	34–78	MSK (CBP)	PMP	UK	16	NK	FG	Thematic analysis
Campbell 2008, ⁶²	36–66	MSK	Non-service users	UK	12	3	Interviews	Thematic analysis
Cook 2000, ⁷⁹	22–63	MSK (CBP)	Back pain rehab	UK	7	3	Semi-structured interview	Thematic analysis
Coole 2010 ^a , ⁹⁰	22–58	MSK (CBP)	Back pain rehab	UK	25	12	Semi-structured interview	Thematic analysis
Coole 2010 ^a , ⁸⁸	22–58	MSK (CBP)	Back pain rehab	UK	25	12	Semi-structured interview	Thematic analysis
Coole 2010 ^a , ⁸⁹	22–58	MSK (CBP)	Back pain rehab	UK	25	12	Semi-structured interview	Thematic analysis
Cooper 2008 ^a , ⁸¹	18–65	MSK (CBP)	PT	UK	25	5	Semi-structured interview	Framework analysis
Cooper 2009 ^a , ⁸⁰	18–65	MSK (CBP)	PT	UK	25	5	Semi-structured interview	Framework analysis
Crowe 2010 ^a , ⁸³	25–80	MSK (CBP)	Adverts and PT	New Zealand	64	33	Semi-structured interview	Thematic analysis
Crowe 2010 ^a , ⁸²	25–80	MSK (CBP)	Adverts	UK	64	33	Semi-structured interview	Thematic analysis
Cunningham 2006, ⁹⁸	30–70	FM	University	Canada	8	1	Semi-structured interview	Thematic analysis
De Souza 2011, ⁴⁸	27–79	MSK (CBP)	Rheumatology	UK	11	5	Unstructured interview	Thematic analysis
De vries 2011, ³⁸	31–60	FM and MSK	Adverts and FM website	Netherlands	21	9	Semi-structured interview	Thematic analysis
Dickson 2003, ⁷⁰	63–80	MSK	PC	US	7	0	Interviews and observation	Thematic analysis
Dragesund 2008, ⁶³	26–68	MSK	PT	Norway	13	5	FG	Thematic analysis
Gullacksen 2004, ⁹⁹	23–55	FM and MSK	PMP	Sweden	18	0	In-depth interviews	Phenomenology
Gustaffson 2004, ¹⁰⁰	23–59	FM and MSK	Pain management	Sweden	18	0	Semi-structured interview	Grounded theory
Hallberg 1998 ^a , ¹⁰²	22–60	FM	Insurance hospital	Sweden	22	0	Semi-structured interview	Grounded theory
Hallberg 2000 ^a , ¹⁰¹	22–60	FM	Insurance hospital	Sweden	22	0	Semi-structured interview	Grounded theory
Harding 2005, ³⁹	29–71	MSK	PMP	UK	15	3	In-depth interviews	Framework analysis
Hellstrom 1999, ¹⁰³	32–50	FM	FM group	Sweden	10	1	In-depth interviews	Phenomenology
Holloway 2007, ⁹¹	28–62	MSK (CBP)	Pain clinic	UK	18	12	Semi-structured interview	IPA
Hunhammar 2009, ⁶⁰	19–58	MSK	PC	Sweden	15	6	In-depth interviews	Grounded theory
Johansson 1996 ^a , ⁶⁴	21–60	MSK	PC	Sweden	20	0	Semi-structured interview	Grounded theory
Johansson 1997 ^a , ⁶⁵	21–60	MSK	PC	Sweden	20	0	Semi-structured interview	Grounded theory
Johansson 1999 ^a , ⁷³	21–60	MSK	PC	Sweden	20	0	Semi-structured interview	Grounded theory
Kelley 1997, ¹⁰⁴	50 mean	FM	PMP	US	22	0	In-depth interviews	Narrative analysis
Lachapelle 2008, ⁹⁶	23–75	FM and MSK	Adverts	Canada	45	0	Ethnography and FG	Ethnography
Lempp 2009, ¹⁰⁵	20–69	FM	Rheumatology	UK	12	1	Semi-structured interview	Thematic analysis
Liddle 2007, ⁸⁴	20–65	MSK (CBP)	University	N Ireland	18	4	FG	Thematic analysis

... continued

Appendix 1 continued. Characteristics of included studies

Author and year	Age range, years	Condition	Source of participants	Country	Number included	Males	Data collection	Methodology ^a
Liedberg 2002, ¹⁰⁶	26–64	FM	Questionnaire survey	Sweden	39	0	In-depth interviews	Thematic analysis
Lofgren 2006, ¹⁰⁷	30–63	FM	PMP	Sweden	12	0	Diaries, FG, interviews	Grounded theory
Lundberg 2007, ⁴⁸	30–64	MSK	PT	Sweden	10	5	In-depth interviews	Phenomenology
Madden 2006, ¹⁰⁸	25–55	FM	Hospital databases	UK	17	1	Semi-structured interview	Induction/abduction
Mannerkorpi 1999, ¹⁰⁹	29–59	FM	FM group	Sweden	11	0	In-depth interviews	Phenomenology
Mengshoel 2004, ²⁸	37–49	FM	PMP	Norway	5	0	Semi-structured interview	Thematic analysis
Osborn 1998, ²⁹	25–55	MSK (CBP)	Back pain rehab	UK	9	0	Semi-structured interview	IPA
Osborn 2006, ³³	36–52	MSK (CBP)	Pain clinic	UK	6	4	Semi-structured interview	IPA
Osborn 2008, ⁴⁰	36–52	MSK (CBP)	Pain clinic	UK	10	5	Semi-structured interview	IPA
Patel 2007, ⁶⁶	29–62	MSK (CBP)	Benefits office	UK	38	15	Semi-structured interview	Thematic analysis
Paulson 2001 ^a , ¹¹⁰	41–56	FM	Rheumatology	Sweden	14	14	Narrative interview	Phenomenology
Paulson 2002 ^a , ⁴¹	41–56	FM	Rheumatology	Sweden	14	14	Narrative interview	Phenomenology
Paulson 2002 ^a , ¹¹¹	41–56	FM	Rheumatology	Sweden	14	14	Narrative interview	Phenomenology
Raheim 2006, ¹¹²	34–51	FM	PC, PT, FM group	Norway	12	0	Life form interviews	Phenomenology
Raymond 2000, ¹¹³	38–47	FM	FM association	Canada	7	1	Semi-structured interview	Thematic analysis
Rhodes 1999, ³⁰	25–65	MSK (CBP)	Healthcare plan	US	54	20	In-depth interviews	Thematic analysis
Sallinen 2010 ^a , ¹¹⁵	34–65	FM	PMP	Finland	20	0	Narrative interview	Thematic analysis
Sallinen 2011 ^a , ¹¹⁴	34–65	FM	PMP	Finland	20	0	Narrative interview	Thematic analysis
Sanders 2002, ³⁴	51–91	MSK	Survey	UK	27	10	In-depth interviews	Grounded theory
Satink 2004, ⁷⁶	42–70	MSK (CBP)	PMP	Netherlands	7	3	Narrative interview	Phenomenology
Schaefer 2005, ¹¹⁶	37–59	FM	Adverts	US	10	0	In-depth interviews	Phenomenology
Skuladottir 2011, ⁶⁹	35–55	MSK	Adverts	Iceland	5	0	In-depth interviews	Grounded theory
Slade 2009 ^a , ⁸⁶	26–64	MSK (CBP)	Adverts and university	Australia	18	2	FG	Grounded theory
Slade 2009 ^a , ⁸⁵	26–65	MSK (CBP)	Adverts and university	Australia	18	2	FG	Grounded theory
Smith 2007 ^a , ³¹	36–52	MSK (CBP)	Pain clinic	UK	6	4	Semi-structured interview	IPA
Snelgrove 2009, ³²	39–66	MSK (CBP)	Pain clinic	UK	10	3	Semi-structured interview	IPA
Soderberg 1999 ^a , ¹¹⁷	35–50	FM	Rheumatology	Sweden	14	0	In-depth interviews	Phenomenology
Soderberg 2001 ^a , ¹¹⁸	35–60	FM	Rheumatology	Sweden	25	0	In-depth interviews	Thematic analysis
Steen 2001, ⁶⁷	Adults	MSK	RCT	Norway	48	NK	Semi-structured interview	Phenomenology
Strong 1994, ⁷⁴	30–75	MSK (CBP)	Adverts	Australia	7	3	FG	Thematic analysis
Strong 1995, ⁷⁵	30–75	MSK (CBP)	Adverts	New Zealand	15	4	FG	Thematic analysis
Sturgejacobs 2002, ⁴²	20–57	FM	PMP	Canada	9	0	Unstructured interview	Phenomenology
Teh 2009, ⁸⁷	63–86	MSK (CBP)	Pain clinic	US	15	5	In-depth interviews	Grounded theory
Toye 2010 ^a , ⁹⁴	29–67	MSK (CBP)	PMP	UK	20	7	Semi-structured interview	Grounded theory
Toye 2012 ^a , ⁹²	29–67	MSK (CBP)	PMP	UK	20	7	Semi-structured interview	Grounded theory

... continued

Appendix 1 continued. Characteristics of included studies

Author and year	Age range, years	Condition	Source of participants	Country	Number included	Males	Data collection	Methodology ^a
Toye 2012 ^{a, 93}	29–67	MSK (CBP)	PMP	UK	20	7	Semi-structured interview	Grounded theory
Undeland 2007, ¹¹⁹	42–67	FM	FM group	Norway	11	0	FG	Thematic analysis
Walker 1999 ^{a, 43}	28–80	MSK (CBP)	Pain clinic	UK	20	12	In-depth interviews	Phenomenology
Walker 2006 ^{a, 95}	28–80	MSK (CBP)	Pain clinic	UK	20	12	In-depth interviews	Phenomenology
Werner 2003 ^{a, 35}	26–58	MSK	PC and PMP	Norway	10	0	In-depth interviews	Phenomenology
Werner 2003, ³⁶	31–53	MSK	PMP	Norway	6	0	In-depth interviews	Phenomenology
Werner 2004 ^{a, 37}	26–58	MSK	PC and PMP	Norway	10	0	In-depth interviews	Phenomenology

^a More than one paper reporting experience of same group of people. ^b The authors' original description to define methodology was used. CBP = chronic back pain. FG = focus group. FM = fibromyalgia. IPA = interpretative phenomenological analysis. MSK = chronic musculoskeletal pain. PC = primary care. PMP = pain management programme. PT = physiotherapy. RCT = randomised controlled trial.