LETTER TO THE EDITOR-IN-CHIEF

This is a letter to the Editor-in-Chief in response to JOSPT article "When treating coexisting low back pain and hip impairments, focus on the back: adding specific hip treatment does not yield additional benefits—a randomized controlled trial" by Burns et al. J Orthop Sports Phys Ther. 2021;51(12):581-601. https://doi.org/10.2519/jospt.2021.10593

TREATING THE HIPS FOR LOW BACK PAIN MAY BE EFFECTIVE: FOR THE RIGHT PATIENT

J Orthop Sports Phys Ther 2022;52(5):300. doi:10.2519/jospt.2022.0202

We read with great interest the aforementioned study by Burns et al[4] focusing on the treatment of patients with low back pain and concurrent hip impairments. This is an important area of study, and we anticipate that this line of research will help shed light on the most effective approaches for treating low back pain, which is a major financial burden on US health systems. However, we have concerns with the methodology of this study and feel that the results should be interpreted with caution.

Hip-spine syndrome, as coined by Offierski and MacNab,[6] was originally used to describe patients with low back pain associated with hip osteoarthritis, a condition that primarily affects hip mobility. Since that time, several studies (including those referenced by Burns et al) have reported a high rate of hip impairments among those with low back pain.[1,7] Upon closer inspection, we find that most of the impairments reported by these studies are related to hip mobility (ie, range of motion). However, the study performed by Burns and colleagues included patients in their study with impairments potentially unrelated to hip mobility, such as hip strength deficits and positive special tests for intra-articular hip conditions. Moreover, a limitation in hip strength was the most frequent finding among eligible patients in this study.

It is possible that the inclusion of patients with impairments unrelated to mobility may have affected the results of this study. As stated by the authors, previous studies have shown that including interventions targeting the hips is beneficial for those with low back pain.[2,3,5] There are important differences between these studies and the study by Burns and colleagues. One of these studies only included patients with concurrent hip mobility impairments.[5] The other study showed that hip interventions were most effective for those who also reported hip pain.[2,3] While the reason (ie, diagnosis) for hip pain was not included in the previous studies, the presence of hip pain indicates a greater involvement of the hip than asymptomatic hip weakness, which was used as an inclusion criterion in the study by Burns et al. It should also be noted that manual muscle testing has questionable interrater reliability and that asymptomatic hip weakness is likely common among healthy adults without hip or low back pain.

Further research is needed to identify patients with low back pain that will benefit from interventions directed toward the hip region. While the study by Burns et al provides important information on this approach, the reported results should not be viewed as conclusive, and we caution those who may abandon this treatment approach based on the results of this study. Larger studies on this topic are needed that allow for statistical approaches that identify subgroups of patients with low back pain that respond to physical therapy treatment of the hips.

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RESPONSE TO THE LETTER TO THE EDITOR-IN-CHIEF

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We thank the Editor for allowing us to respond and the authors for their thoughtful critique. The authors of the letter highlight important discussion points related to the results of this trial. We agree that the results should be interpreted cautiously, and additional research is needed to provide clarification regard-

ing the role of the hip impairments in individuals with low back pain LBP. We agree that clinicians should not abandon treatment of the hip(s) in patients with (LBP) until further research provides clarification.

The authors argue that having hip weakness alone (without hip range of motion limitations or hip pain) may not constitute a hip impairment that would benefit from interventions to the hip. Thus, in our trial, including participants with hip weakness only may have reduced our ability to demonstrate a significant effect from adding hip interventions to the treatment of LBP. We considered hip weakness to be an impairment because it is commonly observed in the LBP population, and physical therapists often render treatments to improve hip muscle strength in patients with LBP.[3,6] Further, hip muscle strengthening exercises in addition to low back exercise in people with LBP have been shown to produce greater reductions pain and disability compared to sham manual therapy.[6] Addressing hip weakness with muscle strengthening interventions has the potential to contribute to reducing LBP symptoms and is commonly performed by physical therapists.[3,6] Therefore, hip muscle weakness was included as one possible hip impairment that met our inclusion criteria for participation. We intentionally had a broad set of possible hip impairments that met our inclusion criteria because we wanted to mimic clinical practice and typical patient populations that are seen by physical therapists thus making it more generalizable to clinical practice. We used manual muscle testing (MMT) to test for hip muscle weakness as it is commonly used in clinical practice. While we acknowledge that interrater reliability is poor to moderate for assigning a specific grade (0-5) of weakness using MMT, MMT can detect the presence or absence of weakness,[2] and that is how it was used in our study.

The wide range of possible hip impairments included in our trial, rather than specifically the inclusion of participants with hip weakness only, likely led to heterogeneity across the sample and is a more probable reason for the similar outcomes observed in each treatment group. It is likely that our trial captured individuals who may have different responses to hip interventions.[7,8]

Subgroups of hip-spine syndrome have been described[7] as (1) simple: coexisting hip pathology (eg, hip osteoarthritis); (2) secondary: hip impairments that preceded and reproduce LBP; and (3) complex: hip impairments that overlap between the low back and hip. Our study likely included participants from each category, resulting in a heterogeneous sample that diluted any possible differences between groups. Some participants may have had coincidental findings that were not directly related to their LBP symptoms.

We did not differentiate potential subgroups at baseline because they lack strict definitions. It would be unreliable for clinicians to try to differentiate these groups using clinical measures, and it was not ethically appropriate or financially viable to conduct additional imaging that was not clinically indicated. In addition, our inclusion criteria only noted the presence of a hip impairment and did not determine the relationship of the hip impairment to the LBP symptoms, which would have provided information about whether the hip impairment was clinically related to the LBP symptoms.

Perhaps only including participants with a hip impairment that was related to their LBP symptoms through physical examination tests, measures, and/or symptom responses may have identified a sample that was less heterogeneous and changed the results.[1,4,5] If the hip impairment was a coincidental finding, it may be less likely to respond to treatment directed at the hip. Future studies should determine if there are subgroups of individuals with LBP and concurrent hip impairment(s) that may respond more favorably to the inclusion of hip interventions in the treatment approach to LBP. Additionally, more research is needed to determine the nature of the relationships between hip impairments and LBP symptoms in people with a primary complaint of LBP. These future studies will assist in clarifying whether hip interventions are a useful addition to the treatment of LBP when a hip impairment is identified.

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Knee Osteoarthritis Education Interventions in Published Trials Are Typically Unclear, Not Comprehensive Enough, and Lack Robust Development: Ancillary Analysis of a Systematic Review

OBJECTIVE: To summarize the content, development, and delivery of education interventions in clinical trials for people with knee osteoarthritis (OA).

DESIGN: Ancillary analysis of a systematic review.

LITERATURE SEARCH: MEDLINE, EMBASE, SPORTDiscus, CINAHL, and Web of Science were searched from inception to April 2020.

STUDY SELECTION CRITERIA: Randomized controlled trials involving patient education for people with knee OA.

DATA SYNTHESIS: Content of education interventions was matched against a predefined topic list (n = 14) and categorized as accurate and clear, partially accurate/lacks clarity, or not reported. We examined whether education interventions included skill development or stated learning objectives and if they were developed based on theory, previous research, or codesign principles. Delivery methods and mode(s) were also identified. Data were summarized descriptively.

RESULTS: Thirty-eight education interventions (30 trials) were included. Interventions lacked comprehensiveness (median topics per intervention = 3/14, range = 0-11). Few topics were accurately and clearly described (10%, 13/136). Sixty-one percent (n = 23/38) of interventions targeted skill development, and 34% (n = 13/38) identified learning objectives. Forty-two percent (n = 16/38) were based on theory; 45% (n = 17/38) were based on research for chronic conditions, including 32% (n = 12/38) based on OA. Eleven percent of interventions (n = 4/38) were codesigned. Education was typically facilitated through face-to-face sessions (median = 9, range = 0-55), supplemented with telephone calls and/or written materials.

CONCLUSION: Education interventions for people with knee OA lacked comprehensiveness plus accurate and clear descriptions of topics covered. Most interventions failed to identify learning objectives and were not based on theory, previous research, or codesign principles. *J Orthop Sports Phys Ther 2022;52(5):276-286. Epub 14 Dec 2021. doi:10.2519/jospt.2022.10771*

KEY WORDS: *co-production, facilitation, learning theory, patient education, self-management*

Education is recommended as first-line care for most musculoskeletal conditions.[3,24,35,57,60] Yet, evidence supporting these guideline recommendations is conflicting and of low certainty.[18,41,47] Clinical practice guidelines for musculoskeletal conditions generally provide broad education-specific content recommendations, typically referring to "information about the condition" and/or "self-management strategies".[24,35,57,64] Further guidance about how to implement recommendations is scarce, possibly due to incomplete reporting of trials informing them,[24,35,57,59,60,64,70] and this may undermine implementation into clinical practice. Recent systematic reviews on patient education for musculoskeletal conditions[29,41,58,87] do not provide clear guidance on the value of face-to-face group or individual interventions, compared with self-directed interventions.

Developing patient education interventions based on previous research and/or theoretical frameworks may improve compliance, satisfaction, and patient outcomes.[11,22,26,51,63,91] Actively involving patients throughout the learning process to identify their learning objectives, develop skills, and encourage behavior change is considered important to change behavior.[37,63,71,90] Developing interventions through codesign with people with a lived experience of chronic conditions is increasingly

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employed by healthcare organizations to tailor interventions and improve patient satisfaction.[10,16,25] However, little is known about whether these development considerations are implemented and reported within clinical trials evaluating the efficacy and effectiveness of patient education for musculoskeletal conditions.

Knee osteoarthritis (OA) is a leading cause of disability worldwide,[28,61] providing a key example where patient education is uniformly recommended by guidelines.[24,36,57,64] Findings from our recent systematic review[41] for people with knee OA indicate that (1) patient education is superior to usual care for pain and function in the short-term, but differences may not be clinically important; (2) patient education as a standalone intervention is inferior with a large and clinically important difference compared to exercise therapy for pain in the short term; and (3) combining patient education with exercise therapy results in clinically important short-term differences in pain and/or function compared to either intervention alone. Our review did not include a detailed evaluation of content, development, and delivery approaches for patient education interventions in included trials. Further exploration is warranted to add context to the findings and to inform clinical practice.

This study is an ancillary analysis of our previous systematic review and meta-analysis.[41] The primary aims are to summarize (1) the content of patient education interventions reported in clinical trials, (2) how patient education interventions were reported to be developed, and (3) how patient education interventions were delivered to people with knee OA. The secondary aims were to summarize differences in content, development, or delivery when patient education is provided as an intervention or a control condition within trials.

METHODS

Our primary systematic review and meta-analysis[41] was prospectively registered on the PROSPERO (International Prospective Register of Systematic Reviews) website (registration number CRD42019122004) in January 2019. Full details of the search strategy, screening, and risk of bias assessment can be found in our previous publication.[41]

Deviations From Protocol

We planned a meta-analysis for effectiveness of patient education, with subanalysis of education content, plus a cross-sectional analysis of general web-based content for knee OA. We separated this ancillary analysis from our primary systematic review and web-based content analysis to improve clarity and impact of each component. The other deviations preregistered protocol deviations were:

1. omitting the planned analysis to determine the effectiveness and association of education topics on patient outcomes due to widespread, incomplete trial reporting;
2. extracting and reporting descriptive data including content comprehensiveness, accuracy and clarity of patient education topics provided, intervention development, and delivery method/mode(s) due to their importance for effective translation of interventions to clinical practice; and
3. adding a comparison of the content, development, and delivery of patient education provided as an intervention compared to control conditions—an important consideration when assessing the effectiveness of patient education.

Data Extraction: Previously Published

Patient-Reported Outcomes of Pain and Function Data extraction and analysis of patient-reported outcomes are presented in our primary systematic review and meta-analysis.[41]

Data Extraction: Ancillary Analysis

Content Four members of the research team (AJG, DOS, AME, and CJB) identified overarching themes from recommendations in clinical practice guidelines,[24,35,57,64] expert opinion,[39] and clinical research.[15,27,56,62,67,75,78,80,81] Specific content topics were then created based upon the researchers' interpretation of the themes:

1. general information about the condition (7 topics);
2. information to inform and support first-line care (4 topics); and
3. information about other treatment options (3 topics).

A transparent, criterion-based scoring rubric was developed to determine when topic descriptions were (1) accurate and clear, (2) partially accurate/lacks clarity, (3) inaccurate, and (4) not reported (**SUPPLEMENTAL FILE 1**). For example, for exercise therapy, a clear and accurate description was "Advise people with osteoarthritis to exercise as a core treatment irrespective of age, comorbidity, pain severity or disability. Exercise should include local muscle/neuromuscular strengthening and general aerobic fitness".[24] An inaccurate description included information that exercise is unsafe or harmful for people with knee OA.[15,69]

Topic descriptions from included trial manuscripts, supplementary materials, and/or published protocols were extracted and matched against the scoring rubric by two independent researchers involved in creating the rubrics (AJG and AME). An alignment meeting was held prior to extraction to ensure consistent interpretation. A third researcher (CJB) was available to facilitate final agreement if required. Comprehensiveness, accuracy and clarity of content for patient education interventions were then determined using this information.

Two researchers (AJG and AME) identified whether interventions emphasized 1 or more pain coping skills as originally identified by Keefe et al.[52] Pain coping skills were chosen due to their frequent use and known effectiveness for people with OA[48,89] and were recorded as "yes" or "not reported". A third researcher (CJB) was available to facilitate final agreement, if required.

Development Two researchers (AJG and ECB) independently extracted details

about the development of patient education interventions including whether it was based on:

1. learning/behavior change theory (ie, theory-based);
2. previous research in chronic conditions and/or OA; or
3. codesign principles.

These items were considered important in the development of patient education interventions by the research team and were categorized as either "yes" or "not reported".

We classified an intervention as theory-based if the trial stated a recognized learning or behavior change theory upon which it was developed. We did not consider whether the theory had established efficacy for people with chronic conditions, as judging that this was beyond the scope of this ancillary analysis.

An intervention was classified as based on previous research if the trial reported and provided a reference for the same or related published, peer-reviewed intervention for people with chronic conditions, including OA.[79] We classified an intervention as codesigned when a trial or reference that the intervention was based upon explicitly stated that people with a lived experience of the condition were involved in the development process. A third researcher (CJB) was available to facilitate final agreement, if required.

Delivery Two researchers (AJG and AME) independently extracted information relating to the number of sessions; delivery method (group, one-to-one, mixed, or self-directed); and delivery mode(s) (written, audio, audiovisual, telephone, face-to-face, or online) for all interventions. Two researchers (AJG and ECB) independently screened trial manuscripts to identify whether learning objectives were stated. A learning objective was defined as a statement about the larger goals of the course or program.[43] Apart from number of sessions, delivery items were categorized as "yes" or "not reported". A third researcher (CJB) was available to facilitate final agreement, if required.

Secondary Aims For secondary aims, two researchers (AJG and AME) independently extracted information from included trials relating to whether patient education interventions were provided as an intervention or control condition within trials. To be considered a control condition, trials either had to explicitly state that the intervention was being used as a control or were classified as a control based on identical education components provided in both arms of a comparison (eg, education vs the same education + exercise therapy).

Data Analysis for Primary Aims

If two trials reported the same intervention (eg, 1 trial reports short-term outcomes and another long-term outcomes of the same trial), they were pooled and only reported once to avoid duplication. If the identical patient education intervention was provided in two arms of a trial, they were pooled and classified as a control to avoid duplication.

Comprehensiveness, accuracy and clarity of content For comprehensiveness, we calculated the number of the 14 content topics provided in each education intervention regardless of accuracy and clarity, and calculated the median and range. For accuracy and clarity we calculated the frequency and proportion (percentage (%)) of topic descriptors that matched each of our scoring rubrics categories (accurate and clear, partially accurate/lacks clarity, inaccurate or not reported).

Development We calculated the frequency and proportion of interventions reporting "yes" to our 4 predefined development items.

Delivery We reported the number of sessions as mean, median, and range, and we calculated frequency and proportion of method (group, one-to-one, mixed, or self-directed) and mode(s) of delivery (written, audio, audiovisual, telephone, face-to-face, or online).

Data Analysis for Secondary Aims

The frequency and proportion of content, development, and delivery items were compared between interventions when patient education was used as an intervention or a control condition.

RESULTS

Full details on inclusion/exclusion of trials, risk of bias appraisal, characteristics of all patient education and comparator interventions, and effectiveness for pain and function have been previously published.[41]

Ancillary Analysis

Thirty-eight unique patient education interventions were identified and analyzed across 30 included trials.[1,3–5,7,8,12,17,19–21,23,30–34,40,44–46,53–55,66,68,72–74,77,84,88] Fifteen patient education interventions were used as a control condition.[1,17,19–21,30–33,45,66,73,77,88]

Patient Education Content

Full details of comprehensiveness, accuracy and clarity of content by intervention can be found in **FIGURE 1**. Pooled summaries of comprehensiveness for all interventions and when patient education was used as an intervention or control condition can be found in **SUPPLEMENTAL FILE 2**. Median topics provided for all patient education interventions was 3/14 of our predefined topics (range, 0-11). Pooled summaries of accuracy and clarity for all interventions and when patient education was used as an intervention or control condition can be found in **FIGURES 2A**, **2B,** and **2C**, respectively. No content topics were classified as having an inaccurate description for any patient education intervention. Refer to **SUPPLEMENTAL FILE 4** for a breakdown of skill emphasis results by intervention. Sixty-one percent (n = 23/38) of all interventions emphasized at least 1 pain coping skill.[1,3–5,12,23,30,31,34,44,45,55,72–74,84,88] When patient education was provided as an intervention, 83% (n = 19/23) emphasized developing at least 1 pain coping skill.[1,3–5,12,23,30,31,34,44,45,55,66,72,74,84,88] When patient education was provided as a control, 27% (n = 4/15) emphasized at least 1 pain coping skill.[1,29,30,73]

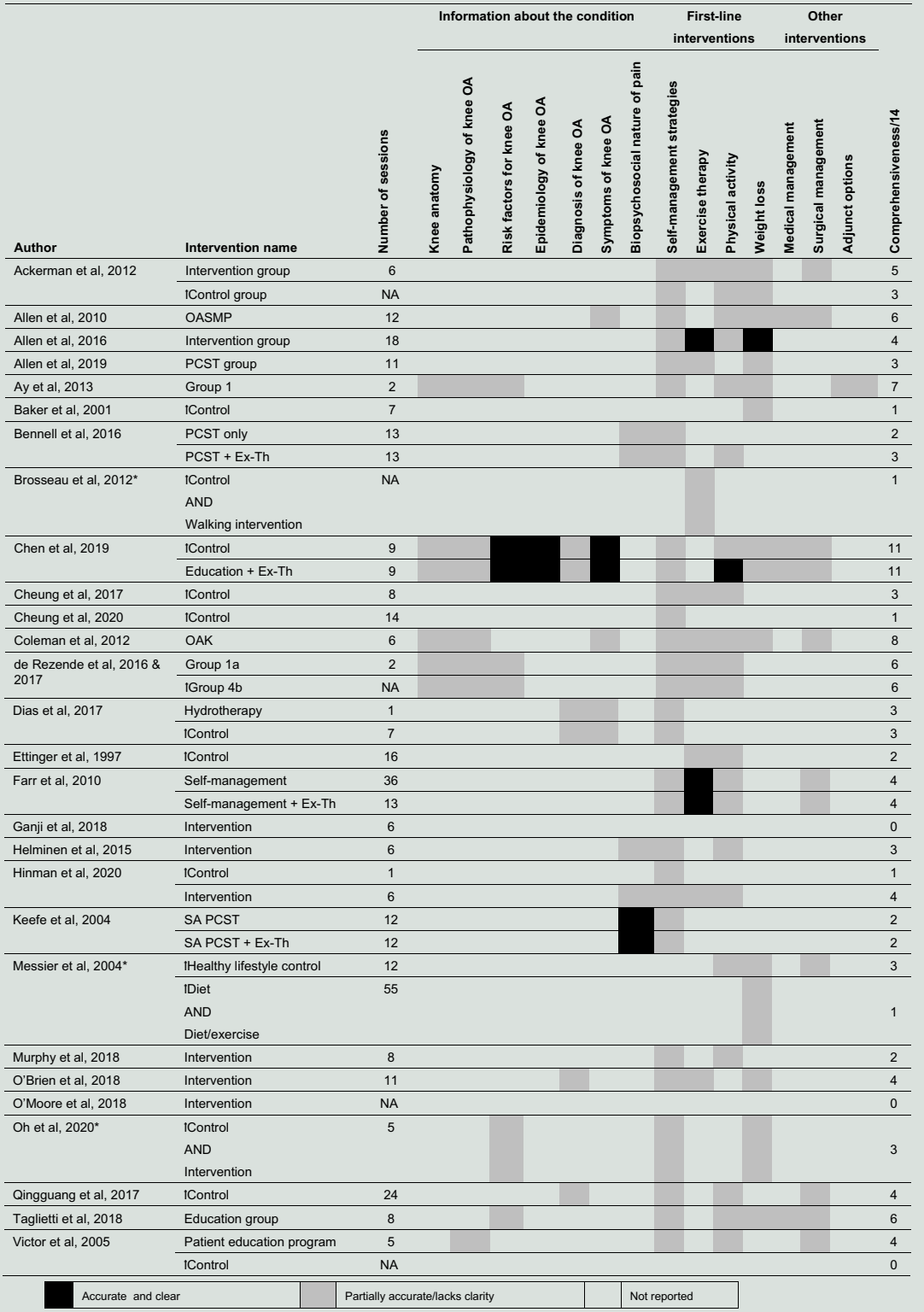
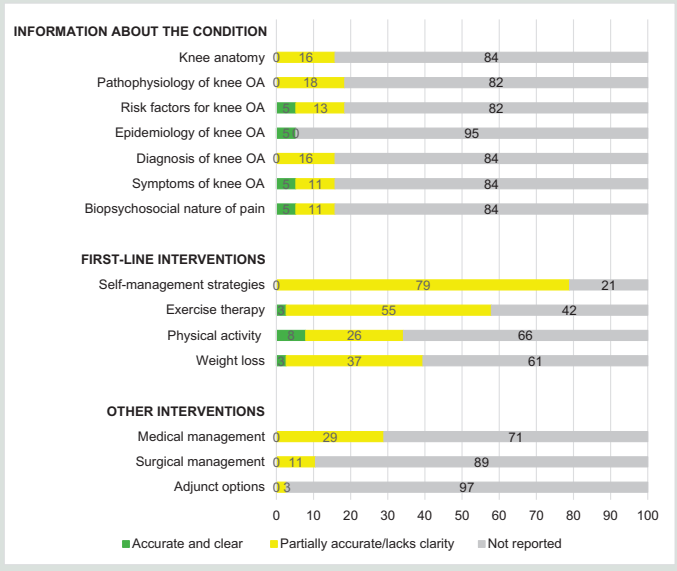


FIGURE 1. Comprehensiveness, accuracy and clarity of patient education interventions. Abbreviations: Ex-Th, exercise-therapy; NA, not applicable—self-directed intervention; OA, osteoarthritis; OAK, osteoarthritis of the knee group; OASMP, osteoarthritis self-management program; PCST, pain coping skills training; PEP, patient education program; SA, spouse assisted. †, identified as a control intervention; *, trial where education was identical between groups therefore combined.



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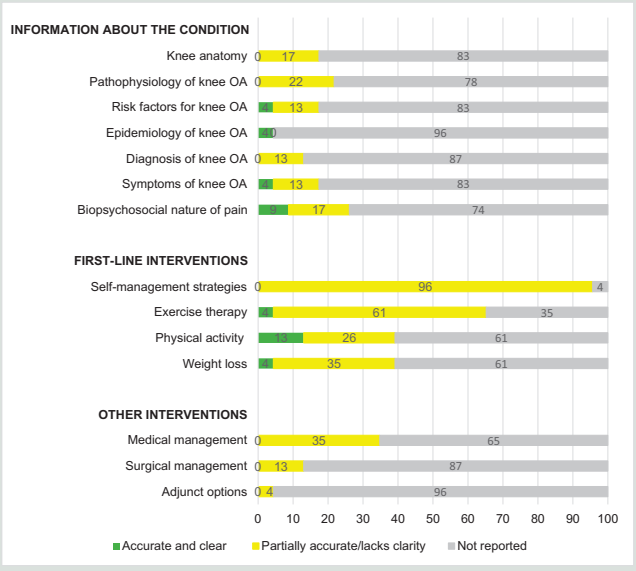

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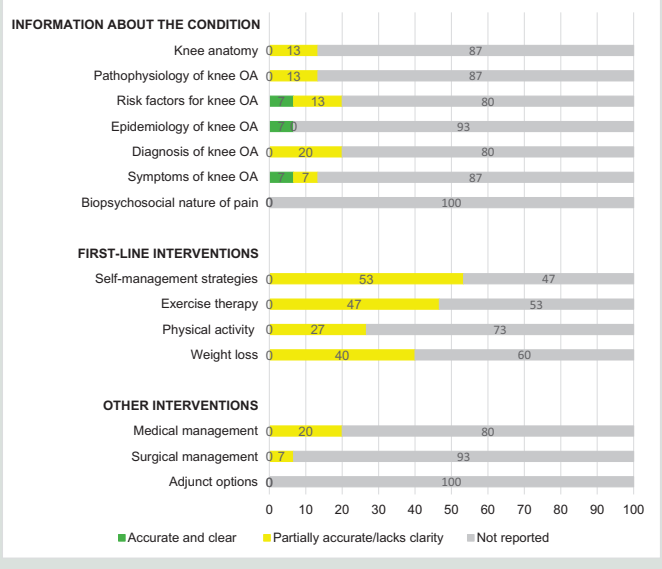

C

FIGURE 2. A. Accuracy and clarity (%) of content for all patient education interventions (n = 38). Abbreviation: OA, osteoarthritis. **B.** Accuracy and clarity (%) of content for patient education used as an intervention (n = 23). Abbreviation: OA, osteoarthritis. **C.** Accuracy and clarity (%) of content for patient education used as a control condition (n = 15). Abbreviation: OA, osteoarthritis.

Patient Education Development

Summary characteristics for the development of patient education interventions can be found in **FIGURE 3**. Refer to **SUPPLEMENTAL FILE 3** for a breakdown by intervention.

Patient Education Delivery

Summarized patient education delivery characteristics are reported in **FIGURES 4A** and **4B**. Refer to **SUPPLEMENTAL FILE 4** for a breakdown of learning objective results by intervention. Learning objectives were identified in 34% (n = 13/38) of all included interventions in this ancillary analysis.[3,12,23,34,44,45,55,66,72,88] When patient education was provided as an intervention, 52% (n = 12/23) identified learning objectives.[3,12,23,34,44,45,55,72,88] When patient

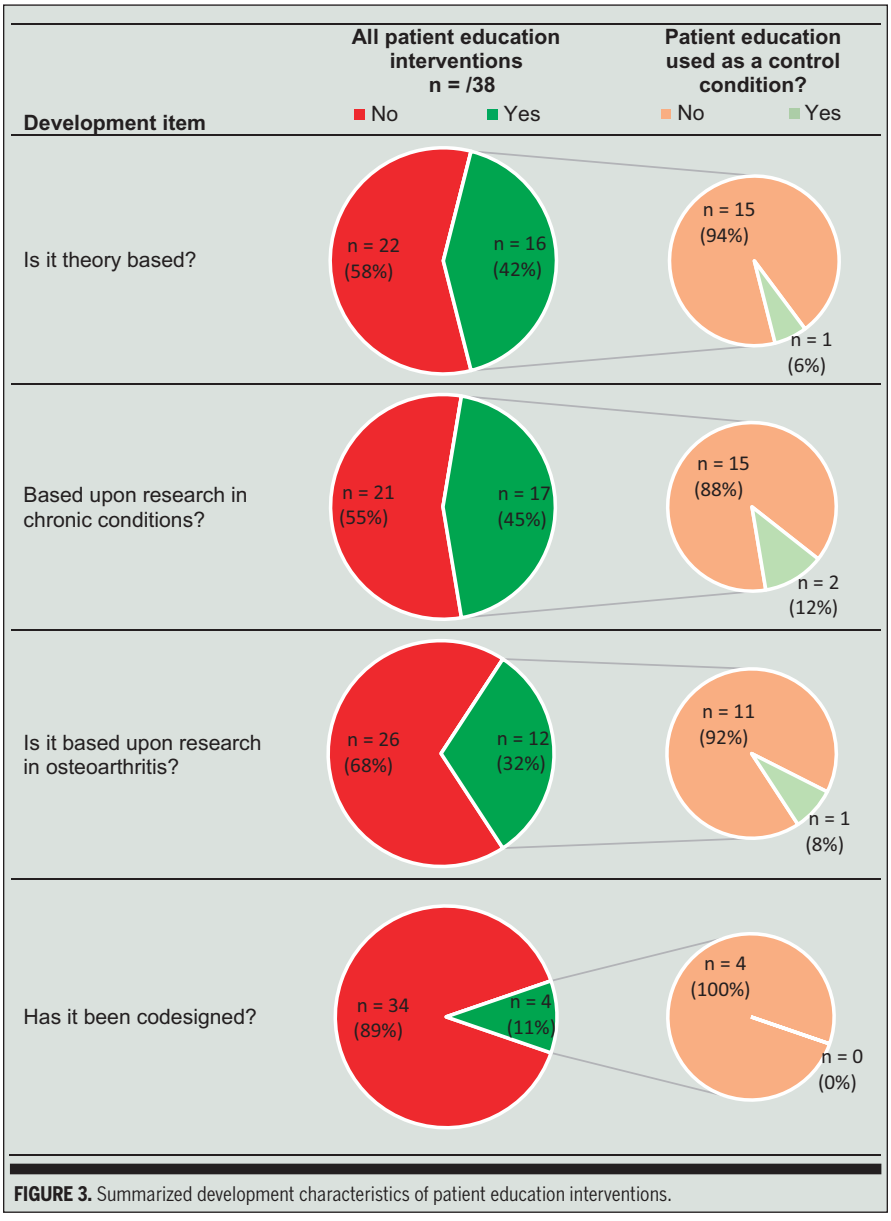

FIGURE 3. Summarized development characteristics of patient education interventions.

education was used as a control, 7% (n = 1/15) identified learning objectives.[66]

DISCUSSION

This ancillary analysis provides detailed information about the content, development, and delivery of patient education interventions reported in published clinical trials for people with knee OA. This analysis identified that inadequate reporting prevents guidelines from providing specific recommendations on implementation and prevents clinicians from knowing what effective patient education for people with knee OA looks like. Topics covered were broad and inconsistent, and they frequently lacked clear and accurate descriptions. Less than half of interventions evaluated stated learning objectives or were developed based on theory, previous research, or codesign.

The poor accuracy and clarity of patient education content descriptions identified in this ancillary analysis is consistent with published trials evaluating patient education for low back pain.[42] Information about self-management was provided by the majority (79%) of interventions evaluated, with 61% emphasizing at least one pain-coping skill. However, descriptions in these interventions were always partially accurate/lacked clarity, limiting clinical applicability. Information about other first-line treatments for knee OA (exercise therapy, physical activity, and weight loss) was typically either not provided or partially accurate/lacked clarity, limiting the ability of education interventions evaluated to facilitate effective self-management and key health behavior changes.[24,35,57,64] We encourage future trials evaluating patient education interventions for people with knee OA to improve clarity and transparency of content to enhance clinical applicability and to have a greater focus on developing self-management skills aligned with guideline recommended first-line care.[24,35,57,64]

Few interventions identified learning objectives or were theory-based. This finding is consistent with trials of patient education related to asthma,[83] as well as physical activity and diet within a general population.[76] Using learning objectives and theory is encouraged in future patient education research given that these functions are considered fundamental for effective patient education and communication.[6,11,38,91] Interventions based upon cognitive behavioral theory are effective for improving psychological outcomes in people with knee OA[14] and for pain and disability in other musculoskeletal conditions.[42] Illustrating this potential in knee OA, our primary systematic review indicates that the trials that evaluated interventions informed by cognitive behavioral theory[12,55] resulted in superior short-term outcomes for pain coping and self-efficacy compared to exercise-therapy.[41] Further investigation of the importance of theory-based patient education interventions on pain and function outcomes

FIGURE 4. A. Delivery characteristics (number of sessions and method of delivery) of patient education interventions. **B.** Delivery characteristics (mode) of patient education interventions.

is warranted to facilitate specific recommendations within clinical practice guidelines.

Few interventions were developed based upon previous research or codesign, which may help explain the broad and inconsistent range of topics provided. Basing interventions on previous research or codesign may assist in tailoring content topics toward those that are valued by people with knee OA and has the potential to improve health outcomes.[25,37]

Consistent with other chronic conditions,[42,91] patient education interventions

for people with knee OA were typically facilitated by healthcare professionals in face-to-face group sessions and supplemented by written materials or telephone calls. Total number of sessions, as well as delivery method and mode, varied substantially across interventions. Online resources were rarely used to deliver education, which is consistent with clinical trends in the delivery of patient education in Australia and Canada for people with knee OA.[9] Considering the increasing use of online health information[49,50] and known effectiveness of blended learning in other contexts,[85,86] research to determine how best to use online resources to deliver patient education is encouraged.

Education interventions used as a control condition were rarely developed based on theory or codesign principles. Interventions often failed to identify learning objectives or develop self-management skills. Collectively, these limitations may mask the true effectiveness of patient education and may inflate the effectiveness of comparators for people with knee OA.[13,14,41,58] We recommend that when patient education is used as a control condition within future clinical trials, it is developed and delivered with the same rigor as when provided as an intervention.

Limitations

This ancillary analysis was restricted to included trials from our published systematic review, which focused on pain and function outcomes.[41] Additionally, we did not contact authors of trials to retrieve additional information about aspects related to interventions that were not reported in manuscripts, supplementary materials, or published protocols. Therefore, results may not represent all patient education interventions for people with knee OA or reflect the full scope of interventions provided in trials.

We did not ascertain the number of self-management skills included or the extent to which skills were developed or evaluated within interventions. The scoring rubric developed to assess content comprehensiveness and accuracy were based upon the research team's interpretation of clinical practice guidelines and clinical research. Further research to determine its validity and reliability is warranted and may alter criterion descriptors. Lastly, we could not investigate whether inclusion of certain content topics or development features was associated with improved patient outcomes. This should be a focus of future research.

A Call to Action

Reporting content, development, and delivery may be improved by reporting standards for patient education interventions. The development of a tool that is equivalent to the Consensus on Exercise Reporting Template (CERT)[82] for exercise therapy or the Workgroup for Intervention Development and Evaluation Research (WIDER) checklist[2] for behavior change interventions is encouraged to assist reporting. This could help (1) identify whether certain content topics are associated with improved patient outcomes, (2) facilitate more efficient clinical translation, and (3) inform the development of future high-quality patient education interventions or resources. In the absence of such a tool, the features identified in this ancillary analysis may provide a guide for reporting and/or assessing the development of high-quality patient education interventions in the future.

Guidelines recommend that patient education is provided alongside other first-line interventions for people with knee OA.[24,36,57,65] This ancillary analysis highlights the variation and disparity of content, development and delivery of patient education interventions in clinical research. Careful consideration of these factors is required when developing future recommendations based upon findings from meta-analyses, especially when patient education is used as a control condition.

Our ancillary analysis cannot provide specific recommendations for *what* and *how* to provide patient education for people with knee OA. Subsequently, we recommend that clinicians adhere to theoretically driven principles for patient education and behavior change to first identify patient-centered learning objectives and then tailor content toward developing self-management skills. When developing future resources, clinicians should ensure that they are based upon theory, previous research, and/or codesign principles.

CONCLUSION

Education interventions for knee OA described in published clinical trials lack comprehensiveness, accuracy, and clarity. Most interventions fail to identify learning objectives and are not based on theory, previous research, or codesign principles. ◉

KEY POINTS

FINDINGS: Most patient education interventions for people with knee osteoarthritis aim to develop self-management skills. Yet, a broad, inconsistent range of topics is covered, and descriptions are often partially accurate/lacking clarity or incomplete. Few patient education interventions for people with knee osteoarthritis identify learning objectives or are based on theory, previous research, or codesign principles.

IMPLICATIONS: Incomplete reporting of patient education interventions for people with knee osteoarthritis prevents guidelines from providing specific recommendations for its implementation. Greater emphasis on the use of theory and codesign principles during intervention development may improve the effectiveness of patient education within clinical research and clinical practice.

CAUTION: Results from this ancillary analysis are limited to trials included in our previous systematic review and meta-analysis and may not represent all patient education interventions for knee osteoarthritis.

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"My Pain Is Unbearable...I Cannot Recognize Myself!" Emotions, Cognitions, and Behaviors of People Living With Musculoskeletal Disorders: An Umbrella Review

It is time to deepen clinicians' understanding of how people who are living with musculoskeletal disorders behave, feel, and think about the disorders. A recent quantitative umbrella review highlighted which emotions (eg, anger or pain-related fear), cognitions (eg, pain catastrophizing), and behaviors (eg, active or passive coping approaches) are implicated in how musculoskeletal pain develops and persists.[44]

OBJECTIVE: To summarize (1) the emotions, cognitions, and behaviors of people who are living with musculoskeletal disorders related to symptoms and (2) the interactions of emotions, cognitions, and behaviors with the person's environment (family, social, and work roles).

DESIGN: An umbrella review of qualitative research syntheses and meta-summaries (meta-synthesis, meta-ethnographies, meta-aggregation, meta-summary).

LITERATURE SEARCH: We searched CINAHL, EMBASE, PsycARTICLES, PsycEXTRA, PsycINFO, PubMed, and PubPsych from database inception to January 2021. We also searched gray literature via Open Grey and Google Scholar.

STUDY SELECTION CRITERIA: We included qualitative evidence syntheses evaluating adults with musculoskeletal disorders, based on the multidimensional diagnostic criteria for acute and chronic pain. Emotions, cognitions, and behaviors were the phenomenon of interest.

DATA SYNTHESIS: We developed 3 categories of themes ([1] emotions, [2] cognitions, and [3] behaviors) for each objective. We selected the 3 most common emotions, cognitions, and behaviors that appear as themes in our narrative synthesis.

RESULTS: We included 20 qualitative evidence syntheses that retrieved 284 original qualitative studies. Despair, distress, and fear were the main emotions reported by people living with musculoskeletal disorders. The alterations of the self and how people described their symptoms, what caused them, and how the symptoms impacted their lives were the most common cognitions. Cognitive strategies (ie, acceptance) and perceptions about social support emerged. People often used passive behaviors (eg, social isolation or hiding symptoms) to cope with the challenges that arose related to musculoskeletal symptoms. However, some people actively faced their symptoms, planning their activities or practicing them despite their symptoms.

CONCLUSION: Clinicians who support people living with musculoskeletal disorders should consider (1) assessing other emotions than pain-related fear (eg, despair and distress), (2) observing their cognitive responses (ie, acceptance), and (3) evaluating what type of behaviors people use (eg, active or passive). *J Orthop Sports Phys Ther 2022;52(5):243-261. doi:10.2519/jospt.2022.10707*

KEY WORDS: *meta-summaries, musculoskeletal disorders, qualitative evidence synthesis, qualitative research, systematic review/meta-analysis*

Quantitative research methods cannot illuminate how emotions, cognitions, and behaviors (eg, altered sense of self, desperation, or grief) are related to *how* musculoskeletal symptoms impact the person or their environment (family, social, and work roles).[8,74] People with musculoskeletal disorders want to feel heard and often make sense of their symptoms by telling someone about their own experiences and perspectives.[8,9,52] Listening to the person with musculoskeletal pain may enhance patient-centered care, a cornerstone of high-value musculoskeletal pain management.[35]

Qualitative methods facilitate a fuller understanding of how the person views their musculoskeletal symptoms as well as their values and priorities when managing symptoms.[70] Better understanding helps clinicians build a strong therapeutic alliance with people in pain and may promote adherence to treatment.[2,49]

Previous overviews of qualitative research syntheses in chronic conditions[76,77]

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have focused on general objectives—*experiences of living with a chronic illness*—and did not adequately cover emotions, cognitions, and behaviors. There are 7 contemporary qualitative research syntheses[14,21,57,59,60,66,69] that were not included in previous syntheses. Therefore, an updated umbrella review to incorporate all available qualitative evidence is warranted.

We aimed to summarize qualitative research syntheses to explore

[I] the emotions, cognitions, and behaviors of people with musculoskeletal disorders related to their symptoms and

[II] the emotions, cognitions, and behaviors that emerge when people interact with their environment (family, social, and work roles).

METHODS

We registered the review protocol at Open Science Framework (https://doi.org/10.17605/OSF.IO/TMBDF) before selecting reviews and extracting data.

Data Sources and Search Strategy

We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses literature search extension checklist to guide the construction and reporting of our search strategy.[58] A systematic search strategy was subsequently conducted from database inception to January 2021 in CINAHL (via EBSCOhost), EMBASE, PsycARTICLES (via ProQuest), PsycEXTRA (via ProQuest), PsycINFO (via ProQuest), PubMed, and PubPsych. Gray literature was searched via Open Grey (http://www.opengrey.eu/) and Google Scholar.[25] We conducted citation tracking from the reference lists of the included reviews. We did not search study registries or contact experts in the field to obtain additional records. No limits or restrictions were imposed during the search strategies.

A comprehensive search strategy was developed for PubMed and translated into a syntax for the other databases. Search filters by title and abstract [tiab] and Medical Subject Headings terms [mh] were used in PubMed and adapted for each database. **APPENDIX A** (available at www.jospt.org) shows the complete search strategy and the search filters applied for each database and gray literature. Manual searches updated the searches described in **APPENDIX A** (available at www.jospt.org) for CINAHL (via EBSCOhost), EMBASE, PsycARTICLES (via ProQuest), PsycEXTRA (via ProQuest), PsycINFO (via ProQuest), PubMed, and PubPsych until March 31, 2021. We listed the total number of records identified from each database and other sources in **FIGURE 1**. We eliminated duplicate records using citation management software (Mendeley Desktop v1.17.4) and by hand checking.[32]

Eligibility Criteria

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool for qualitative evidence synthesis guided the eligibility criteria.[15] We included literature published in the English or Spanish language. We did not impose ethnicity, gender, or setting restrictions.

The inclusion criteria were as follows:

[I] Sample: reviews that evaluated adults with musculoskeletal disorders, based on the multidimensional diagnostic criteria for acute and chronic pain.[22,29] We excluded conditions that were not principally musculoskeletal system disorders (eg, Parkinson's disease, scleroderma, Sjögren's syndrome, systemic lupus erythematosus, osteoporosis).

[II] Phenomenon of Interest: emotions, cognitions, and behaviors that emerged from the musculoskeletal symptoms or the interactions of people with musculoskeletal disorders with their environment (family, social, and work roles). We used the American Psychological Association Dictionary of Psychology (https://dictionary.apa.org/) to define "emotion," "cognition," and "behavior," as follows. Emotion: "a complex reaction pattern emerges to manage a relevant matter or event, involving experiential, behavioral, cognitive, and physiological factors (eg, fear or anger)." Cognition: "any form of knowledge and awareness (perception, idea, memory, reason, judgment, imagination, and problem solving)." When problem solving referred to ideas or thoughts to modulate symptoms, it was judged as a cognition. We considered problem solving a behavior when the individual had already executed or was executing the action. Our review only focused on cognitions in terms of beliefs and thoughts about musculoskeletal symptoms. We did not consider other cognitive aspects of the individual (eg, loss of memory). Behavior: "observable or measurable actions/functions to respond to stimuli (ie, hiding symptoms)."

[III] Design: We included systematic reviews or meta-summaries (meta-synthesis, meta-ethnographies, meta-aggregation, or meta-summary) of qualitative research. These reviews only satisfied our inclusion criteria when the review's authors clearly defined a strategy to (1) search for, (2) appraise, and (3) synthesize primary qualitative studies.

[IV] Evaluation: The phenomenon of interest must have appeared in the generated themes/subthemes of systematic reviews or meta-summaries of qualitative research.

[V] Research type: systematic reviews or meta-summaries (meta-synthesis, meta-ethnographies, meta-aggregation, or meta-summary) of qualitative research that include qualitative and/or mixed-methods research. If a review used mixed methods (qualitative and quantitative), we only included the review if the authors separated qualitative and quantitative data.

The exclusion criteria were reviews where

[I] any or all included primary research reported data from participants with musculoskeletal disorders who were scheduled for surgery or after a surgical procedure;

[II] any or all included primary research reported data from participants with fractures;

[III] there was no clear separation into musculoskeletal and nonmusculoskeletal conditions in the elaboration of themes/subthemes;
[IV] all themes were associated with the patient's perspectives about treatment, diagnosis, or patient-clinician interaction; and
[V] systematic review protocols and abstracts are without full text.

Review Selection

Two reviewers independently screened and selected reviews. We first evaluated titles and abstracts. Then, we analyzed full texts if it was unclear after reading titles and abstracts whether a review was eligible. Any disagreements were resolved via consensus.

Data Extraction

Two reviewers independently extracted the following information from each review only when it came from primary qualitative studies:

- the first author's name, year of publication, and the method to summarize the qualitative findings
- years covered by each database search
- the number of primary qualitative studies included
- participants with musculoskeletal disorders, musculoskeletal diagnosis, range of age, and the number of women
- the purpose of the review
- methodological quality assessment and confidence in the evidence assessment
- themes addressed
- subthemes addressed
- themes we did not include from the included reviews (ie, patient's perspectives about diagnosis)
- statements that expressed the emotions, cognitions, and behaviors described in the included themes or subthemes

We only extracted information from the themes of each included review when all the subthemes/categories referenced some of the objectives. We did not obtain any information from the themes that included subthemes/categories covering the patient's perspectives about treatment, diagnosis, or the interaction between the patient and the clinician.

Methodological Quality Assessment

The AMSTAR 2 tool[62] and the ROBIS tool[80] are used to evaluate the methodological quality of systematic reviews that used quantitative data. We did not find any research tool to judge the methodological quality of systematic reviews and meta-summaries using qualitative data.

Data Synthesis

There are several approaches (eg, meta-ethnography, grounded theory, thematic synthesis, textual narrative synthesis, or meta-study) to summarizing the qualitative evidence from primary qualitative studies.[4] However, there is not a consensus approach on how to summarize the information yielded by synthesizing qualitative evidence.

Qualitative evidence syntheses often provide a line of argument or model to present the reviewers' perceptions about the included themes and subthemes. However, some included reviews did not report a line of argument. We summarized the findings provided from the themes and subthemes of each qualitative research synthesis.

We did not consider the information from each included review reported in quotation. This information came from primary qualitative studies, and the present design is an umbrella review. Therefore, we did not include the information that appears in the tables of Daker-White et al's[17] review. The authors did not specify whether the information came directly from the original studies or whether they described the information after evaluating these studies.

Steps to Classify the Emotions, Cognitions, and Behaviors

Two reviewers independently read the included reviews in alphabetical order and constructed 2 tables (see "Themes" in the Results section). The same reviewers classified statements that reflected emotions, cognitions, and behaviors in the first or third person (verbatim from the original reviews, when possible). When a particular emotion, cognition, or behavior showed different opinions between participants (eg, "I am learning to accept to live with the pain" versus "I do not want to live with the pain"), we described it as contrary opinions/behaviors. We did not consider statements that reflected emotions, cognitions, and behaviors related to interventions, diagnosis, or patient-therapist interaction (topics were beyond the scope of our umbrella review).

Next, we developed 3 categories of themes ([1] emotions, [2] cognitions, and [3] behaviors) for each objective (**APPENDIX B**, available at www.jospt.org). A reviewer counted the number of times (only once for each included review) an emotion, a cognition, or a behavior category appeared in the included reviews. When several words were used to express a similar emotion, cognition, or behavior, we grouped these factors in the same emotion, cognition, or behavior category. We solved any disagreement by consensus. After counting, we selected the 3 most common emotions, cognitions, and behaviors to appear as themes in our narrative synthesis.

We used the dictionary proposed by the American Psychological Association (https://dictionary.apa.org/) to determine which words expressed an emotion (ie, fear) or a cognition (ie, self-confidence) and where we grouped them. If the dictionary did not define a particular emotion or cognition, we decided where to classify them. We decided how to group the behaviors. **APPENDICES B** and **C** (available at www.jospt.org) show all the processes used to select the themes for each category.

Developing a Line-of-Argument Synthesis

Finally, a line-of-argument synthesis helped reveal which parts of the individual reviews connected to each other. The concepts explored in this umbrella review (emotions, cognitions, and behaviors) reflect the broad topic of "the psychological

profile" of people with musculoskeletal disorders when facing their symptoms or interacting with their environment. Therefore, a synthesis that shows a line of argument is appropriate for this purpose.[76]

Detecting a Possible Overlap Between Reviews

We used citation matrices and corrected covered area (CCA) calculations[55] to evaluate the degree of overlap between reviews considering primary qualitative research. **APPENDIX D** (available at www.jospt.org) shows the citation matrix. We interpret the CCA as the area covered after removing all primary publications the first time these publications were counted.[55] A slight overlap appears when the CCA value is less than 5. A CCA value ranging from 6 to 10 is moderate overlap. High overlap is a CCA value ranging from 11 to 15. We considered values greater than 15 as very high overlap.[55]

Co-occurrence Analysis

We used the software VOSviewer 1.6.16 (www.vosviewer.com/) to create a map based on bibliographic data. Specifically, we used co-occurrence key words added by the included reviews with the application of a full counting method. This approach helps readers understand potential connections between reviews covering the same or a similar topic. The VOSviewer maps can detect patterns of terms in a topic.

RESULTS

Databases retrieved a total of 3577 records. Citation searching and gray literature found 102 additional references. A total of 2194 records were evaluated by title and abstract after removing duplicates. We evaluated 260 full texts, and finally, we included 20 qualitative research syntheses (**FIGURE 1**). We listed the excluded full-text records (n = 240) in **APPENDIX E** (available at www.jospt.org).

The included reviews retrieved a total of 284 original qualitative studies (**TABLE 1**). These reviews included participants with fibromyalgia, gout, low back pain, mixed musculoskeletal disorders, rheumatoid arthritis, and whiplash. Eleven reviews used the Critical Appraisal Skills Programme qualitative checklist[12] or a modified version of it to assess the methodological quality of primary qualitative research.[14,17,21,53,57,59,60,66,69,74,75] No review used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) tool[33] to evaluate certainty of evidence.

Co-occurrence Analysis

The VOSviewer maps (network and density visualization analyses) detected some patterns in the use of key words. Words or expressions such as meta-ethnography, meta-synthesis, qualitative research, chronic pain, low back pain, patient experience, and rheumatoid arthritis were often used (**FIGURES 2** and **3**).

Overlapping

The included reviews retrieved a total of 489 publications, comprised of 284 unique studies. The citation matrix shows publications represented in more than 1 of the included reviews (see **APPENDIX D**, available at www.jospt.org). We calculated the CCA to determine the degree of overlap across the included reviews, as follows:

$$CCA = \frac{N\text{-}r}{rc\text{-}r} = \frac{489-284}{5.680-284} = \frac{205}{5.396}\,0.038 = 3.8\%,$$

where "N" is the number of included publications (including double counting) in the available evidence synthesis (this is the sum of the ticked boxes in the citation matrix), "r" is the number of rows (number of index publications), and "c" is the number of columns (number of reviews).[55]

The CCA was 0.038 (3.8% overlap). Therefore, there was a slight overlap across the included reviews.

Themes

APPENDICES F and **G** (available at www.jospt.org) show the statements that reflect the emotions, cognitions, and behaviors reported in each included review.

1. Emotions and musculoskeletal symptoms

The 3 emotions mainly reported across the included reviews were (see **APPENDIX F** for all emotions, available at www.jospt.org)

- fear,
- despair, and
- distress.

1.1. Fear/afraid

Fear often emerged related to the unpredictability of the illness, development of the symptoms, the execution of daily activities, or the concept of self.[8,14,17,21,24,59,65,67–69,74]

1.2. Despair/frustration/hopelessness or hope/helplessness or help/overwhelm/fluctuations between hope and despair

Despair appeared in 11 reviews[8,14,17,21,37,53,57,63,65,66,69] associated with ruminating thoughts and the concept of self or directly associated with the symptoms. Hope emerged when people struggled for normality. Fluctuations between hope and despair also appeared regarding the fluctuations of pain.

1.3. Distress/worry/concerns

Distress, directly associated with the symptoms, often emerged related to the unpredictability of the illness, the concept of self, and the management of the condition. However, some people were not worried about the pain experience.[8,14,17,21,23,37,53,63,65,69]

2. Cognitions and musculoskeletal symptoms

The 3 cognitions mainly observed across the included reviews were (see **APPENDIX F** for all cognitions, available at www.jospt.org)

- the description of the symptoms,
- the impact of the symptoms on other variables and factors believed to cause them, and
- cognitive strategies to manage the symptoms.

2.1. Description of the symptoms

Fourteen reviews[8,14,17,21,34,37,53,57,60,63,65,67–69] showed that people perceived their symptoms as the worst they have ever experienced. They often expressed their symptoms as chronic, incurable, invisible, omnipresent, salient, unbearable, or unpredictable.

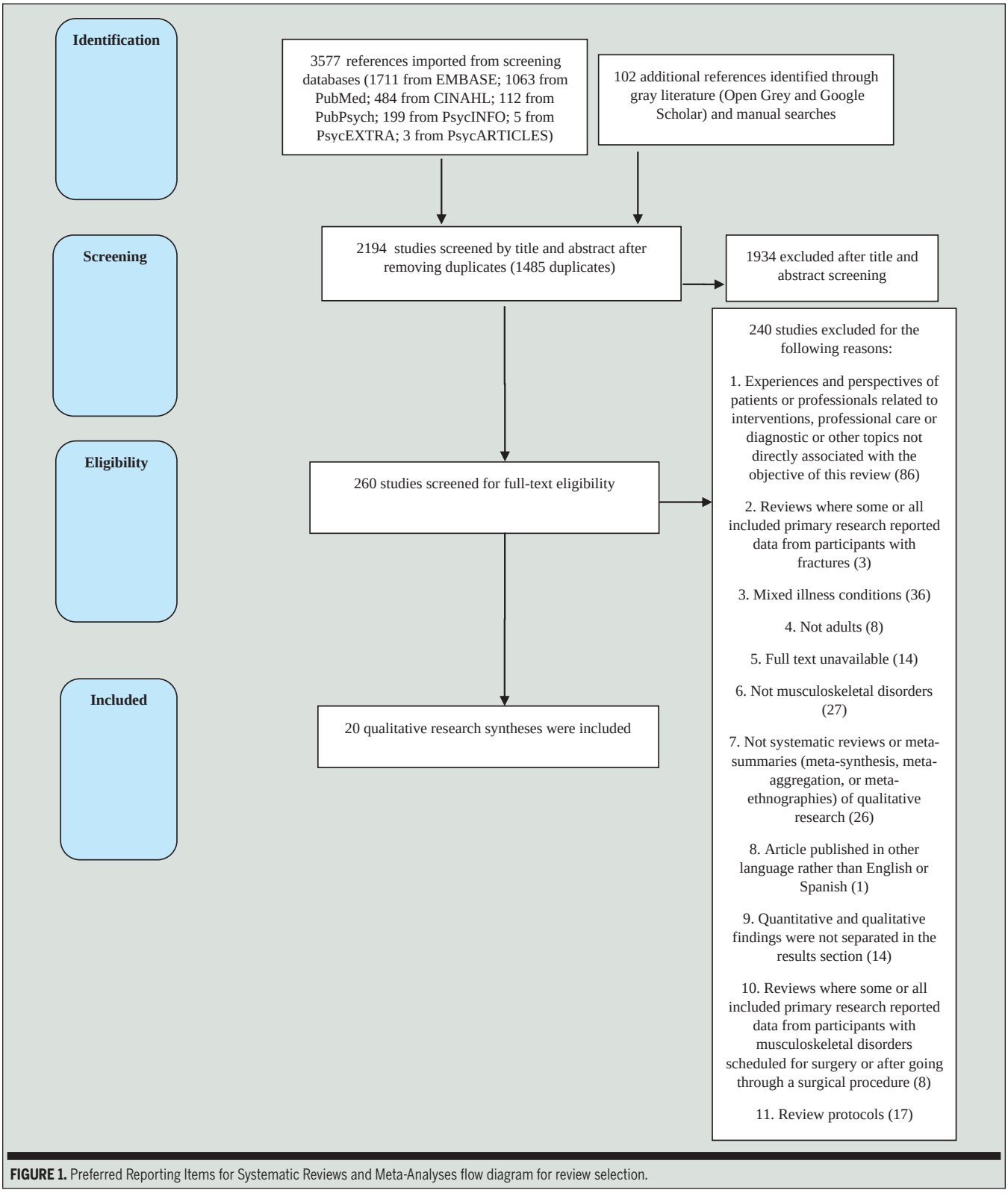

FIGURE 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram for review selection.

TABLE 1 Characteristics of the Included Reviews[a] (n = 20)

First Author and Year of Publication	Purpose of the Review	The Databases Years Covered	Synthesis Method	The Number of Primary Qualitative Studies Included in Each Review	Total Number of Participants, Diagnosis, Age Range, and Number of Women Included in Each Review	Methodological Quality Assessment and Confidence in the Evidence Assessment	Themes Included in Each Review	Subthemes/Categories Underpinning Each Theme	Themes Excluded in This Overview
Bunzli et al (2013)[8]	To explore the patient's chronic low back pain experience	MEDLINE, EMBASE, AMED, CINAHL, PsycINFO, Sociological Abstracts, and Scopus were searched twice over the period from January 2011 to October 2011.	Meta-synthesis An adaptation from Sandelowski and Barroso[61] criteria	25 articles comprised 18 studies	713 participants with chronic low back pain (age ranged from 19 to 80 years [unknown data reported by 1 study]; 125 women [unknown data reported by 3 studies])	An adaptation of Popay et al[56] criteria Confidence in the evidence was not evaluated.	(I) The social construction of chronic low back pain (II) The psychological impact of the nature of chronic low back pain (III) Coping with chronic low back pain	(I) Stigma; Experience with health system; Establishing credibility (II) Omnipresence of pain; Fluctuating/unpredictable; Effect of pain in life disruption; Effect of pain in psychological and physical symptoms (III) Acceptance; Coping strategies	(I)
Climent-Sanz et al (2020)[14]	To explore how people diagnosed with fibromyalgia experience and manage poor sleep quality following the concepts of the Symptom Management Theory	PubMed, Scopus, ISI Web of Science, and CINAHL Plus. The last update of the search was on January 3, 2020.	Meta-synthesis and meta-summary An adaptation from Sandelowski and Barroso[61] criteria	17 articles	376 participants with fibromyalgia (age ranged from 20 to 70 years; 336 women)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Experience of poor sleep quality (II) Poor sleep quality management strategies	(I) Evaluation of poor sleep quality; Response to poor sleep quality (II) Management strategies to favor sleep; Managing the consequences of a sleepless night	All themes were included.

Daker-White et al (2014)[17]	To explore the lived experience of rheumatoid arthritis	MEDLINE, EMBASE, Social Science Citation Index, Science Citation Index, CINAHL, PsycINFO, and Zetoc; studies published between January 1992 and December 2001 An update using MEDLINE in early 2010 to include studies between 2002 and 2009	Meta-ethnography	21 articles comprised 24 studies (first synthesis) 28 articles (second synthesis) However, only 42 references appear in the result section.	Rheumatoid arthritis (the number of participants, age range, and the number of women were not reported)	A modified version of the CASP qualitative checklist[11,12] Confidence in the evidence was not evaluated.	First synthesis: (I) Disease conditions in the medical body (II) Consequences in the social body (III) Responses and coping strategies: individual, interpersonal, and environmental (IV) Gender issues Second synthesis: (V) The nature of symptoms and strategic responses (VI) Perceptions of control (VII) Biographical issues – redefining "normal" life (VIII) The body in rheumatoid arthritis	(-)	All themes were included.
Donnelly et al (2020)[21]	To explore the lived experience of self-management described by adults living with rheumatoid arthritis	MEDLINE, EMBASE, CINAHL, PsycINFO, and ASSIA in March 2018 and again in January 2019	Meta-synthesis Thomas and Harden's[72] thematic synthesis approach	32 articles	665 participants including mixed arthritis conditions (mostly rheumatoid arthritis, n = 640) (age and the number of women were not reported)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Cognitive-emotional (II) Behavioral (III) Social (IV) Environmental (V) Physical (VI) Technological	(I) Acceptance, lack of; Anger, frustration, and irritability; Blame, cause; Social comparison; Depression, sadness, despair, and suicide; Hopes and fears; Optimism, positivity, and humor; Religion and spirituality; Self (concept, esteem, efficacy); Shame, guilt, and embarrassment (II) Adjustment and adaptation; Planning and pacing; Self-care; Help-seeking (III) Invisible illness; Domestic roles; Employment; Economic; Gender; Loss, loneliness, and isolation; Personal and social relationships (IV) Access and built environment, weather, and temperature (V) Body as ill, deformed, and disabled; Symptoms (VI) Assistive devices and aids; Health care professionals and services; Medical treatment	(VI)

Table continues on page 250.

TABLE 1 Characteristics of the Included Reviews[a] (N = 20) (continued)

First Author and Year of Publication	Purpose of the Review	The Databases Years Covered	Synthesis Method	The Number of Primary Qualitative Studies Included in Each Review	Total Number of Participants, Diagnosis, Age Range, and Number of Women Included in Each Review	Methodological Quality Assessment and Confidence in the Evidence Assessment	Themes Included in Each Review	Subthemes/Categories Underpinning Each Theme	Themes Excluded in This Overview
Feddersen et al (2017)[23]	To explore how women with rheumatoid arthritis manage their illness, motherhood, and paid work	CINAHL, Cochrane, EMBASE, PsycINFO, PubMed, Scopus, Sociological Abstracts, SveMed+, and Web of Science between November 2014 and April 2015	Meta-ethnography Noblit and Hare's[51] approach Burke and Stets[10] identity theory to develop the line of argument	6 articles	156 participants with rheumatoid arthritis (114 women; age range was not reported)	Items proposed by Dixon-Woods et al[19] Confidence in the evidence was not evaluated.	Social interactions in the performance of 3 interdependent sub-identities	Paid work; Motherhood; Living with rheumatoid arthritis	All themes were included.
Froud et al (2014)[24]	To explore the impact of low back pain in people's lives	CINAHL, EMBASE, PsycINFO, PEDro, and MEDLINE from inception to July 2011	Meta-synthesis Marston and King's[6,40] approach Development of a line of argument	49 articles comprised 42 studies	Low back pain (age ranged from 36 to 55 years [most primary studies did not report age data]) The total sample and the number of women were not included in this overview due to that the meta-synthesis did not specify which studies belong to the same cohort.	The COREQ framework[50,73] Confidence in the evidence was not evaluated.	(I) Activities (II) Relationships (III) Work (IV) Stigma (V) Changing outlook	(I) Domestic; Leisure, rest, and sleep (II) Damage and isolation; Family and cohabitation; Sex; Social (III) Anxiety; Off sick; Financial (IV) Delegitimization; Diagnosis; Meeting expectations (V) Quest for diagnosis; Psycho-emotional; Adaptation and acceptance	(IV) and (V)

Lin et al (2011)[34]	To explore the status of spiritual well-being in rheumatoid arthritis patients	Academic Search Complete, CINAHL, MEDLINE, PsycARTICLES, and SocINDEX; articles from 1995 to 2009	Meta-synthesis Sandelowski and Barroso[61] criteria	10 articles	123 participants with rheumatoid arthritis (age ranged from 21 to 80 years [1 study did not report age data]; 110 women)	Standards proposed by Sandelowski and Barroso[61] Confidence in the evidence was not evaluated.	(I) Living with the disease (II) Reclaiming control (III) Reframing the situation (IV) Bolstering courage	(I) Redefining the concept of normal life; Accepting disease restrictions; Accepting limitations and changes in roles; Accepting disease as a part of life (II) Reorganizing lifeways; Using new strategies; Listening to the body; Seeking resources; Being flexible; Concentrating on recovery (III) Positive thinking; Finding meaning; Changing values (IV) Strengthening the will to live; Having responsibility for nurturing; Having confidence and optimism; Maintaining hope	(II) and (IV)
MacNeela et al (2015)[37]	To explore the subjective experience of chronic low back pain	MEDLINE, PsycINFO, CINAHL, Scopus, PubMed, EBSCO Academic Search Complete, and EBSCO Health Source: Nursing/Academic Edition in May 2012 to identify publications up to the end of 2011	Meta-ethnography based on reciprocal translation and refutational analysis Development of a line of argument	38 articles comprised 28 studies	1077 participants with chronic low back pain (age ranged from 18 to 83 years; 350 women [2 studies did not report gender data])	Meyrick's[48] criteria Confidence in the evidence was not evaluated.	(I) The undermining influence of pain (II) A disempowering impact on all levels (III) The person as a patient: Unsatisfying relationships with health care (IV) Learning to live with pain	(I) Discomfort, distress, and loss; Worry and fear for the future (II) Hopelessness; An oppressive intrusion on the self; Family strain; Loss of job and lack of money; Social withdrawal (III) Needing confirmation; Disappointment with health care; Listening and communication (IV) Coming to terms with pain; Self-management practices; Attitudes to collaboration	(III) and (IV)
Parenti et al (2020)[53]	To explore how rheumatoid arthritis affects daily life	CINAHL, ProQuest, PsycINFO, PubMed, Scopus, and Web of Science from February until April 2016 and from April to May 2020	Meta-synthesis Sandelowski and Barroso[61] criteria	21 articles	480 participants with rheumatoid arthritis (age ranged from 18 to 86 years; 333 women)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Impact on daily life (II) Independence and normality (III) Health (IV) Confronting the illness	(I) Physical domain; Psychological domain; Social domain (II) No subthemes included (III) No subthemes included (IV) Fighting attitude; Resignation	(I)
Primdahl et al (2019)[57]	To explore the experience of living with rheumatoid arthritis–related fatigue	PubMed, CINAHL, EMBASE, SveMed+, PsycINFO, and Web of Science until February 2017, to identify studies published in the past 15 years	Meta-synthesis Malterud's[38,39] systematic text condensation	8 articles	212 participants with rheumatoid arthritis (age ranged from 20 to 83 years; 146 women)	CASP[12] qualitative checklist and the standards proposed by Sandelowski and Barroso[61] Confidence in the evidence was not evaluated.	A vicious circle of an unpredictable symptom	Being alone with fatigue; Time as a challenge; Language as a tool for increased understanding; Strategies to manage fatigue	All themes were included.

Table continues on page 252.

TABLE 1 Characteristics of the Included Reviews[a] (n = 20) (continued)

First Author and Year of Publication	Purpose of the Review	The Databases Years Covered	Synthesis Method	The Number of Primary Qualitative Studies Included in Each Review	Total Number of Participants, Diagnosis, Age Range, and Number of Women Included in Each Review	Methodological Quality Assessment and Confidence in the Evidence Assessment	Themes Included in Each Review	Subthemes/Categories Underpinning Each Theme	Themes Excluded in This Overview
Riggs and Killingback (2019)[59]	To explore the experiences of people with rheumatoid arthritis to develop a better insight into the factors that influence physical activity participation	MEDLINE, CINAHL, ScienceDirect, PsycINFO, Web of Science up to 11 November, 2017; no date limitations	Qualitative literature review Thomas and Harden's[72] thematic synthesis approach	7 articles	106 participants with rheumatoid arthritis (age ranged from 23 to 83 years; 79 women)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Professional knowledge and guidance (II) Part of a community (III) Knowing me, knowing rheumatoid arthritis (IV) What's in it for me (V) Where, when, how much?	(-)	(I)
Robart and Boyle (2021)[60]	To explore what factors facilitated a return to work for those in employment and what factors may be in preventing others from making a successful return to work	PubMed, Health Research Premium Collection, AMED, CINAHL, MEDLINE, and PsycINFO published between January 1, 2009, and January 23, 2019	Meta-ethnography Noblit and Hare's[51] approach	10 articles	Low back pain (the number of participants, age range, and the number of women were not reported)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Enabling injured workers to return to work safely (II) Challenging negative assumptions (III) Overcoming organizational barriers	(I) The workers' characteristics, attitudes, and perceptions; Significant others; Modification of work duties, activity, and environment (II) Credibility; Uncertainty (III) Communication; Workplace relations; System issues	(III)
Sim and Madden (2008)[63]	To explore the subjective impact of fibromyalgia	MEDLINE, CINAHL, Social Science Citation Index, Science Citation Index, Sociofile, PsycINFO, Sociological Abstracts, and AMED until October 31, 2006	Meta-synthesis	28 articles comprised 23 studies	383 participants with fibromyalgia (age range was not reported; 360 women)	An adaptation of Popay et al[56] criteria Confidence in the evidence was not evaluated.	(I) Experience of symptoms (II) Search for a diagnosis (III) Legitimacy (IV) Coping	(I) Pain; Describing pain; Fatigue; Psychological problems (II) Pre-diagnosis; Receiving a diagnosis for fibromyalgia; Post-diagnosis (III) Legitimacy (IV) Coping; Reevaluation of life	(II) and (III)

Snelgrove and Liossi (2013)[65]	To explore the experiences of patients with low back pain	PsycINFO, CINAHL Plus with Full Text, PubMed, Web of Knowledge, Cochrane Library, Google Scholar, ASSIA, Scopus, and IPA website; studies published between 2000 and 2012	Meta-synthesis Noblit and Hare's[51] approach (meta-ethnography)	33 articles comprised 28 studies	Chronic low back pain (age ranged from 17 to 84 years; the number of participants and women was not specified)	No formal appraisal was used, but established appraisal criteria were applied.[45] Confidence in the evidence was not evaluated.	(I) The impact of chronic low back pain in self (II) Relationships with significant others: Health professionals and the organization of care, family, and friends (III) Coping with chronic low back pain	(-)	(II)
Söderlund et al (2018)[66]	To explore patients' experiences of whiplash-associated disorders and the injury-recovery process	PubMed, PsycINFO, Scopus, and Web of Science until June 2017	Meta-synthesis Sandelowski and Barroso[61] and Walsh and Downe[79] criteria	4 articles	81 participants with whiplash injuries (mean age ranged from 40.6 to 44.3 years; 56 women)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Distancing from normalcy (II) Self-efficacy in controlling the life situation after the injury (III) Readjustment and acceptance	(I) Interference and loss; Existential uncertainty (II) Perceiving struggling with control; Knowledge and understanding (III) Recapture life roles; Happiness	All themes were included.
Stack et al (2011)[67]	To explore drivers of and barriers to help-seeking behavior in adults with a new onset of rheumatoid arthritis	EMBASE Classic+EMBASE (1947 to November 2010), HMIC Health Management Information Consortium (2010), CAB Abstracts (1973 to November 2010), Ovid MEDLINE (1950 to October 2010) and PsycINFO (1806 to November 2010), and online abstracts from the European League Against Rheumatism (2002-10) and American College of Rheumatology (2006-10) conferences	A systematic synthesis of qualitative literature Thematic synthesis and grounded theory frameworks[7,13]	21 articles	Rheumatoid arthritis The number of participants; range age and the number of women was not reported.	No formal qualitative tool; used quality criteria[16,18,30,31] Confidence in the evidence was not evaluated.	(I) The early rheumatoid arthritis symptom experience (II) Making sense of early symptom experience and prototypes of rheumatoid arthritis (III) Minimizing the impact of symptoms (IV) Speaking to others, gathering information, and seeking alternative treatments (V) Accessing health services and attitudes toward health care professionals	(-)	(IV) and (V)

Table continues on page 254.

TABLE 1 Characteristics of the Included Reviews[a] (N = 20) (continued)

First Author and Year of Publication	Purpose of the Review	The Databases Years Covered	Synthesis Method	The Number of Primary Qualitative Studies Included in Each Review	Total Number of Participants, Diagnosis, Age Range, and Number of Women Included in Each Review	Methodological Quality Assessment and Confidence in the Evidence Assessment	Themes Included in Each Review	Subthemes/Categories Underpinning Each Theme	Themes Excluded in This Overview
Stack et al (2013)[68]	To explore the experiences of patients with rheumatoid arthritis in terms of symptoms at the onset of their disease	Ovid MEDLINE (PubMed; 1950 to June 2012), CINAHL (1937 to June 2012), and PsycINFO (1806 to June 2012)	A synthesis of qualitative literature Thematic synthesis and grounded theory frameworks	26 articles comprised 25 studies	510 participants with rheumatoid arthritis (the number of participants was not reported in 1 study) (age range was not reported; 375 women [the number of women was not reported in 3 studies])	No formal qualitative tool; used quality criteria[30,31] Confidence in the evidence was not evaluated.	(I) Swelling (II) Pain and tenderness (III) Stiffness (IV) Fatigue and weakness (V) The emotional impact of symptoms	(-)	All themes were included.
Stewart et al (2020)[69]	To explore the experience of patients about gout flares	MEDLINE (Ovid) (1946-2019), EMBASE (1980-2019), CINAHL Plus (1937-2019), and PsycINFO (1967-2019) in October 2019	Meta-synthesis Thematic analysis[5]	16 articles	527 participants with gout (age ranged from 16-25 to 87 years; 184 women)	CASP[12] qualitative checklist Confidence in the evidence was not evaluated.	(I) Gout flare characteristics (II) Function and difficulties with activities of daily living (III) Effects on social and family life (IV) Psychological impacts	(I) Pain; Effect of join swelling; Duration and frequency; Flare location (II) Footwear; Sleep; Walking; Self-care; Driving; Housework and yard work; Exercise and sports (III) Employment; Social participation; Relationships; Inability to plan; Dependency; Intimacy (IV) Depression/anxiety; Financial worry; Fear, isolation; Shame/embarrassment; Irritability; Boredom	All themes were included.

Toye et al (2013)[74]	To explore the experiences of patients with chronic nonmalignant musculoskeletal pain	MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, HMIC from inception to February 2012	Meta-ethnography Noblit and Hare's[51] approach	77 articles comprised 60 studies	Chronic mixed musculoskeletal pain (age ranged from 18 to 91 years; the number of participants and women was not specified)	CASP[12] qualitative checklist; JBI-QARI[71]; and papers were categorized as key papers, satisfactory papers, irrelevant papers, or fatally flawed papers[20] Confidence in the evidence was not evaluated.	(I) Struggling to affirm a sense of myself (II) Altered construction of time (III) Struggling to explain why I am suffering (IV) Struggling to negotiate the health care system (V) Struggling to prove that I am credible (VI) Moving forward with chronic pain	(I) My body is now against me; The old me is my real self; I am becoming isolated from others (II) My days are unpredictable; My future will not be what I thought (III) It does not make sense there is no medical reason; No one believes me because I have nothing to show for it; There must be some other reason (IV) I cannot see the point of going to the doctor again, but I must; I need someone to listen to me and understand what pain has done to me (V) Should I hide or show my pain? I need to show that I am not like other people with pain (VI) I now cooperate why my body and work with it; I am still me and can enjoy my life; There are other people like me that believe and value my experience; I do not have to hide my pain and can let people know my limitations; I realize that I have changed but do not need to continue searching for a medical answer; I am confident to give things a go and make changes	(IV)
Toye et al (2016)[75]	To explore barriers to stay in work with chronic pain	MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, and HMIC until February 2012	Meta-ethnography Noblit and Hare's[51] approach Development of a line of argument	19 articles comprised 15 studies	332 participants with chronic mixed musculoskeletal pain (age ranged from 20 to 80 years; the number of women was not reported)	CASP[12] qualitative checklist; JBI-QARI[71]; and papers were categorized as key papers, satisfactory papers, irrelevant papers, or fatally flawed papers[20] Confidence in the evidence was not evaluated.	(I) Struggling to affirm myself as a good worker (II) Balancing life and work in the face of unpredictable symptoms (III) My work colleagues don't believe me (IV) The system does not facilitate return to work (V) The battle for legitimacy	(-)	(IV) and (V)

Abbreviations: AMED, Allied and Complementary Medicine Database; ASSIA, Applied Social Sciences Index and Abstracts; CASP, Critical Appraisal Skills Programme; CINAHL, Cumulative Index to Nursing and Allied Health Literature; COREQ, Consolidated Criteria for Reporting Qualitative Research; HMIC, Health Management Information Consortium; ISI, The Institute for Scientific Information; JBI-QARI, Joanna Briggs Institute Qualitative Assessment and Review Instrument; PEDro, Physiotherapy Evidence Database.

[a]*We excluded all the subthemes included on an excluded theme in the last column. A lack of subthemes appears in some included reviews since these reviews did not report subthemes in their findings. Themes or subthemes/categories that entirely covered the patient's perspectives about treatment, diagnosis, or the patient-clinician interaction were not included in this overview.*

(-) *review did not subcategorize its themes into different subthemes.*

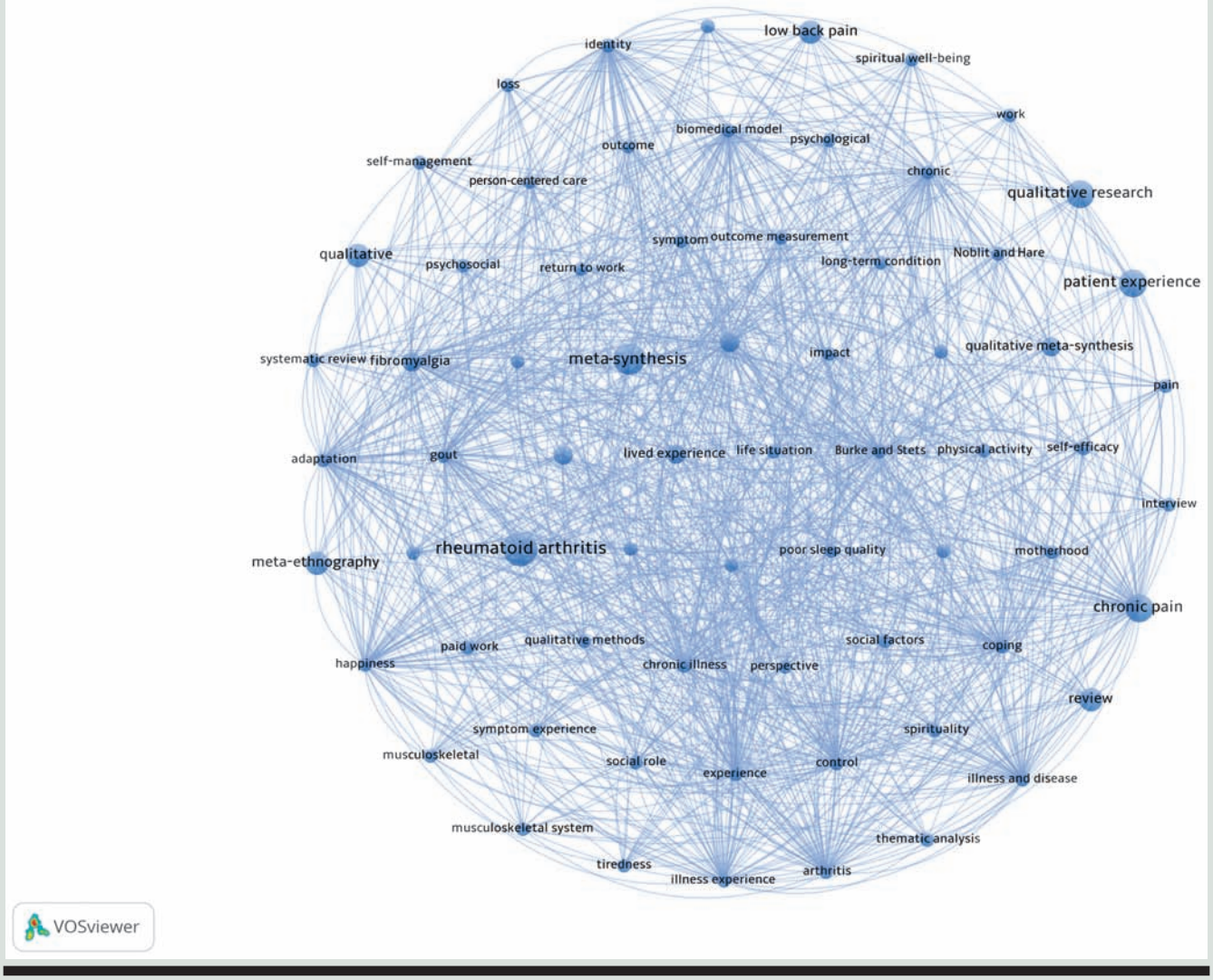

FIGURE 2. Network visualization analysis.

2.2. The impact of the symptoms on other variables and factors believed to cause them

Seventeen reviews[8,14,17,21,23,24,37,53,57,59,63,65–69,74] described (1) how people perceive the symptoms that affect other aspects of their lives (ie, sleep disturbances) and (2) how biomedical factors (ie, genetic explanations) explain the symptoms.

2.3. Cognitive strategies to manage the symptoms

Thirteen reviews[8,14,17,21,24,34,53,57,59,63,65,66,74] described how people used different cognitive strategies to try to solve the problems related to their musculoskeletal symptoms, such as learning to accept the symptoms and developing psychological flexibility.

3. Behaviors and musculoskeletal symptoms

The 3 behaviors mainly reported were (see **APPENDIX F** for all behaviors, available at www.jospt.org)

- activity avoidance/restrictions,
- fighting with the symptoms/continuing with normal activities, and
- planning/prioritizing/pacing activities.

3.1. Activity avoidance/restrictions

Eight reviews[8,14,17,37,57,63,65,69] showed how people avoided or restricted their activities (eg, leaving home or participating in recreational activities) to cope with their symptoms.

3.2. Fighting with the symptoms/continuing with normal activities

Seven reviews[8,53,63,65,66,69,74] described how people struggle for normality and try to find a balance between showing their pain or not.

3.3. Planning/prioritizing/pacing activities

People planned, prioritized, and paced their activities (ie, diving tasks) to regulate their bad days and, thus, save energy for other tasks.[21,23,24,57,63,65,66]

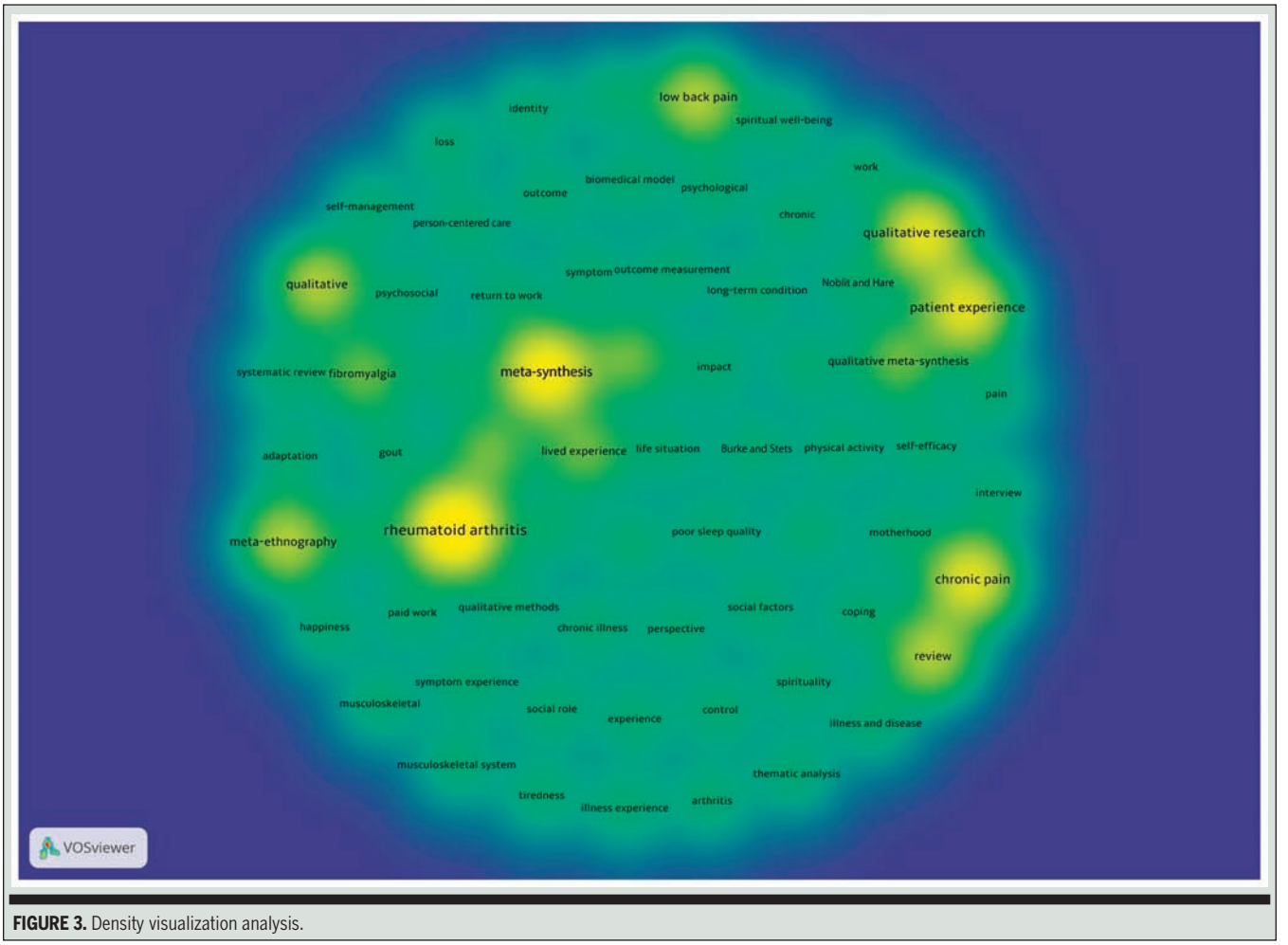

FIGURE 3. Density visualization analysis.

4. Emotions emerge when interacting with the environment

The 3 emotions mainly reported across the included reviews were (see **APPENDIX G** for all emotions, available at www.jospt.org)

- fear,
- distress, and
- despair.

4.1. Fear/intimidation/dread

Twelve reviews[8,17,21,23,24,57,59,60,65,69,74,75] described how fear emerged when people interacted with their environments in family, social, and work roles. Dread also appeared when people met individuals with more advanced illness stages.

4.2. Distress/worry/concerns/self-absorption

Eight reviews[14,17,24,37,57,60,69,75] showed the feeling of worry that people had in their occupational, social, and personal environments.

4.3. Despair/despondency/hope or hopelessness/help or helplessness/frustration/overwhelm

Ten reviews[8,17,21,37,57,60,65,66,69,74] described the desperation of people with musculoskeletal disorders when interacting with their social, family, and work environments.

5. Cognitions emerge when interacting with the environment

The 4 main cognitions observed across the included reviews were (see **APPENDIX G** for all cognitions, available at www.jospt.org)

- support/being a burden,
- the impact of the individuals' symptoms in their interaction with their environment,
- cognitive strategies to manage their symptoms, and
- changes of selves.

5.1. Support/being a burden

Discrepancies emerged regarding social support. Some people felt well supported and desired social support during their process. However, others described they were a burden or they received too little or too much support.[17,21,23,24,34,37,57,59,60,65,66,74,75]

5.2. The impact of the symptoms in the interaction of the individuals with their environment

People described how their musculoskeletal symptoms (ie, fatigue) affected their daily functioning. Some people perceived a reduction in their abilities to work; others reported that social and family roles

were altered (ie, challenges to make plans).[8,14,17,21,23,24,37,57,60,63,65–69,75]

5.3. Cognitive strategies to manage the symptoms

Thirteen reviews[8,17,21,24,34,57,59,60,63,65,66,74,75] described how people use different cognitive strategies, such as (1) learning to accept the situation, (2) psychological flexibility, or (3) social comparisons to manage the consequences of their symptoms on their environment.

5.4. Changes of selves

Thirteen reviews[17,21,23,24,34,37,53,59,60,65,66,74,75] reflected the alterations of the self when people with musculoskeletal disorders interacted with their environment. Some people reported that their social context could threaten the integrity (ie, a loss of self-worth) of their selves. Others mentioned that the environment (ie, stay connected in the labor market) could represent a positive identity marker.

6. Behaviors emerge when interacting with the environment

The 3 most common behaviors were (see **APPENDIX G** for all behaviors, available at www.jospt.org)

- practicing activities despite the symptoms,
- activity avoidance or restrictions/social withdrawal/social isolation, and
- hiding symptoms.

6.1. Practicing activities despite the symptoms

People practiced different activities (eg, waking up in the morning or doing work tasks) despite their symptoms to minimize potential alterations in social situations and the workplace.[14,24,34,37,57,65,75]

6.2. Activity avoidance or restrictions/social withdrawal/social isolation

People avoided, restricted, withdrew, or isolated from society to avoid showing their symptoms and the possibility of stigma.[8,21,24,37,57,63,65,69]

6.3. Hiding symptoms

People hid their symptoms, such as physical deformities, fatigue, or pain in social and work situations. People also avoided divulging their suffering to their friends/colleagues.[21,23,24,57,69,74,75]

Line-of-Argument Synthesis

Musculoskeletal disorders have a detrimental impact on people living with them. The lack of a clear map to help people fosters distress, despair, and fear. These emotions affect the person when managing their symptoms and interacting with their environment. People use different expressions when referring to their symptoms and often think about what is happening to them, what caused the condition, and how this condition affects their daily lives.

People try to develop cognitive strategies (eg, acceptance or flexibility) to manage the consequences of their symptoms. People perceive that social support is not always a positive approach, which can erode their social relationships. People also showed that their selves can be altered or improved when interacting with their environment. They try to face the process using passive (eg, social isolation or hiding symptoms) or active (eg, planning the activities or practicing them despite their symptoms) behaviors.

DISCUSSION

Our umbrella review of qualitative research syntheses focused on exploring the emotions, cognitions, and behaviors that people with musculoskeletal disorders have about their symptoms and on determining which psychological factors emerge during the interaction with their environment. Previous studies that evaluated reviews of qualitative studies analyzed a broad issue: "the experience of people living with heterogeneous chronic non-malignant pain"[76] or "rheumatoid arthritis."[77] Both overviews agreed with our findings.

Emotions, Cognitions, and Behaviors in Musculoskeletal Disorders

There is a clear line of argument about how people with chronic musculoskeletal symptoms confront their experiences. People with chronic pain or rheumatoid arthritis expressed that their journey was an emotional challenge. Most people revealed that they often felt negative emotions, such as distress, despair, and fear circling their chronic illness future. Quantitative research focusing on exploring emotions related to pain-related fear is available (fear of pain, kinesiophobia, pain-related anxiety, or fear-avoidance beliefs).[36,42] However, some of the emotions we identified are difficult to measure using quantitative methods (patient-reported outcome measurements) (eg, *despair related to pain*). Another relevant point is how emotions are assessed in the context of pain. They are sometimes measured using research tools that evaluate global aspects of a patient's life[81,83] or they are scarcely used in the context of pain,[26] for example, *distress* (the Hospital Anxiety and Depression Scale[83] or the Polysymptomatic Distress Scale[81]) or *hope/hopelessness* (the Kiel Pain Inventory[26]).

Our umbrella review and previous works[76,77] underscore that people with musculoskeletal disorders perceive their pain as an essential symptom. Many words (incurable, invisible, omnipresent, unbearable, and unpredictable) were used to detail what pain means for people who suffer from it. However, quantitative research has mainly explored pain dimensions, such as intensity, severity, and interference with functioning.[82] Many unidimensional, multidimensional, and behavioral scales are available to measure pain.[82] We argue that these tools have missed essential components related to the pain that people usually describe (eg, *pain is invisible*). We believe that using qualitative approaches (including open-ended questions) may better reflect how people feel, think, and behave about their symptoms rather than using patient-reported outcome measures alone. We call on the pain community to focus efforts on evaluating how people live with their musculoskeletal symptoms as well as their priorities and concerns about how to manage symptoms.

People use cognitive strategies (eg, acceptance or flexibility) and passive (eg, social isolation or hiding symptoms) or active (eg, planning the activities or

practicing them despite their symptoms) behaviors to face their symptoms. People with chronic musculoskeletal pain who often use passive behaviors are at a lower risk of social isolation but at a greater risk of loneliness.[64] People feel stigmatized about their symptoms[65] and feel like a burden on their social environment.[21] Some reviews have reflected how people with musculoskeletal disorders hide their symptoms[23,74] and withdraw from social activities.[8,24,37] We believe this isolation could nurture the feeling of loneliness, but further research is needed to confirm our hypothesis.

How Might Clinicians Modulate Emotions, Cognitions, and Behaviors?

In clinical practice, fear of pain exacerbation or difficulty understanding the causes of pain could affect how people with musculoskeletal disorders adhere to interventions.[3,47] Health care providers might consider using strategies aimed at fostering adherence and reducing escape behaviors. Self-efficacy is an essential factor for promoting adherence toward healthy behaviors that improve the practice of exercise in people with low back and neck pain.[1] Self-efficacy has received the most empirical attention in chronic disorders.[28,41] One approach is to help people feel confident to set goals and self-monitor/evaluate.[54]

Combining psychosocial interventions and exercise therapy is likely the best approach to improve pain self-efficacy in individuals with chronic musculoskeletal pain.[43] We encourage clinicians to focus on improving self-efficacy beliefs. We also encourage health professionals to help people enhance healthy cognitive strategies such as acceptance or psychological flexibility. These factors are essential processes in acceptance and commitment therapy,[46] which can elicit important benefits for people with chronic pain (eg, pain interference, anxiety, or depression).[27,78]

Limitations

Umbrella reviews about qualitative research can lose the specific context and the subtle differences that emerged from the original primary studies.[77] We made a concerted effort to keep an open mind and transparency to extrapolate every emotion, cognition, and behavior. However, we recognize that our ideas and interpretations of the findings could affect the elaboration of the line of argument.

Qualitative research syntheses use broad themes and subthemes to describe the experience of people living with a chronic disorder. We had difficulties identifying themes and subthemes specifically evaluating emotions, cognitions, and behaviors. However, the included reviews showed themes and subthemes that reported relevant information that covered the goals of this umbrella review, and they deserve to be synthesized.

It is possible that some information could have been missed when transcribing the data from the included reviews to our umbrella review. We encourage readers to interpret our results through the lens of their personal and clinical experience.

CONCLUSION

We share 5 recommendations for clinicians who work with people who are living with musculoskeletal disorders:

1. Consider assessing other emotions than pain-related fear (eg, despair and distress).
2. Observe how the person perceives and describes symptoms and their causes, as well as how the condition impacts the person's environment.
3. Identify what social situations erode or enhance the self (ie, self-worth).
4. Account for the specific cognitive strategies (ie, acceptance) that people use to manage their symptoms, as well as the perceptions the person has about social support.
5. During a clinical assessment, observe whether people use more passive (eg, social isolation or hiding symptoms) or active (eg, planning the activities or practicing them despite their symptoms) coping approaches.

KEY POINTS

- Despair, distress, and fear were the main emotions reported by people who are living with chronic musculoskeletal symptoms.
- Cognitions focused on how people described their symptoms, what caused them, and how the symptoms impacted their lives were found.
- Cognitive strategies (ie, acceptance) and perceptions about social support were found.
- People often used passive behaviors (ie, social isolation) to cope with the challenges that arose related to musculoskeletal symptoms.

STUDY DETAILS

AUTHOR CONTRIBUTIONS: All authors have made a substantial scientific contribution to the study in terms of (1) conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content; and (3) the final approval of the version to be published.

DATA SHARING: All data relevant to the study are included in the article or are available as supplemental files.

PATIENT AND PUBLIC INVOLVEMENT: Patients/athletes/public partners were not involved in this umbrella review.

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APPENDIX A

SEARCH STRATEGY

Search Strategy in PubMed (Date: 03/01/2021)

((review[ptyp] OR review [tiab]) AND (neck pain [tiab] OR whiplash [tiab] OR shoulder pain [tiab] OR rotator cuff [tiab] OR back pain [tiab] OR elbow pain [tiab] OR hand pain [tiab] OR hip pain [tiab] OR knee pain [tiab] OR ankle pain [tiab] OR musculoskeletal pain [tiab] OR pelvic pain [tiab] OR arthritis [tiab] OR osteoarthritis [tiab] OR ankylosing spondylitis [tiab] OR spondylarthritis [tiab] OR fibromyalgia [tiab] OR temporomandibular [tiab] OR orofacial pain [tiab] OR chronic pain [tiab] OR neck pain [mh] OR whiplash injuries [mh] OR shoulder pain [mh] OR rotator cuff [mh] OR back pain [mh] OR musculoskeletal pain [mh] OR pelvic pain [mh] OR arthritis [mh] OR osteoarthritis [mh] OR spondylitis, ankylosing [mh] OR spondylarthritis [mh] OR fibromyalgia [mh] OR temporomandibular joint disorders [mh] OR chronic pain [mh]) AND ("qualitative research"[mh] OR qualitative [tiab] OR meta-ethnography [tiab] OR meta-summary [tiab] OR metasynthesis [tiab] OR meta-synthesis [tiab] OR thematic synthesis [tiab] OR mixed-methods [tiab])) **(number of studies retrieved = 1063)**

Search Strategy in CINAHL (Date: 03/01/2021)

AB (review AND (neck pain OR whiplash OR shoulder pain OR rotator cuff OR back pain OR elbow pain OR hand pain OR hip pain OR knee pain OR ankle pain OR musculoskeletal pain OR pelvic pain OR arthritis OR osteoarthritis OR ankylosing spondylitis OR spondylarthritis OR fibromyalgia OR temporomandibular OR orofacial pain OR chronic pain OR MM "neck pain" OR MM "whiplash injuries" OR MM "shoulder pain" OR MM "rotator cuff" OR MM "back pain" OR MM "elbow pain" OR MM "knee pain" OR MM "muscle pain" OR MM "pelvic pain" OR MM "arthritis" OR MM "osteoarthritis" OR MM "spondylitis ankylosing" OR MM "spondylarthritis" OR MM "fibromyalgia" OR MM "temporomandibular joint" OR MM "chronic pain")) AND (qualitative OR meta-ethnography OR meta-summary OR metasynthesis OR meta-synthesis OR thematic synthesis OR mixed-methods OR MM "qualitive studies" OR MM "ethnographic research" OR MM "meta synthesis" OR MM "thematic analysis")) **(number of studies retrieved = 484)**

Search Strategy in PubPsych (Date: 03/01/2021)

(review AND (neck pain OR whiplash OR shoulder pain OR rotator cuff OR back pain OR elbow pain OR hand pain OR hip pain OR knee pain OR ankle pain OR musculoskeletal pain OR pelvic pain OR arthritis OR osteoarthritis OR ankylosing spondylitis OR spondylarthritis OR fibromyalgia OR temporomandibular OR orofacial pain OR chronic pain) AND (qualitative OR metasynthesis OR meta-synthesis OR thematic synthesis OR mixed-methods)) **(number of studies retrieved = 112)**

Search Strategy in PsycINFO (Date: 03/01/2021)

ab((review) AND (neck pain OR whiplash OR shoulder pain OR rotator cuff OR back pain OR elbow pain OR hand pain OR hip pain OR knee pain OR ankle pain OR musculoskeletal pain OR pelvic pain OR arthritis OR osteoarthritis OR ankylosing spondylitis OR spondylarthritis OR fibromyalgia OR temporomandibular OR orofacial pain OR chronic pain) AND (qualitative OR metasynthesis OR meta-synthesis OR thematic synthesis OR mixed-methods OR meta-summary OR meta-ethnography)) **(number of studies retrieved = 196)**

ab ((review) AND (MAINSUBJECT.EXACT.EXPLODE("Whiplash") OR MAINSUBJECT.EXACT.EXPLODE("Back Pain") OR MAINSUBJECT.EXACT.EXPLODE("Musculoskeletal Disorders") OR MAINSUBJECT.EXACT.EXPLODE("Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Rheumatoid Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Fibromyalgia") OR MAINSUBJECT.EXACT.EXPLODE("Chronic Pain")) AND (MAINSUBJECT.EXACT.EXPLODE("qualitative methods") OR MAINSUBJECT.EXACT.EXPLODE("thematic analysis"))) **(number of studies retrieved = 3)**

Search Strategy in PsycEXTRA (Date: 03/01/2021)

ab((review) AND (neck pain OR whiplash OR shoulder pain OR rotator cuff OR back pain OR elbow pain OR hand pain OR hip pain OR knee pain OR ankle pain OR musculoskeletal pain OR pelvic pain OR arthritis OR osteoarthritis OR ankylosing spondylitis OR spondylarthritis OR fibromyalgia OR temporomandibular OR orofacial pain OR chronic pain) AND (qualitative OR metasynthesis OR meta-synthesis OR thematic synthesis OR mixed-methods OR meta-summary OR meta-ethnography)) **(number of studies retrieved = 5)**

ab ((review) AND (MAINSUBJECT.EXACT.EXPLODE("Whiplash") OR MAINSUBJECT.EXACT.EXPLODE("Back Pain") OR MAINSUBJECT.EXACT.EXPLODE("Musculoskeletal Disorders") OR MAINSUBJECT.EXACT.EXPLODE("Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Rheumatoid Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Fibromyalgia") OR MAINSUBJECT.EXACT.EXPLODE("Chronic Pain")) AND (MAINSUBJECT.EXACT.EXPLODE("qualitative methods") OR MAINSUBJECT.EXACT.EXPLODE("thematic analysis"))) **(number of studies retrieved = 0)**

Search Strategy in PsycARTICLES (Date: 03/01/2021)

ab((review) AND (neck pain OR whiplash OR shoulder pain OR rotator cuff OR back pain OR elbow pain OR hand pain OR hip pain OR knee pain OR ankle pain OR musculoskeletal pain OR pelvic pain OR arthritis OR osteoarthritis OR ankylosing spondylitis OR spondylarthritis OR fibromyalgia OR temporomandibular OR orofacial pain OR chronic pain) AND (qualitative OR metasynthesis OR meta-synthesis OR thematic synthesis OR mixed-methods OR meta-summary OR meta-ethnography)) **(number of studies retrieved = 1)**

ab ((review) AND (MAINSUBJECT.EXACT.EXPLODE("Whiplash") OR MAINSUBJECT.EXACT.EXPLODE("Back Pain") OR MAINSUBJECT.EXACT.EXPLODE("Musculoskeletal Disorders") OR MAINSUBJECT.EXACT.EXPLODE("Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Rheumatoid Arthritis") OR MAINSUBJECT.EXACT.EXPLODE("Fibromyalgia") OR MAINSUBJECT.EXACT.EXPLODE("Chronic Pain")) AND (MAINSUBJECT.EXACT.EXPLODE("qualitative methods") OR MAINSUBJECT.EXACT.EXPLODE("thematic analysis"))) **(number of studies retrieved = 2)**

APPENDIX A (CONTINUED)

Search Strategy in EMBASE (Date: 03/01/2021)

((‘review’/exp OR ‘review’:ab,ti) AND (‘neck pain’:ab,ti OR ‘whiplash’:ab,ti OR ‘shoulder pain’:ab,ti OR ‘rotator cuff’:ab,ti OR ‘back pain’:ab,ti OR ‘hand pain’:ab,ti OR ‘hip pain’:ab,ti OR ‘knee pain’:ab,ti OR ‘ankle pain’:ab,ti OR ‘musculoskeletal pain’:ab,ti OR ‘arthritis’:ab,ti OR ‘osteoarthritis’:ab,ti OR ‘ankylosing spondylitis’:ab,ti OR ‘spondylarthritis’:ab,ti OR ‘fibromyalgia’:ab,ti OR ‘pelvic pain’:ab,ti OR ‘temporomandibular’:ab,ti OR ‘chronic pain’:ab,ti OR ‘neck pain’/exp OR ‘whiplash injury’/exp OR ‘shoulder pain’/exp OR ‘rotator cuff injury’/exp OR ‘backache’/exp OR ‘elbow pain’:ab,ti OR ‘hand pain’/exp OR ‘hip pain’/exp OR ‘knee pain’/exp OR ‘ankle pain’/exp OR ‘musculoskeletal pain’/exp OR ‘arthritis’/exp OR ‘osteoarthritis’/exp OR ‘ankylosing spondylitis’/exp OR ‘spondylarthritis’/exp OR ‘fibromyalgia’/exp OR ‘pelvic pain’/exp OR ‘temporomandibular joint disorder’/exp OR ‘orofacial pain’:ab,ti OR ‘chronic pain’/exp) AND (‘qualitative’:ab,ti OR ‘qualitative research’/exp OR ‘ethnographic research’/exp OR ‘meta-summary’:ab,ti OR ‘meta-ethnography’:ab,ti OR ‘metasynthesis’:ab,ti OR ‘meta-synthesis’:ab,ti OR ‘thematic synthesis’:ab,ti OR ‘mixed-methods’:ab,ti)) **(number of studies retrieved = 1711)**

Search Strategy in Google Academic

allintitle: review AND neck pain AND qualitative **(number of studies retrieved = 2)**
allintitle: review AND whiplash AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND shoulder pain AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND rotator cuff AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND back pain AND qualitative **(number of studies retrieved = 13)**
allintitle: review AND hand pain AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND hip pain AND qualitative **(number of studies retrieved = 2)**
allintitle: review AND knee pain AND qualitative **(number of studies retrieved = 3)**
allintitle: review AND ankle pain AND qualitative **(number of studies retrieved = 3)**
allintitle: review AND musculoskeletal pain AND qualitative **(number of studies retrieved = 5)**
allintitle: review AND pelvic pain AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND arthritis AND qualitative **(number of studies retrieved = 7)**
allintitle: review AND osteoarthritis AND qualitative **(number of studies retrieved = 8)**
allintitle: review AND ankylosing spondylitis AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND spondylarthritis AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND fibromyalgia AND qualitative **(number of studies retrieved = 8)**
allintitle: review AND temporomandibular AND qualitative **(number of studies retrieved = 3)**
allintitle: review AND orofacial pain AND qualitative **(number of studies retrieved = 0)**
allintitle: review AND chronic pain AND qualitative **(number of studies retrieved = 14)**
allintitle: (neck pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 2)**
allintitle: (whiplash AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
allintitle: (shoulder pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
allintitle: (rotator cuff AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
allintitle: (back pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 23)**
allintitle: (hand pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
allintitle: (hip pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 3)**
allintitle: (knee pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 5)**
allintitle: (ankle pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
allintitle: (musculoskeletal pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 9)**
allintitle: (pelvic pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
allintitle: (arthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 21)**
allintitle: (osteoarthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 17)**
allintitle: (ankylosing spondylitis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
allintitle: (spondylarthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
allintitle: (fibromyalgia AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 4)**
allintitle: (temporomandibular AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
allintitle: (orofacial pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
allintitle: (chronic pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 37)**

APPENDIX A (CONTINUED)

Search Strategy in Open Grey

review AND neck pain AND qualitative **(number of studies retrieved = 1)**
review AND whiplash AND qualitative **(number of studies retrieved = 1)**
review AND shoulder pain AND qualitative **(number of studies retrieved = 0)**
review AND rotator cuff AND qualitative **(number of studies retrieved = 0)**
review AND back pain AND qualitative **(number of studies retrieved = 1)**
review AND hand pain AND qualitative **(number of studies retrieved = 1)**
review AND hip pain AND qualitative **(number of studies retrieved = 0)**
review AND knee pain AND qualitative **(number of studies retrieved = 1)**
review AND ankle pain AND qualitative **(number of studies retrieved = 0)**
review AND musculoskeletal pain AND qualitative **(number of studies retrieved = 1)**
review AND pelvic pain AND qualitative **(number of studies retrieved = 1)**
review AND arthritis AND qualitative **(number of studies retrieved = 1)**
review AND osteoarthritis AND qualitative **(number of studies retrieved = 1)**
review AND ankylosing spondylitis AND qualitative **(number of studies retrieved = 0)**
review AND spondylarthritis AND qualitative **(number of studies retrieved = 0)**
review AND fibromyalgia AND qualitative **(number of studies retrieved = 2)**
review AND temporomandibular AND qualitative **(number of studies retrieved = 1)**
review AND orofacial pain AND qualitative **(number of studies retrieved = 0)**
review AND chronic pain AND qualitative **(number of studies retrieved = 8)**
(neck pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
(whiplash AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
(shoulder pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(rotator cuff AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(back pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 3)**
(hand pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(hip pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(knee pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(ankle pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(musculoskeletal pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(pelvic pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(arthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
(osteoarthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(ankylosing spondylitis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 1)**
(spondylarthritis AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(fibromyalgia AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(temporomandibular AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(orofacial pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 0)**
(chronic pain AND (meta-synthesis OR metasynthesis OR ethnographic OR mixed-methods OR meta-summary)) **(number of studies retrieved = 5)**

APPENDIX B

STATEMENTS REPORTED IN TABLES 2 AND 3 ALONG WITH THE CATEGORY WHERE THEY WERE INCLUDED

Emotions in Table 2

Author	Statement	Categories
Bunzli et al[8]	[I] Fluctuations in pain caused continuous adjustments, leaving people with feelings of insecurity and uncertainty.	➢ Insecurity/uncertainty/ambivalence/indecision
	[II] People […] describing themselves as "short-tempered."	➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy
	[III] Fluctuations in pain were directly related to fluctuations between hope and despair.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[IV] People felt anxiety and distress, considering an uncertain future.	➢ Anxiety/agitation ➢ Distress/worry/concerns/preoccupied
	[V] Changes in behavior and mood were reported to result in feelings of depression.	➢ Depression
	[VI] People had feelings of shame (this emotion was associated with cognition [IX]).	➢ Shame/embarrassment
	[VII] The new "me but not me" was associated with feelings of distress and grief. This battle was more distressing than the pain itself.	➢ Distress/worry/concerns/preoccupied ➢ Grief/sadness/mourn/cried
	[VIII] People felt fearful about their mundane activities of daily living (this emotion was associated with cognition [VIII]).	➢ Fear/afraid
	[IX] People expressed despair at the thought of pain always being present.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[X] People felt self-denigration and self-loathing (these emotions were related to cognition [IX]).	➢ Loathing/hate/denigration
	[XI] People felt from a trajectory of despair to one of hope for the future (these emotions were related to cognition [XII]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
Climent-Sanz et al[14]	[I] People felt frustration and hatred toward life and usually developed feelings of […] despair (these emotions were perceived to be associated with poor sleep quality).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Loathing/hate/denigration
	[II] People could develop a fear of not sleeping. People also developed a fear of the bedroom and fear of going to bed.	➢ Fear/afraid
	[III] People felt anxiety (this emotion was related to behavior [I]).	➢ Anxiety/agitation
	[IV] Concerns about poor sleep quality were reported to manifest constantly, generating fear of going to bed.	➢ Distress/worry/concerns/preoccupied ➢ Fear/afraid
	[V] People felt fear of not being able to meet their sleep needs.	➢ Fear/afraid

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 2 (continued)

Author	Statement	Categories
Daker-White et al[17]	[I] People experiencing a flare-up would not only have to cope with the symptoms of the flare-up but also deal with worries that they might, despite the uncertainty, get worse rather than get better.	➢ Distress/worry/concerns/preoccupied
	[II] The root dissatisfaction for women with rheumatoid arthritis was related to cognition [XXV].	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being
	[III] Symptoms of arthritis led to secondary symptoms, largely related to pain: […] anger, depression, despair, self-pity, and […].	➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy ➢ Depression ➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Pity
	[IV] People felt fearful of exposure to their distorted bodies.	➢ Fear/afraid
	[V] People felt distressed because of fatigue and pain.	➢ Distress/worry/concerns/preoccupied
	[VI] The fundamental issues faced by the person with rheumatoid arthritis were related to the unpredictable nature of symptoms and the uncertainty over the rate and the extent of disease progression.	➢ Insecurity/uncertainty/ambivalence/indecision
	[VII] People felt a pervasive uncertainty and unpredictability of rheumatoid arthritis.	➢ Insecurity/uncertainty/ambivalence/indecision
	[VIII] People felt insecurity (this emotion was related to cognition [XXII]).	➢ Insecurity/uncertainty/ambivalence/indecision
	[IX] A person expressed feelings of embarrassment and guilt.	➢ Shame/embarrassment ➢ Guilt
Donnelly et al[21]	[I] People felt a sense of injustice toward developing the illness.	➢ Feeling of injustice
	[II] Feelings of sadness, despair, and depression were common.	➢ Depression ➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Grief/sadness/mourn/cried
	[III] Hopes and fears were often addressed.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Fear/afraid
	[IV] People were concerned about how they would manage their illness in the future.	➢ Distress/worry/concerns/preoccupied
	[V] Feelings of shame, embarrassment, and guilt were described around various aspects of self-managing the condition. These feelings were expressed, for example, concerning using visible aids, guilt around not being physically or emotionally available to others, and feelings of embarrassment around asking for help.	➢ Shame/embarrassment ➢ Guilt
	[VI] People felt uncertainty (this emotion was related to cognition [XVI]).	➢ Insecurity/uncertainty/ambivalence/indecision
	[VII] People felt hope (this emotion was related to cognition [IV]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
Feddersen et al[23]	[I] Some people were concerned (this emotion was related to cognition [XIII] in Table 3).	➢ Distress/worry/concerns/preoccupied
	[II] I felt preoccupied (this emotion was related to cognition [II]).	➢ Distress/worry/concerns/preoccupied
Froud et al[24]	[I] People felt fearful of having to sit in pain for protracted periods.	➢ Fear/afraid
Lin et al[34]	[I] People felt satisfied with their present physical condition and desired to live only for themselves.	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being
	[II] Sometimes I got to feel a sense of well-being (this emotion was related to behavior [II]).	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 2 (continued)

Author	Statement	Categories
MacNeela et al[37]	[I] Heightened episodes of pain were debilitating and led to dismay.	➢ Dismay
	[II] A person felt despair alternating with hope.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[III] The general hopelessness is illustrated more specifically by examples [...]. Feeling weak and overwhelmed set the context for strong emotional responses. The intensity of feelings of anger and depression and of being very upset, agitated, and angry with oneself.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Depression ➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy ➢ Anxiety/agitation
	[IV] People felt [...] guilt or embarrassment about the label (back pain).	➢ Shame/embarrassment ➢ Guilt
	[V] Concerns emerged about further damage. Helps makes sense of this person's behavior of activity avoidance.	➢ Distress/worry/concerns/preoccupied
	[VI] Bewilderment was identified around the experience of chronic low back pain.	➢ Bewilderment
Parenti et al[53]	[I] The sense of helplessness connected to the illness's deteriorating effects.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[II] The need for improvements regarding people's physical health and psychological support [...] was derived from elements such as the embarrassment of physical changes and mood disturbances.	➢ Shame/embarrassment ➢ Mood states
	[III] The phase of resignation left people with a feeling of hopelessness.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[IV] People with early-stage rheumatoid arthritis experienced less mental well-being (this emotion was related to cognition [III]).	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being
	[V] People reported concerns over their physical and psychological health status.	➢ Distress/worry/concerns/preoccupied
Primdahl et al[57]	[I] Fatigue negatively influenced motivation and enthusiasm.	➢ Feeling unmotivated/unenthusiastic
	[II] Fatigue led to a feeling of imbalance in everyday life, which was dominated by the experience of hopelessness and loneliness.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Loneliness
	[III] Physical activity was associated with irritability and anger (these emotions were related to cognition [XII]).	➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy
Riggs and Killingback[59]	[I] Pain and fatigue caused uncertainty about the appropriateness of activity (this emotion was related to cognition [VII]).	➢ Insecurity/uncertainty/ambivalence/indecision
	[II] Unpredictability of rheumatoid arthritis provoked safety fears.	➢ Fear/afraid
	[III] Physical activity enhanced mental well-being, evoking feelings of pleasure and pride [...]. Participation in physical activity gave people the satisfaction that they were accomplishing wellness rather than illness.	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being ➢ Pride
	[IV] Inactivity was associated with [...] a fear of reduced mobility.	➢ Fear/afraid
	[V] Some people felt a lack of motivation or discipline.	➢ Feeling unmotivated/unenthusiastic
Sim and Madden[63]	[I] Some people [...] found pain to be both worrying and non-worrying depending on its impact on function.	➢ Distress/worry/concerns/preoccupied
	[II] Negative feelings about the future emerged associated with the presence of the illness.	➢ Unspecified negative emotions
	[III] People [...] were identified: [...] to feel in despair [...].	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[IV] People felt depression (this emotion was related to cognition [VII]).	➢ Depression

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 2 (continued)

Author	Statement	Categories
Snelgrove and Liossi[65]	[I] People felt distressed during their pain experiences (this emotion was related to cognition [VIII]).	➢ Distress/worry/concerns/preoccupied
	[II] People had feelings of frustration, anger, self-loathing, self-denigration, and even depression (these emotions were related to cognition [IX]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy ➢ Loathing/hate/denigration ➢ Depression
	[III] People continued to mourn the loss of the previous valued life.	➢ Grief/sadness/mourn/cried
	[IV] People mentioned a fearful self (this emotion was related to behavior [I]).	➢ Fear/afraid
	[V] People felt a negative alteration of their well-being (this emotion was related to cognition [XI]).	➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being
	[VI] People could feel depression associated with behavior [VI].	➢ Depression
	[VII] People fluctuated although between hope and despair (this emotion was related to behavior [III]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[VIII] Feelings of guilt were reported (this emotion was related to cognition [XII]).	➢ Guilt
Söderlund et al[66]	[I] People felt a loss of hope […] (this emotion was related to cognition [XIV]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[II] People felt an existential uncertainty due to the changes in their image.	➢ Insecurity/uncertainty/ambivalence/indecision
	[III] People felt hope and happiness (these emotions were related to behavior [II]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being
	[IV] People felt insecurity (this emotion was related to cognition [II]).	➢ Insecurity/uncertainty/ambivalence/indecision
	[V] People felt sad and helpless (these emotions were related to cognitions [XVI] and [XIX]).	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair ➢ Grief/sadness/mourn/cried
Stack et al[67]	[I] People felt fearful when symptoms appeared rapidly.	➢ Fear/afraid
	[II] Uncertainty emerged about whether the illness existed and what action, if any, should be taken.	➢ Insecurity/uncertainty/ambivalence/indecision
	[III] Fear of symptoms becoming more intense and permanent, and it could drive to behaviors [I] and [II].	➢ Fear/afraid
	[IV] Uncertainty emerged when the symptoms began slowly.	➢ Insecurity/uncertainty/ambivalence/indecision
Stack et al[68]	[I] The symptoms were associated with feelings of depression […], while others described anger or feelings of fearfulness.	➢ Depression ➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy ➢ Fear/afraid
	[II] When the onset of symptoms was rapid, feelings of fear were greater.	➢ Fear/afraid
	[III] In the early stages of rheumatoid arthritis where the onset of symptoms was slow, the uncertainty about the significance of symptoms appeared.	➢ Insecurity/uncertainty/ambivalence/indecision
	[IV] An insidious onset and fluctuating symptoms created ambivalence and indecision.	➢ Insecurity/uncertainty/ambivalence/indecision
	[V] The ambiguity and vagueness of symptoms were related to uncertainty and, in some cases, emotional upset.	➢ Insecurity/uncertainty/ambivalence/indecision ➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 2 (continued)

Author	Statement	Categories
Stewart et al[69]	[I] People felt frustration and despair to relieving pain.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[II] People also felt frustration with the duration of pain experienced during flares lasting multiple days.	➢ Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair
	[III] Sleep disruptions due to the intensity of the pain affected the overall mood of some people.	➢ Mood state
	[IV] The unpredictable nature of gout flares was a concern for many people.	➢ Distress/worry/concerns/preoccupied
	[V] Many people [...] became snappy and short-tempered during flares.	➢ Short-tempered/anger/irritation/emotional upset/aggravation/snappy
	[VI] Several people reported depression and cried [...] during flares.	➢ Depression ➢ Grief/sadness/mourn/cried
	[VII] People showed anxiety and fear related to not knowing when to expect a gout flare.	➢ Fear/afraid ➢ Anxiety/agitation
	[VIII] The overall psychological impact of gout flares was mentally draining, which resulted in emotional fragility.	➢ Mentally draining ➢ Emotional fragility
	[IX] People felt fearful of triggering a flare.	➢ Fear/afraid
Toye et al[74]	[I] "I feel afraid, agitated, ashamed, and guilty." These were associated with the discrepancy between culturally accepted explanations and personal experience.	➢ Fear/afraid ➢ Anxiety/agitation ➢ Shame/embarrassment ➢ Guilt
	[II] People were aware that they had changed, but they felt grief for the old "real self."	➢ Grief/sadness/mourn/cried
	[III] "I want to feel like my old self."	➢ Desire
	[IV] Some people felt shame at having medically unexplained pain can emerge (this emotion was related to behavior [III]).	➢ Shame/embarrassment

APPENDIX B (CONTINUED)

Cognitions in Table 2

Author	Statement	Categories
Bunzli et al[8]	[I] Pain was described as omnipresent, salient, and characterized by unpredictable fluctuations in intensity.	➢ The description of symptoms
	[II] People described a lack of sleep and disrupted sleep because of pain.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] People described a battle lost, where a new, altered identity emerged because of pain.	➢ Changes of selves
	[IV] This new "me but not me" was met with [...] suicidal ideation thoughts, in a study.	➢ Changes of selves ➢ Suicidal ideation thoughts
	[V] People held biomedical beliefs about their back pain.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] Contrary opinions associated with the acceptance to live with pain: Although in many studies people described a "battle" or "fight" to control the pain and the assault on the self, people also acknowledged the need to learn to live with the pain.	➢ Cognitive strategies to manage the symptoms
	[VII] People described a dichotomy between the past and the present self.	➢ Changes of selves
	[VIII] The most mundane activities of daily living [...] had gone from being unconscious and thoughtless to planned and threatening.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IX] Perceived changes in identity resulted in self-denigration and self-loathing.	➢ Changes of selves
	[X] People described the ability of pain to disrupt even the smallest and most mundane activities of daily living.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XI] People highlighted difficulties in accepting pain when fluctuations in pain meant continuous adjustment.	➢ Cognitive strategies to manage the symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XII] Learning to live with the pain facilitated the turning point from a trajectory of despair to one of hope for the future.	➢ Cognitive strategies to manage the symptoms

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APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Climent-Sanz et al[14]	[I] People sometimes described poor sleep quality as the worst symptom of their health condition.	➢ The description of symptoms
	[II] Poor sleep quality was perceived to affect the joints and muscles so that they do not "rest" properly, increasing pain intensity.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] Being unable to sleep properly was perceived as a betrayal of the body, which may indicate that, at least in some cases, people suffering from fibromyalgia considered that they had no control over the symptom.	➢ Perceptions about the control or not of the symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves
	[IV] Contrary opinions about most common sleep disturbances associated with the maintenance of sleep (ie, while people were arguing that their sleep problems were mainly related to sleep maintenance, others reported problems falling asleep).	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[V] People commonly identified poor sleep quality as one of the symptoms that had the greatest impact on fatigue, pain, cognitive functioning, ability to manage symptoms, eating behavior, and symptom flare-ups.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[VI] Contrary opinions about the best solution to reduce fatigue: In some cases, people considered that the only solution to reduce the levels of fatigue was a good rest at night, whereas others indicated that fatigue maintained or appeared even when it was possible to have a satisfactory amount of sleep.	➢ Cognitive strategies to manage the symptoms
	[VII] Regarding the poor sleep-pain-fatigue cluster, it was described as a vicious circle in which insufficient sleep resulted in an increase in pain intensity the next day, which, at the same time, led to a state of fatigue that prevented a good rest at night.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VIII] Contrary opinions about the causes of the sleep problems: While there were people unable to identify a cause for their sleep problems, others pointed out that working night shifts during a long period resulted in problems initiating and maintaining sleep.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IX] People identified good sleep quality as the feeling of "disconnection" with the environment during the night.	➢ The relationship between positive outcomes and other variables
	[X] People believed that there is no possible solution for their sleep problems.	➢ Perceptions about the control or not of the symptoms
	[XI] Concerns about poor sleep quality were reported to manifest constantly, generating ruminating thoughts.	➢ Ruminating thoughts
	[XII] Sleep problems led people to consider motherhood (this cognition was related to emotion [V]).	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XIII] People believed that lack of sleep was aging them.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XIV] Constantly waking up is the worst thing about their health condition.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[XV] Good sleep quality was mainly related to feeling renewed upon waking and having the energy to face their daily tasks.	➢ The relationship between positive outcomes and other variables
	[XVI] People considered that "sleep is such a gift" and that they "never take it for granted."	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XVII] When people were very tired, they experience pain and small muscle cramps, being unable to fall asleep.	➢ The impact of the symptoms in other variables and/or factors believed to cause them

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Daker-White et al[17]	[I] Rheumatoid arthritis was perceived as an invisible, chronic, and incurable disease.	➢ The description of symptoms
	[II] An individual identified fatigue as the most "pervasive" symptom.	➢ The description of symptoms
	[III] The primary symptoms of arthritis led to secondary symptoms, largely related to pain: exhaustion […] and perception of loss of control.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Perceptions about the control or not of the symptoms ➢ The description of symptoms
	[IV] People commonly described themselves as either feeling "out of control" or less commonly as being controlled by arthritis.	➢ Perceptions about the control or not of the symptoms
	[V] People mentioned that their main symptoms were pain, stiffness, or immobility. A particular feature of these symptoms was that they were seen to vary or fluctuate in a manner that was unpredictable on a day-to-day basis.	➢ The description of symptoms
	[VI] People noted an expectation of pain when moving following periods of inactivity.	➢ Expectations
	[VII] The role of the weather was mentioned as a factor in worsening or lessening symptoms.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VIII] How women perceived they looked also seemed to have an additional role in how they felt.	➢ Changes of selves
	[IX] People perceived a loss of the ability to engage in activities once seen as mundane (ie, people perceived taken-for-granted activities […] constituted a large measure of self-identity).	➢ Perceptions about the control or not of the symptoms
	[X] People described that tolerate variable uncertainty is the key concept in living with arthritis.	➢ Perceptions about the control or not of the symptoms
	[XI] Rheumatoid arthritis was shown to afford opportunities for growth and/or development of life in positive ways.	➢ The relationship between positive outcomes and other variables
	[XII] People who successfully challenged their illness and its management do so according to a path that moves from dependent to "independent with help."	➢ Perceptions about the control or not of the symptoms
	[XIII] Once the grieving for their past life is over, disease "denial" is free to move from acknowledgment and on to acceptance.	➢ Cognitive strategies to manage the symptoms
	[XIV] Symptoms of arthritis led to secondary symptoms, largely related to pain: "low self-confidence," reduced libido, and difficulties reaching orgasm.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes in selves
	[XV] Pain and fatigue provided considerable ambiguity as they are not visible forms of disability.	➢ The description of symptoms
	[XVI] Apart from pain and fatigue, the only other typification of the condition of rheumatoid arthritis was a "crippling disease."	➢ The description of symptoms
	[XVII] Fatigue found in rheumatoid arthritis was more dramatic or severe than "normal tiredness."	➢ The description of symptoms
	[XVIII] Fatigue was mentioned as a separate symptom.	➢ The description of symptoms
	[XIX] Pain in rheumatoid arthritis had a "circuitous" relationship with fatigue, such that "pain drains energy and fatigue produces more pain."	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XX] People attempted to control a balance between energy and fatigue.	➢ Perceptions about the control or not of the symptoms
	[XXI] Activity, however minimal, required physical and psychological effort. The erstwhile, taken-for-granted world of everyday life became fraught with danger.	➢ Perceptions about the control or not of the symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XXII] People suggested a form of a negative feedback loop, whereby "inflammation," "working the joints harder," and "unrefreshing sleep" were articulated as causes of symptoms.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XXIII] A person described himself as awkward and ugly.	➢ Changes of selves
	[XXIV] Control was related to fluctuations in symptoms. Typically, people described themselves as having a feeling "out of control."	➢ Perceptions about the control or not of the symptoms
	[XXV] Some women perceived "visible swollen and disfigured appearance of…painful body parts."	➢ The description of symptoms

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Donnelly et al[21]	[I] Learning to accept the illness was an important part of managing life with rheumatoid arthritis.	➢ Cognitive strategies to manage the symptoms
	[II] In some instances, people expressed suicidal ideation thoughts.	➢ Suicidal ideation thoughts
	[III] This sense of injustice created a need to identify a cause (this cognition was related to emotion [I]).	➢ Perceptions about the control or not of the symptoms
	[IV] People described how religious beliefs and practices helped to maintain a positive outlook.	➢ Cognitive strategies to manage the symptoms
	[V] Rheumatoid arthritis was often experienced as a threat (or disruption) to self-identity. The predominant feature of the lived experience of self-managing rheumatoid arthritis related to "the self," a broad category constructed to reflect various dimensions of self-concept, self-esteem, and self-efficacy. Physical deformity played a role concerning self-identity, self-esteem, and self-confidence.	➢ Changes of selves
	[VI] Adjusting and adapting to an illness required resilience and the ability to draw from accumulated knowledge to employ effective self-management behaviors.	➢ Cognitive strategies to manage the symptoms
	[VII] The lack of a clear cause of a flare [...] reduced self-efficacy.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves
	[VIII] Rheumatoid arthritis was experienced as an invisible illness.	➢ The description of symptoms
	[IX] Exposure to extreme hot or cold temperatures was thought to aggregate symptoms.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[X] The perception of people as ill or not was intrinsic to how they approached their self-management and the role it played in their lives.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XI] People need to minimize **the** impact on their joints, preserve their energy, and avoid additional pain and fatigue (this cognition was related to behavior [IV]).	➢ Cognitive strategies to manage the symptoms
	[XII] Learning to listen to the body was recognized as an important tool of self-management.	➢ Cognitive strategies to manage the symptoms
	[XIII] People with rheumatoid arthritis perceived stairs or public transport could be particularly challenging.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XIV] Pain associated with rheumatoid arthritis could be particularly unbearable.	➢ The description of symptoms
	[XV] A lack of spontaneity was perceived (this cognition was related to behavior [IV]).	➢ Lack of spontaneity
	[XVI] Some people could not recognize a cause of a flare.	➢ The description of symptoms ➢ Lack of knowledge about the condition
Feddersen et al[23]	[I] People considered health effects were related to a potential worsening of the illness due to pregnancy.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[II] The degree to which people were preoccupied with the illness was linked to the degree of symptom severity.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] For some women, a lack of energy meant that they did not have enough strength to do the things they wanted for their benefit or pleasure.	➢ The impact of the symptoms in other variables and/or factors believed to cause them

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Froud et al[24]	[I] Modifying tasks, where possible, were thought to facilitate function.	➢ Cognitive strategies to manage the symptoms
	[II] People emphasized the need for vigilance […] to accommodate function and to enable activity and participation.	➢ Cognitive strategies to manage the symptoms
	[III] People described difficulties with gardening, housework, and shopping. Sleep, leisure activities, and outlets for stress that people had previously enjoyed were often no longer available.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IV] The inability to predict the onset of pain led to compromised ability to plan.	➢ Perceptions about the control or not of the symptoms
Lin et al[34]	[I] People perceived […] rethink and redefine what a so-called "normal life" should be to identify more practical criteria to suit their condition.	➢ Cognitive strategies to manage the symptoms
	[II] People related their attempts to accept their disease to soothe their minds from continued worry and pain.	➢ Cognitive strategies to manage the symptoms
	[III] People identified that the key to successfully maintain a positive behavior was to recognize the negative feelings and immediately pursue strategies that counteracted them.	➢ Cognitive strategies to manage the symptoms
	[IV] People accepted the ups and downs of the disease and the pain.	➢ Cognitive strategies to manage the symptoms
	[V] People perceived their self-esteem enhanced (this cognition was related to emotion [I])	➢ Changes of selves
	[VI] People experienced the illness like any other unusual or disturbing event, and they attempted to make sense of such in terms of previous experiences.	➢ Cognitive strategies to manage the symptoms ➢ The description of symptoms
	[VII] Reprioritizing values were also important to people to reflect on the positive changes that occurred in their lives due to living with rheumatoid arthritis and emphasize the personal growth obtained through adversity.	➢ Cognitive strategies to manage the symptoms
	[VIII] People altered the basis of their self-worth to understand the disease's progress (changing values).	➢ Cognitive strategies to manage the symptoms ➢ Changes of selves
	[IX] People showed honesty and calmness to face their condition.	➢ Honesty ➢ Calmness
MacNeela et al[37]	[I] The [...] back pain, its [...] consequences, and the prospect of future disability [...] undermined the person's capacity to remain independent as well as beliefs about personal control and sustainability.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Perceptions about the control or not of the symptoms
	[II] Pain was usually described as an ever-present sensation of an impending threat, varying in severity between good and bad days.	➢ The description of symptoms
	[III] Conceiving oneself as a back pain patient additionally impacted on personal self-worth.	➢ Changes of selves
	[IV] Dysfunctional and unreliable, the body was externalized and placed outside oneself.	➢ Changes of selves
	[V] People had suicidal ideation thoughts (this cognition was related to emotion [III]).	➢ Suicidal ideation thoughts
	[VI] Severe and intense sensations were illustrated by descriptors of pain such as twisting, crippling, raw, red, shooting, aching, and burning.	➢ The description of symptoms
	[VII] Pain was directly responsible for disrupted, unsatisfying sleep; reduced mobility; and impaired self-care.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VIII] The emerging pain identity represented an unwelcome intrusion.	➢ Changes of selves
	[IX] Some people considered the symptoms as an "assault on the self."	➢ Changes of selves

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Parenti et al[53]	[I] People reported a gradual loss of ability to function autonomously due to the illness progression.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[II] Independence was perceived as being essential to conduct a normal life.	➢ Perceptions about the control or not of the symptoms
	[III] Contrary opinions about the most important aspects for health maintenance: People with long-stage rheumatoid arthritis tended to define health as an equilibrium, giving more importance to mental well-being [...] than the physical absence of pain [...]. People with early-stage rheumatoid arthritis tended to focus on physical limitations and how they negatively affected their life.	➢ The description of symptoms ➢ Cognitive strategies to manage the symptoms
	[IV] People with long-stage rheumatoid arthritis perceived the physical absence of pain appeared to be more under control thanks to a better understanding of the symptoms and acceptance of the chronic illness. People with an early stage of rheumatoid arthritis tended to focus on physical limitations [...], which was related to [...] the absence of personal adjustments and the acceptance of the chronic condition.	➢ Cognitive strategies to manage the symptoms ➢ Perceptions about the control or not of the symptoms
	[V] Some people entered a phase of confrontation with the destruction of the self, as it was before for themselves and others.	➢ Changes of selves
	[VI] The need for improvements regarding people's physical health [...] was derived from elements such as [...] low self-confidence.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves
	[VII] Some strategies (acceptance, equanimity, flexibility, managing sense of control, pursuing valued goals, etc) were adopted to increase resilience in facing rheumatoid arthritis challenges, which promoted their psychological well-being and self-care behaviors.	➢ Cognitive strategies to manage the symptoms ➢ Perceptions about the control or not of the symptoms
	[VIII] Some people developed a passive resignation during the phase of resignation.	➢ Cognitive strategies to manage the symptoms
	[IX] Some people considered rheumatoid arthritis as a challenging stimulus (this cognition was related to behavior [I]).	➢ The description of symptoms
	[X] The phase of resignation left people unable to exert any type of willpower over the future development of the disease.	➢ Cognitive strategies to manage the symptoms

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Primdahl et al[57]	[I] People perceived fatigue as inexplicable, unpredictable, difficult to control, and with considerable consequences for all aspects of their everyday lives. It is different from the fatigue that people without rheumatoid arthritis experience.	➢ The description of symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Perceptions about the control or not of the symptoms
	[II] Fatigue affected several cognitive aspects of the individual: concentration, memory, learning, solving problems, the assimilation of information, and participation in conversations.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] People perceived themselves to be limited and always one step behind due to their cognitive problems.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IV] Fatigue also caused positive experiences: People learned to be more conscious about the choices in life, let things pass, and recognize the advantages of resting.	➢ The relationship between positive outcomes and other variables ➢ Cognitive strategies to manage the symptoms
	[V] Fatigue is experienced as exhausting, negatively impacting the ability to take initiative and to get things done.	➢ The description of symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] People with fatigue described the importance to take good care of themselves and their bodies to feel good and try to restore the imbalance in life and ease fatigue.	➢ Cognitive strategies to manage the symptoms
	[VII] People described the chance to be spontaneous as reduced since it takes time to adjust plans.	➢ Lack of spontaneity
	[VIII] Fatigue related to the illness reduced sleep quality, with episodes of being awake at night and feeling unrefreshed after sleep, and a body that feels heavy or as though they are ill.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves
	[IX] Some everyday tasks become slow and troublesome due to joint pain and physical limitations.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[X] To be "tired" is not considered an appropriate word, and people use words such as "fatigued," "exhausted," and "lack of energy." People used metaphors such as "heaviness" or "weight."	➢ The description of symptoms
	[XI] Some people could distract themselves from their fatigue by concentrating on something else.	➢ Cognitive strategies to manage the symptoms
	[XII] People perceived that physical activity became extremely exhausting.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
Riggs and Killingback[59]	[I] Contrary opinions about what physical activity means for people: Some people described physical activity as a "duty," while others considered it as a part of the management plan.	➢ The description of other factors rather than symptoms
	[II] Activity improved self-awareness, enabling people to acquire a better understanding of their symptoms and limitations. Consequentially, this fact enhanced self-efficacy and the ability to cope with unpredictable "flare-ups."	➢ Changes of selves ➢ The relationship between positive outcomes and other variables
	[III] People accepted their role in managing their condition.	➢ Cognitive strategies to manage the symptoms
	[IV] Some people described more flexibility when practicing physical activity at home. However, they preferred prearranged activity over home-based programs (this cognition was related to emotion [V]).	➢ Cognitive strategies to manage the symptoms
	[V] People described pain and fatigue were barriers to staying active.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] The fundamental incentive for people was to counteract disease progression and preserve independence, maintaining their self-identity.	➢ Motivational situations ➢ Changes of selves
	[VII] Some people doubted whether activity was appropriate or would make symptoms worse.	➢ The description of other factors rather than symptoms
Robart and Boyle[60]	[I] Lower back pain was described as an "invisible disability."	➢ The description of symptoms

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Sim and Madden[63]	[I] Some people described the pain as being both bodily and mental or were using words such as "burning" or "cutting."	➢ The description of symptoms
	[II] The overall impression was that the pain was hard to reduce to a single description or a single quality.	➢ The description of symptoms
	[III] People identified factors affecting their pain: their levels of activity or the weather. However, the intensity and the location of the pain in response to those factors were unpredictable.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[IV] Pain brought the previously taken-for-granted body into conscious awareness and created a disjunction between the body and the self.	➢ Changes of selves
	[V] Pain was commonly reported as having a dramatic impact on daily life.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] Pain and fatigue were connected. Although the pain was [...] reported as having a dramatic impact on daily life, some people described fatigue as more debilitating.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VII] Several factors were cited as causing depression, including pain, fatigue, a loss of control of the illness and life in general, and the feeling of loss of the former life.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves ➢ Perceptions about the control or not of the symptoms
	[VIII] Acceptance of the biomedical explanation of fibromyalgia could influence coping patterns.	➢ Cognitive strategies to manage the symptoms
	[IX] The ability of the self to understand fibromyalgia (eg, becoming aware of one's symptom patterns or gaining information about fibromyalgia) was essential to manage the condition.	➢ Changes of selves ➢ Perceptions about the control or not of the symptoms
	[X] Contrary opinions about the reevaluation of life due to the impact of the illness (loss of the previous life and identity): Some people described the changes as positive, as the illness allowed reevaluating and appreciating what is important in life [...]. For others, the illness only produced negative feelings about the future.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The relationship between positive outcomes and other variables ➢ Changes of selves ➢ Cognitive strategies to manage the symptoms
	[XI] Contrary opinions about the course of pain: People described pain could have a specific location. However, pain is also perceived as diffuse and shifting and both constant and varying. The pain was also experienced when active or when resting.	➢ The description of symptoms
	[XII] Symptoms were individually mundane but collectively devastating in their impact.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[XIII] People described that they could feel ill and well at the same time or ill but looking well.	➢ The description of symptoms
	[XIV] People also perceived pain could be elusive although it feels powerful.	➢ The description of symptoms
	[XV] People described the body became a burden and something against which one must struggle.	➢ Changes of selves ➢ Perceptions about the control or not of the symptoms
	[XVI] People described that the subjective and incommunicable nature of pain made it difficult to cope with.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[XVII] People described that they felt weary and with sleep disturbances due to the consequences of pain and fatigue.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ The description of symptoms
	[XVIII] Fatigue and lack of strength affected daily activities.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XIX] People described the importance to maintain a balance between battling against fibromyalgia ("struggling") and living with it ("adapting").	➢ Cognitive strategies to manage the symptoms

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APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Snelgrove and Liossi[65]	[I] Chronic low back pain was reported as debilitating and reduced a secure and positive sense of the self.	➢ The description of symptoms ➢ Changes of selves
	[II] People perceived their dignity was threatened due to the impaired and awkward mobility that promoted perceptions of premature aging.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Changes of selves
	[III] Changes in the self lagged the demands of chronic low back pain, not necessarily accommodating for a degree of acceptance or adaptation.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Cognitive strategies to manage the symptoms
	[IV] A dualism of the self emerged, with people referring to a subject-object distinction (as a protective function) between their painful bodies (external and threatening object) and the valued sense of the self (subject).	➢ Changes of selves
	[V] Illness and cultural beliefs mediated coping strategies. Biomedical beliefs were determinant to people's experiences. These beliefs were related to [...] a reduction of well-being, psychological inflexibility, and comprehensive enmeshment with pain, with little engagement or acceptance and a loss-orientated focus.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] When the cause was not determined, people also identified other potential factors that hindered the rehabilitation efforts: genetic explanations or cultural-based idioms of stress.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VII] People described factors such as the degree of motivation and self-efficacy, the perceptions of control, or whether people had a primary or secondary relationship with pain influenced pain experiences.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Perceptions about the control or not of the symptoms
	[VIII] Pain experiences were reported mainly as persistent and disruptive, causing a loss of the previous lifestyle and personality changes.	➢ The description of symptoms ➢ Changes of selves
	[IX] People attributed the loss of the valued "self" to an increase of functional limitation accompanied by different emotions that have been described in emotion [II].	➢ Changes of selves
	[X] People are described to be enmeshed in pain.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XI] Little causal explanation for the condition adversely affected female well-being more than male well-being.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XII] Contrary opinions about how to modulate self-efficacy: Some people described their efficacy could reduce by perceptions of uncontrolled and unpredictable pain, as well as guilty and lack of readiness to self-manage. On the other hand, others perceived their efficacy could increase with developed positive self-management strategies.	➢ Perceptions about the control or not of the symptoms
	[XIII] People described a period of resignation.	➢ Cognitive strategies to manage the symptoms
	[XIV] People found alternative meanings in life to offset the reduction of self-esteem (eg, joining support groups or listening to successful stories).	➢ Cognitive strategies to manage the symptoms ➢ Changes of selves

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Söderlund et al[66]	[I] People described their previous image as difficult to reestablish.	➢ Changes of selves
	[II] Low perceived control appeared to lead to low confidence regarding the ability to manage injury-related problems and the future.	➢ Perceptions about the control or not of the symptoms ➢ Changes of selves
	[III] The perceived severity, manageability, and realistic expectations of symptom development also influenced how people perceived the control of the condition.	➢ Perceptions about the control or not of the symptoms ➢ Expectations
	[IV] People perceived severe symptoms were difficult to tolerate and manage.	➢ Perceptions about the control or not of the symptoms
	[V] Severe symptoms […] decreased the people's beliefs and confidence regarding their ability to control the situation.	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Perceptions about the control or not of the symptoms ➢ Changes of selves
	[VI] People believed knowledge of how […] pain and other symptoms were associated made the situation more understandable and could lead to the development of better strategies for coping with the situation.	➢ Perceptions about the control or not of the symptoms
	[VII] Understanding the pain was believed to contribute to its elimination.	➢ Perceptions about the control or not of the symptoms
	[VIII] When the expectations of recovery were not fulfilled quickly enough, confusion and conflicting thoughts emerged about the results.	➢ Confusion and conflicting thoughts ➢ Expectations
	[IX] Knowledge about and experiences of participation in physical activity were perceived to be beneficial. However, physical activity was not always a priority.	➢ The relationship between positive outcomes and other variables
	[X] People believed that an optimistic outlook on life would help improve the situation.	➢ The relationship between positive outcomes and other variables ➢ Perceptions about the control or not of the symptoms
	[XI] People interpreted an emotional improvement as getting better even when the pain and other symptoms did not necessarily decrease.	➢ The relationship between positive outcomes and other variables
	[XII] People described the importance of being optimistic despite the pain and other symptoms (this was reinforced when people perceived improvements in their symptoms).	➢ The relationship between positive outcomes and other variables ➢ Cognitive strategies to manage the symptoms
	[XIII] Some people believed that they needed to take responsibility for their situation to increase their ability to control it.	➢ Cognitive strategies to manage the symptoms ➢ Perceptions about the control or not of the symptoms
	[XIV] People described pain and other symptoms interfered in their lives (eg, autonomy, ability, or spontaneity).	➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Lack of spontaneity
	[XV] People believed exercise was beneficial. However, they also described the difficulty to continue with it.	➢ The relationship between positive outcomes and other variables ➢ Perceptions about the control or not of the symptoms
	[XVI] People believe they had lost the physical capacity they had previous the injury.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XVII] The confidence to manage pain and participate in daily activities decreased due to the lack of success in determining how to control the situation.	➢ Perceptions about the control or not of the symptoms ➢ Changes of selves
	[XVIII] The combination of expectations regarding recovery and daily experiences of fluctuating symptoms decreased people's confidence concerning the future.	➢ Changes of selves ➢ Expectations
	[XIX] People also perceived psychological losses that were consequences of whiplash.	➢ The impact of the symptoms in other variables and/or factors believed to cause them

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Stack et al[67]	[I] People described a lack of knowledge about rheumatoid arthritis (eg, the significance of musculoskeletal symptoms, their own risk of the illness, or the causes of the condition).	➢ Lack of knowledge about the condition
	[II] Causal beliefs were associated with rheumatoid arthritis symptoms, including stressful life events, childbirth, an injury, or "overdoing it."	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] Attributing symptoms to external factors often meant that people believed their symptoms to be temporary (internal attributions were less likely).	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IV] Some people did not want to think about themselves as being unhealthy.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[V] People usually described their daily tasks were dramatically affected when the symptoms appeared rapid.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] Some people described they recalled mild symptoms that they had ignored or misattributed.	➢ Recall symptoms
	[VII] People described the difficulty to pinpoint when their relevant symptoms began first when the onset of symptoms was slow, vague, or transitory.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VIII] As symptoms increased in severity and duration, people's explanations for their symptoms changed to match their symptom experience.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IX] Some people mentioned it was difficult to understand the causes of the illness.	➢ Lack of knowledge about the condition
	[X] People believed their illness affected older people or was caused by "wear and tear" (this hindered a correct interpretation of the symptoms).	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XI] Some people with preexisting illnesses (ie, osteoarthritis) attributed the emergence of new symptoms to these preexisting illnesses.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XII] Some people did not consider that their symptoms were related to rheumatoid arthritis since they had no familiar history of this condition.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[XII] People described symptoms as normal "aches and pains" or "normal" (for someone of their age, gender, life circumstance, etc).	➢ The description of symptoms
	[XIV] Some people believed that they focused on other life events that they did not prioritize their symptoms.	➢ Perceptions about the control or not of the symptoms

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APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Stack et al[68]	[I] Pain was often described as "mild," "vague," and "non-disabling." People who used this description made understanding the cause very difficult (with some people attributing their symptoms to exertion or minor trauma).	➢ The description of symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[II] Severe pain was described with words such as "unbearable" or "overpowering" (the pain was related to "bone cancer" or believed to be originated from broken or chipped bone).	➢ The description of symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] The symptoms were associated with [...] suicidal thoughts.	➢ Suicidal ideation thoughts
	[IV] Rapid-onset symptoms were described as "new resistant," "severe," "abnormal," and "debilitating."	➢ The description of symptoms
	[V] Some people described the suddenness and extreme nature of the rheumatoid arthritis onset as a "light switch" or being "cut off."	➢ The description of symptoms
	[VI] Swelling was described as severe and the joint becoming "puffed out."	➢ The description of symptoms
	[VII] People described their symptoms as "diffuse," "gradual," or "episodic" when the onset of the illness was slow.	➢ The description of symptoms
	[VIII] People also described their symptoms as "everyday aches and pains" or "twinges" that began as a nuisance but became severe and were related to functional impairment.	➢ The description of symptoms ➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IX] At the onset, stiffness was a symptom that could be bothersome at night because it prevented sleep.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[X] Some people described generalized "flu-like" symptoms but were not explicit about the specific symptoms that comprised this experience.	➢ The description of symptoms
	[XI] People described fatigue as a very important symptom at the onset of the illness (a person reported that weariness was one of the most significant problems faced at the onset of symptoms).	➢ The description of symptoms
	[XII] People associated that weakness increased after being unable to undertake routine daily activities. Others mentioned that weakness was a mild problem.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
Stewart et al[69]	[I] Gout flares were described as the worst pain ever experienced (ie, being worse than childbirth).	➢ The description of symptoms
	[II] The location of the gout flare was also considered an important contributor to the perceived severity of the flare.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[III] The intensity of the pain meant that people were unable to eat due to loss of appetite.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IV] People believed footwear contributed to the pain and swelling of a flare.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[V] The pain was often described as intense, constant, and throbbing in nature with the sensation that the joint was burning or on fire.	➢ The description of symptoms
	[VI] People commented on the quick onset of gout flares and preferred flares that came fast and went fast.	➢ The description of symptoms
	[VII] People described 2 or 3 flares per year were "not too bad" while going for long periods without flares was perceived as "a miracle."	➢ The description of symptoms
	[VIII] Contrary opinions about the location of the gout flares: Some people described a gout flare as more severe when affecting larger joints. On the other hand, others mentioned that flares that affected the feet were more serious than in other joints (ie, hands), due to their impacts on mobility.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[IX] People described the difficulty to find shoes that they could wear comfortably during a flare.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[X] People mentioned the presence of sleep disruptions because of the intensity of the pain.	➢ The impact of the symptoms in other variables and/or factors believed to cause them

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 2 (continued)

Author	Statement	Categories
Toye et al[74]	[I] "My body has become alienated from me and has become something bad."	➢ Changes of selves
	[II] "I am no longer a person, but I have a body."	➢ Changes of selves
	[III] "Although I struggle to prevent the erosion of my old 'real self' and I am not 'giving in' to my painful body, I face the fact that I am irreparably altered."	➢ Changes of selves ➢ Cognitive strategies to manage the symptoms
	[IV] "I am no longer at the mercy of my body, but I am a co-expert."	➢ Changes of selves
	[V] People believed that recovery is becoming someone different from what you once were.	➢ The impact of the symptoms in other variables and/or factors believed to cause them
	[VI] "I am coming to know my body and gain the confidence to experiment and make my choices."	➢ Changes of selves
	[VII] The ability to redefine oneself, or psychological flexibility, might help people move forward with pain and reduce its impact.	➢ Cognitive strategies to manage the symptoms ➢ Changes of selves
	[VIII] "The day-to-day unpredictability of my pain creates an endless timeless present where my life has become dominated by caution and the emergence of a lack of spontaneity."	➢ Lack of spontaneity ➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Cognitive strategies to manage the symptoms
	[IX] Plans, expectations, and dreams of the future are irreparably altered, and life focuses inward.	➢ Expectations ➢ The impact of the symptoms in other variables and/or factors believed to cause them ➢ Cognitive strategies to manage the symptoms

Behaviors in Table 2

Author	Statement	Categories
Bunzli et al[8]	[I] Physically centered strategies were widely cited, the most common being hypervigilance to painful or threatening movements.	➢ Hypervigilance/anticipation
	[II] Activity restriction or avoidance was also a common strategy.	➢ Activity avoidance/restrictions
	[III] Persistent strategies were cited whereby people exceeded their perceived functional capacities to fight back against the pain.	➢ Fighting against the symptoms/continuing with normal activities
Climent-Sanz et al[14]	[I] People established regular sleep schedules (this was recognized as essential).	➢ The use of structured routines
	[II] People also adopted other strategies such as the use of earplugs or relaxation techniques. However, these strategies were perceived as ineffective and, sometimes, unjustified.	➢ The use of earplugs ➢ Relaxation
	[III] Contrary opinions were associated with the behaviors toward to stay or not in bed (ie, while some people reported that they got out of bed to avoid developing behaviors of rejection toward the bed, others stayed in bed and tried to fall asleep again).	➢ Resting/staying in bed ➢ Activity avoidance/restrictions
	[IV] The most generalized strategy was daytime rest.	➢ Resting/staying in bed
	[V] The use of lavender scent while taking a hot bath helped people to decrease morning stiffness and better cope with the day.	➢ The use of lavender scent
Daker-White et al[17]	[I] One possible response to such dangers was to never leave the house, although this response might leave people feeling that they were "locked-in."	➢ Activity avoidance/restrictions
	[II] Concealing body parts became an important imperative. In extreme cases, people avoided going out of the house.	➢ Activity avoidance/restrictions ➢ Denying/hiding symptoms
	[III] People never managed to master or "take charge" in rheumatoid arthritis (this behavior was related to emotion [VII]).	➢ Unspecified behaviors

Table continues on next page.

APPENDIX B (CONTINUED)

Behaviors in Table 2 (continued)

Author	Statement	Categories
Donnelly et al[21]	[I] People managed their illness under the perceived threat of immobilization, deformity, and dependence. To counter this, strategies of optimism, positivity, and humor were frequently adopted.	➢ Positive approaches (optimism, humor, positive thinking)
	[II] Self-management reduced spontaneity and created a cognitive burden (this behavior was related to cognition [XII]).	➢ Unspecified behaviors
	[III] Behavioral adjustment included more rest, such as going to be earlier or taking a nap during or after work to be able to fulfill their duties.	➢ Resting/staying in bed
	[IV] Pacing and planning daily activities are commonly featured in an individual's experiences.	➢ Planning/prioritizing/pacing activities
	[V] Some participants took the risk of stretching their limits because they so dearly wanted to do special things or to just feel the pleasure of being "normal."	➢ Stretching their limits
Feddersen et al[23]	[I] Women tried to consider the fluctuating course of the illness by planning and prioritizing to complete tasks ahead of time and be prepared for bad days.	➢ Planning/prioritizing/pacing activities
Froud et al[24]	[I] The inability to predict the onset of pain led to anticipation of pain that compromised the ability to plan, leading to a convoluted mental decision-making process surrounding participation.	➢ Planning/prioritizing/pacing activities ➢ Hypervigilance/anticipation
Lin et al[34]	[I] People can treat pain by changing their behavior […]. It includes developing […] optimism.	➢ Positive approaches (optimism, humor, positive thinking)
	[II] Maintaining positive behavior ([…] using humor […], doing things they enjoyed before, […] praying, and refusing to "give in" to the condition) was vital for gaining a sense of well-being.	➢ Positive approaches (optimism, humor, positive thinking) ➢ Praying ➢ Refusing to give in to the condition
MacNeela et al[37]	[I] People showed behaviors related to activity avoidance (this behavior was related to emotion [V]).	➢ Activity avoidance/restrictions
	[II] People endured a traumatizing challenge to personal identity (this behavior was related to cognition [IX]).	➢ Unspecified behaviors
Parenti et al[53]	[I] The term "fighting behavior" indicated a form of proactive coping.	➢ Fighting against the symptoms/continuing with normal activities
	[II] Some people forced an adaptation to the condition during the phase of resignation.	➢ Adaptation to the condition
	[III] [Some authors] identified the importance of "cultivating resilience" as a positive approach. This approach permitted people to focus on recognizing their physical limitations and strengthen their remaining intact abilities.	➢ Positive approaches (optimism, humor, positive thinking)
Primdahl et al[57]	[I] People divided their tasks over a day or several days to be able to manage bad days and save energy for later events and tasks.	➢ Planning/prioritizing/pacing activities
	[II] Contrary behaviors about how to face poor sleep and the unpredictable nature of fatigue: Poor sleep and the unpredictable nature of fatigue require breaks and rest during the day. Some people set time aside, while others described this fact as impossible.	➢ Resting/staying in bed
	[III] "I tried to pace, relax, and rest during the day to save energy for later events and tasks, and be able to manage bad days."	➢ Relaxation ➢ Pace ➢ Resting/staying in bed
	[IV] Some people avoided energy-consuming activities.	➢ Activity avoidance/restrictions
Riggs and Killingback[59]	[I] People used physical activity as a way of taking control.	➢ The use of physical activity to take control

Table continues on next page.

APPENDIX B (CONTINUED)

Behaviors in Table 2 (continued)

Author	Statement	Categories
Sim and Madden[63]	[I] People seek information and understanding to resist or accommodate bodily, activity, and identity constraints.	➢ Seeking information and understanding
	[II] People engaged in positive thinking […]. More psychological or emotion-based methods of coping were also reported – such as […] adopting a new or modified self-identity or self-image to resist or accommodate bodily, activity, and identity constraints.	➢ Adopting a new identity or image ➢ Positive approaches (optimism, humor, positive thinking)
	[III] People resisted the dominance of symptoms or found distraction in pleasurable activities to resist or accommodate bodily, activity, and identity constraints.	➢ Fighting against the symptoms/continuing with normal activities
	[IV] Contrary behaviors toward pacing or not daily activities: While some people continued with their normal activities, others severely limited their activity. Some people adapted successfully. They planned activities and used carefully structured daily routines.	➢ Activity avoidance/restrictions ➢ Fighting against the symptoms/continuing with normal activities ➢ Planning/prioritizing/pacing activities ➢ The use of structured routines
	[V] Psychological or emotion-based coping approaches were reported, such as positive thinking, a new or a modified self-identity or self-image, and spirituality.	➢ Positive approaches (optimism, humor, positive thinking) ➢ Spiritual approaches ➢ Adopting a new identity or image
	[VI] Coping strategies identified were […] adapting, giving up, or struggling […].	➢ Adaptation to the condition ➢ Giving up with the condition ➢ Fighting against the symptoms/continuing with normal activities
Snelgrove and Liossi[65]	[I] People […] developed anticipation toward a disabled future with little reestablishment of behavioral activity.	➢ Hypervigilance/anticipation ➢ Activity avoidance/restrictions
	[II] An increase of stoicism was employed to maintain a normal lifestyle and was related to a reduction of the levels of pain.	➢ Stoicism
	[III] People remained determined to establish a legitimate cause of their illness; adjusted to their limitations and undertook achievable tasks; adopted lower, more realistic expectations about the future; and remained positive although fluctuating between hope and despair. All these behaviors were developed to try to preserve a valued self-identity.	➢ Positive approaches (optimism, humor, positive thinking) ➢ Adaptation to the condition ➢ Planning/prioritizing/pacing activities
	[IV] Physically centered coping strategies, such as personally derived postural adjustments and topical treatments, were adjunct to the use of prescribed medication.	➢ Derived postural adjustments ➢ Topical treatments ➢ Prescribed medication
	[V] Those coping strategies that may be viewed as inhibiting any long-term adaptation included prolonged periods of rest and excessive use of alcohol (these strategies could reduce self-esteem).	➢ Alcohol ➢ Resting/staying in bed
	[VI] Less useful were avoidance strategies than minimized exposure to situations where limitations could be exposed.	➢ Activity avoidance/restrictions
	[VII] People used cognitive-focused coping strategies such as […] ignoring the pain or "disregarding" […] to maintain normative lifestyles.	➢ Ignoring or disregarding the symptoms
	[VIII] People recounted an initial response of resistance followed by resignation.	➢ Fighting against the symptoms/continuing with normal activities
	[IX] People adjusted priorities to offset the reduction of self-esteem (eg, joining support groups or listening to successful stories).	➢ Planning/prioritizing/pacing activities
Söderlund et al[66]	[I] People needed to prioritize different commitments according to their beliefs about how pain and other symptoms would be aggravated.	➢ Planning/prioritizing/pacing activities
	[II] People strived for normalcy.	➢ Fighting against the symptoms/continuing with normal activities
	[III] People sought to resume the normalcy, autonomy, and spontaneity of life experienced before whiplash.	➢ Fighting against the symptoms/continuing with normal activities

Table continues on next page.

APPENDIX B (CONTINUED)

Behaviors in Table 2 (continued)

Author	Statement	Categories
Stack et al[67]	[I] Ignoring symptoms allowed some people to continue with normal daily activities. However, when these activities were disrupted, symptoms could no longer be ignored, and perceptions changed.	➢ Ignoring or disregarding the symptoms
	[II] Denial was used by those who did not want to deal with the stress of a possible chronic illness or additional morbidity for those with a preexisting condition.	➢ Denying/hiding symptoms
	[III] People used a process of adaptation and accommodation to manage the disruption to normal roles and daily activities.	➢ Adaptation to the condition
	[IV] Normalizing symptoms led some to explain away their early symptoms (this behavior was related to cognition [XIII]).	➢ Normalizing the symptoms
Stewart et al[69]	[I] Many people resorted their assistive devices to move around their homes, including wheelchairs and crutches.	➢ Adaptation to the condition
	[II] Other people reported holding on to walls to walk, hopping on one leg, or shuffling around to relieve pain.	➢ Adaptation to the condition
	[III] Others had no choice but to stay in bed.	➢ Resting/staying in bed
	[IV] Many people completely avoided participating in sporting activities they previously enjoyed (this behavior was related to emotion [IX]).	➢ Activity avoidance/restrictions
	[V] A person avoided daily activities such as eating or drinking to avoid the necessity of going to the bathroom during a flare.	➢ Activity avoidance/restrictions
	[VI] Many people chose to go barefoot during this time (this behavior was related to cognition [IV]).	➢ Adaptation to the condition
	[VII] During gout flares, people resorted to wearing shoes that were wider and loose fitting or chose shoes of a larger size.	➢ Adaptation to the condition
	[VIII] Some people opted to sleep in a chair or recliner or sleep with their foot out of the bed.	➢ Adaptation to the condition
	[IX] Some people struggled to conduct household chores and yard work (ie, cleaning).	➢ Fighting against the symptoms/continuing with normal activities
Toye et al[74]	[I] "I listen to and respect my body to align and integrate it. This shows a developing relationship of trust and cooperation with my body."	➢ Listening to and respecting the body
	[II] "I am encouraged to hide my pain" (this behavior was related to emotion [III]; hiding pain can be a double-edged sword because people do not necessarily believe what they cannot see).	➢ Denying/hiding symptoms
	[III] "I struggle to find the right balance between hiding and showing pain." The pull to hide pain and appear "normal" was related to emotion [IV].	➢ Fighting against the symptoms/continuing with normal activities ➢ Denying/hiding symptoms

Emotions in Table 3

Author	Statement	Categories
Bunzli et al[8]	[I] People expressed fear about job loss and future financial insecurity.	Insecurity/uncertainty Fear/dread/intimidation
	[II] People mentioned unreciprocated dependency on family members associated with feelings of helplessness.	Dependence Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted
	[III] People experienced disbelief at why they were suffering. This prompted feelings of frustration, anger, guilt, and despair.	Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted Anger/irritability/grump/aggravation Guilt/resentment/blame
	[IV] People acknowledged that isolation exacerbated feelings of depression.	Depression

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 3 (continued)

Author	Statement	Categories
Climent-Sanz et al[14]	[I] Concerns emerged about the inability to find a comfortable sleep position.	➢ Concerns/distress/worry/self-absorbed
	[II] People felt anxiety and a feeling of constant failure (these emotions were related to cognition [I]).	➢ Anxiety/agitation ➢ Feelings of constant failure
Daker-White et al[17]	[I] Rheumatoid arthritis engendered a "dread of [future] dependency [on others]."	➢ Fear/dread/intimidation ➢ Dependence
	[II] People felt frustration and distress (these emotions were related to cognition [XI]).	➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Concerns/distress/worry/self-absorbed
	[III] People wished to "be believed" regarding the invisibility of their painful symptoms.	➢ Desire or not
	[IV] Concerns emerged to fulfill social obligations.	➢ Concerns/distress/worry/self-absorbed
	[V] People with rheumatoid arthritis lost their independence and did not relish dependency.	➢ Dependence
Donnelly et al[21]	[I] People felt loss and loneliness, particularly during a flare.	➢ Loneliness/loss
	[II] Some people did not wish to reveal their illness for fear (this emotion was related to cognition [IV]).	➢ Fear/dread/intimidation ➢ Desire or not
	[III] Some people felt a potential dependency on family and friends (this emotion was related to cognition [VI]).	➢ Dependence
	[IV] As part of the emotional work of self-management, individuals were required to deal with feelings of frustration, anger, and depression.	➢ Depression ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Anger/irritability/grump/aggravation
Feddersen et al[23]	[I] Performing paid work contributed to general well-being.	➢ Well-being
	[II] Some women increased their dependency when continuing work became impossible.	➢ Dependence
	[III] Others felt gratitude when they received help from their children and partner.	➢ Gratitude
	[IV] People felt fear (this emotion was related to cognition [X]).	➢ Fear/dread/intimidation
	[V] Some people could self-blame (this emotion was related to cognition [XI]).	➢ Guilt/resentment/blame
Froud et al[24]	[I] People felt worried about how they were seen by others.	➢ Concerns/distress/worry/self-absorbed
	[II] People felt fearful of spoiling the experience for loved ones (family).	➢ Fear/dread/intimidation
	[III] People emphasized […] the fear associated with losing a job.	➢ Fear/dread/intimidation
	[IV] Concerns emerged about performing tasks despite the pain. If this was seen as a sign of competence by their coworkers, this could serve to further fuel the delegitimization of their pain.	➢ Concerns/distress/worry/self-absorbed
	[V] Some worries emerged about job security or the stigma from coworkers that could result from taking sick leave. Many were concerned about the ability to maintain bill payments (this emotion was related to cognition [XIV]).	➢ Concerns/distress/worry/self-absorbed
	[VI] Some people felt fearful (this emotion was related to cognition [XV]).	➢ Fear/dread/intimidation
	[VII] Some people described a high degree of dependence on others.	➢ Dependence

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APPENDIX B (CONTINUED)

Emotions in Table 3 (continued)

Author	Statement	Categories
MacNeela et al[37]	[I] Some people felt very distressed (this emotion was related to cognition [XIII]).	➢ Concerns/distress/worry/self-absorbed
	[II] The feeling that pain had taken over severely tested hopes for the future.	➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted
	[III] Continued manual duties were worrying (this emotion was related to cognition [III]).	➢ Concerns/distress/worry/self-absorbed
	[IV] Irritability arising from pain was the final motivating factor to the behaviors mentioned as [I].	➢ Anger/irritability/grump/aggravation
	[V] Depictions of spousal relationships emphasized […] dependence on help from the partner.	➢ Dependence
	[VI] People developed a sense of agitation and antagonism toward other people.	➢ Anxiety/agitation ➢ Antagonism
Parenti et al[53]	[I] People felt an increase in their well-being (this emotion was related to behavior [I]).	➢ Well-being
	[II] The need for improvements regarding people's psychological support […] was derived from elements such as the embarrassment of physical changes and mood disturbances.	➢ Mood states ➢ Embarrassment/shame
Primdahl et al[57]	[I] Physical activity […] is associated with irritability and anger. […] A reduced energy to participate in social activities leads to negative feelings such as anger.	➢ Anger/irritability/grump/aggravation
	[II] The emotional impact of fatigue is related to experiences of frustration, hopelessness, fear […], and lack of patience […] concerning other people.	➢ Fear/dread/intimidation ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Lack of patience
	[III] Younger women with many social roles felt overly sensitive and misunderstood. Other women felt useless. It is hard to fulfill social expectations, which lead to a feeling of being viewed as lazy, boring, and self-absorbed. Feelings of guilt and embarrassment can also arise (these emotions were related to cognition [XI]).	➢ Guilt/resentment/blame ➢ Concerns/distress/worry/self-absorbed ➢ Overly sensitive ➢ Misunderstood ➢ Useless ➢ Lazy ➢ Boredom ➢ Embarrassment/shame
	[IV] The emotional and social consequences of fatigue can result in a particular type of loneliness.	➢ Loneliness/loss
	[V] People had a feeling of being hard to live with (this emotion was related to cognition [IV]).	➢ Feeling of being hard to live with
	[VI] Emotions such as grump or whining could emerge (these emotions were related to cognition [II]).	➢ Whining ➢ Anger/irritability/grump/aggravation
Riggs and Killingback[59]	[I] Meeting people who had more advanced stages of rheumatoid arthritis evoked mixed emotions: intimidation, fear, and motivation.	➢ Fear/dread/intimidation ➢ Motivation
	[II] A desire to limit disease progression, alongside seeing the benefits in others with rheumatoid arthritis, endorsed participation.	➢ Desire or not

Table continues on next page.

APPENDIX B (CONTINUED)

Emotions in Table 3 (continued)

Author	Statement	Categories
Robart and Boyle[60]	[I] People felt motivated.	➢ Motivation
	[II] Others felt fear of pain or re-injury.	➢ Fear/dread/intimidation
	[III] The experience of modified duties led to feelings of guilt.	➢ Guilt/resentment/blame
	[IV] The fear of disclosing a lower back injury can be related to behavior [II].	➢ Fear/dread/intimidation
	[V] People felt fear and uncertainty about the future. These emotions were related to the discriminatory practices that could appear in the workplace.	➢ Fear/dread/intimidation ➢ Insecurity/uncertainty
	[VI] Several uncertainties were reported regarding the return-to-work process and future work capacity. Some people described feeling lost, anxious, and insecure about the future.	➢ Insecurity/uncertainty ➢ Loneliness/loss ➢ Anxiety/agitation
	[VII] Others showed concerns about earlier-than-anticipated retirement and future work capacity.	➢ Concerns/distress/worry/self-absorbed
	[VIII] Some of these uncertainties are driven by fears of being discriminated (in the workplace).	➢ Fear/dread/intimidation
	[IX] Fear of re-injury and despair emerged and influenced people's beliefs about their ability to return to work.	➢ Fear/dread/intimidation ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted
	[X] Some uncertainties could emerge related to the process (this emotion was related to cognition [XVII]).	➢ Insecurity/uncertainty
Sim and Madden[63]	[I] People felt loneliness and grief (these emotions were related to behavior [I]).	➢ Loneliness/loss ➢ Grief/sadness
Snelgrove and Liossi[65]	[I] Despondency, shame, and helplessness were related to impaired social, family, and work roles.	➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Embarrassment/shame
	[II] People could feel anger and guilt (these emotions were related to cognition [V]).	➢ Anger/irritability/grump/aggravation ➢ Guilt/resentment/blame
	[III] Fear of pain and a loss of function in older individuals restricted leisure time in retirement, promoting lowered mood.	➢ Fear/dread/intimidation ➢ Mood states
	[IV] People had feelings of negativity toward others (this emotion was related to cognition [IX] in Table 2).	➢ Negativity toward others
	[V] Some people remain positive reestablishing a valued identity. However, others felt thwarted by difficulties replacing valued roles (these emotions were related with cognition [VII]).	➢ Unspecified emotions ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted
Söderlund et al[66]	[I] People felt sad and helpless about all social losses that were consequences of whiplash.	➢ Grief/sadness ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted

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APPENDIX B (CONTINUED)

Emotions in Table 3 (continued)

Author	Statement	Categories
Stewart et al[69]	[I] Dependency emerged on family members for basic care.	➢ Dependence
	[II] Financial worry emerged associated with the loss of incomes.	➢ Concerns/distress/worry/self-absorbed
	[III] People desired not to be touched for fear of exacerbating the pain.	➢ Fear/dread/intimidation ➢ Desire or not
	[IV] Shame and embarrassment of a gout flare harmed social participation.	➢ Embarrassment/shame
	[V] Some people felt depression, anger, frustration, and feelings of vulnerability (these emotions were related to cognition [V]).	➢ Depression ➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Anger/irritability/grump/aggravation ➢ Feelings of vulnerability
	[VI] Physical isolation caused frustration, irritability, and aggravation.	➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted ➢ Anger/irritability/grump/aggravation
	[VII] Some people developed feelings of boredom (this emotion was related to cognition [VI]).	➢ Boredom
	[VIII] People felt fearful of triggering a flare with certain foods.	➢ Fear/dread/intimidation
	[IX] Some people felt embarrassed about the negative connotations associated with gout.	➢ Embarrassment/shame
Toye et al[74]	[I] "I feel guilty" (this emotion was related to cognition [VI]).	➢ Guilt/resentment/blame
	[II] "Overwhelming doubt permeated my experience at work, social life, […] and family."	➢ Help or helplessness/frustration/despair/hope or hopelessness/despondency/overwhelm/thwarted
	[III] "I feel fear of overburdening others."	➢ Fear/dread/intimidation
Toye et al[75]	[I] Employees […] were particularly concerned not to be seen as "bad workers" or as letting the side down.	➢ Concerns/distress/worry/self-absorbed
	[II] Chronic pain threatened the sense of being integral in the workplace, and some people felt easily dispensable or feared that employers saw them as too risky to keep on.	➢ Fear/dread/intimidation ➢ Feelings of being dispensable
	[III] Uncertainty about the unpredictability and relentlessness of symptoms, along with a fear of symptom progression, emerged.	➢ Insecurity/uncertainty ➢ Fear/dread/intimidation
	[IV] "I feel […] worried about gaining a reputation for being 'work-shy.'" This feeling could be increased by a culture of skepticism and mistrust regarding chronic pain (this emotion was related to cognition [VIII]).	➢ Concerns/distress/worry/self-absorbed
	[V] Feelings of guilt in the workplace are compounded by judgments by colleagues (this emotion was related to cognition [X]).	➢ Guilt/resentment/blame
	[VI] Fear of letting employers down or not being seen as a good worker.	➢ Fear/dread/intimidation
	[VII] Guilt and resentment at losing/not finding suitable employment emerged.	➢ Guilt/resentment/blame
	[VIII] People were concerned that employers would not tolerate the unpredictability and relentlessness of symptoms.	➢ Concerns/distress/worry/self-absorbed
	[IX] Many people felt responsible for back injuries (this emotion was related to cognition [IX]).	➢ Feeling responsible

APPENDIX B (CONTINUED)

Cognitions in Table 3

Author	Statement	Categories
Bunzli et al[8]	[I] People described recurrent flare-ups disrupted the consistency of work-ability.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] People partook in cost analysis or risk assessment where contextual demands influenced whether or not to engage in activities with or without pain.	➢ Cognitive strategies to manage the symptoms
	[III] The challenge of coping with pain daily and making plans had a significant impact on daily functioning, particularly in the workplace and family context.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IV] People described their roles in the family environment changed.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] People perceived stigmatization.	➢ Stigma
Climent-Sanz et al[14]	[I] Sleep problems and fatigue affected the functional capacity in the workplace.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] Sleep problems caused people to barely share the bed with their partners.	➢ The impact of the symptoms in the interaction of the individuals with the environment
Daker-White et al[17]	[I] Many expectations emerged to govern physical functioning or the ability to do things.	➢ Expectations
	[II] The support people received from their partners was perceived as "too much" because it was felt to be eroding their social roles.	➢ Support or lack of support/being a burden
	[III] Rheumatoid arthritis was perceived as a chronic and incurable disease. The effect of these symptoms led to changes and losses in social roles.	➢ The description of the symptoms ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IV] Control was related to the levels of social support. Typically, people described themselves as either (more commonly) feeling "out of control."	➢ Perceptions about the control or not of the symptoms ➢ Support/being a burden
	[V] Contrary opinions about the ability to achieve control of the illness: Some women suggested that it was easier for older women to achieve control in this context because they had fewer social role obligations than their younger counterparts.	➢ Perceptions about the control or not of the symptoms
	[VI] "The onset and development of arthritis is simultaneously an assault on the body and a disruption of social life." The best term to capture these issues in the context of rheumatoid arthritis is probably "biographical disruption." This biographical disruption centered on the loss of previous life and work identities.	➢ Changes of selves
	[VII] The success in coping with rheumatoid arthritis seemed to hinge upon the degree of flexibility possible in both formal structures and informal relationships.	➢ Cognitive strategies to manage the symptoms
	[VIII] Within social relationships, "control" referred to reciprocity (ie, "giving-receiving").	➢ Perceptions about the control or not of the symptoms
	[IX] Informal structures like families contain unstated norms of reciprocity or give-and-take, and for many people, the experience of disablement is one of having these norms upset.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[X] Whether for worker or homemaker, it was precisely taken-for-granted activities that constituted a large measure of self-identity.	➢ Changes of selves
	[XI] Some people described a lack of appreciation by others.	➢ Stigma

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Donnelly et al[21]	[I] Some men reported that relying on others to help with domestic tasks, such as chopping wood, could undermine their sense of masculinity.	➢ Changes of selves ➢ Support or lack of support/being a burden
	[II] Maintaining caring roles could mean a physical and emotional challenge: "I could not tie his [child's] little boots and had to call a neighbour, this was traumatic… I could not take my baby in my arms."	➢ Support or lack of support/being a burden ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[III] Social comparison was a common strategy across the studies. Downward comparisons […]. Upward comparisons […]. Self-comparison […].	➢ Cognitive strategies to manage the symptoms
	[IV] Some people believed that they would be perceived as less productive or competent if they revealed their illness.	➢ The legitimacy of the illness
	[V] […] people perceived they were unsupported by family, friends, and colleagues.	➢ Support or lack of support/being a burden
	[VI] Contrary opinions about seeking help: People described how they felt about seeking help. Support, particularly from family and friends, was widely regarded as having positive effects concerning self-management. However, they perceived that they could be a burden.	➢ Support or lack of support/being a burden
	[VII] People perceived themselves to be a burden (this cognition was related to emotion [IV]).	➢ Support or lack of support/being a burden
	[VIII] The illness affected the ability to work and how a loss of employment impacted self-identity.	➢ Changes of selves ➢ The impact of the symptoms in the interaction of the individuals with the environment
Feddersen et al[23]	[I] People described paid work seemed to be given a higher priority than being a mother and living with rheumatoid arthritis.	➢ Perceptions about priorities
	[II] Participation in the labor market was seen as a positive identity marker.	➢ Changes of selves
	[III] Some women perceived themselves to be a burden to their families because of their lack of capabilities in the house.	➢ Support or lack of support/being a burden
	[IV] The unpredictability of fatigue, the fluctuating course of the illness, and how the illness developed over time were described as some of the greatest challenges of having rheumatoid arthritis concerning motherhood and paid work.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] Pain and reduced mobility were noted as limiting factors that further impacted their paid work and being a mother.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] Social positions in the family changed: Children and partners took over some household tasks.	➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Support or lack of support/being a burden
	[VII] Some people did not have sufficient personal resources to perform anything other than their paid work, rest, and sleep.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VIII] The ability to continue working was dependent on support and recognition from the woman's partner, employer, and coworkers. This included opportunities to work flexibly, reductions in working hours and duties, or changes to tasks.	➢ Support or lack of support/being a burden ➢ The legitimacy of the illness
	[IX] It was considered very worthwhile to stay connected to the labor market.	➢ Changes of selves
	[X] Some people perceived they couldn't cope with daily life with children because of the illness.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XI] Some people perceived they can't provide for their family and to live up to social norms in society.	➢ Perceptions about obligations with the environment
	[XII] When the illness meant that a woman had to give up work, it could be seen as a "biographical disruption" or a loss of identity.	➢ Changes of selves
	[XIII] "I thought the illness could be passed on to the child."	➢ The impact of the symptoms in the interaction of the individuals with the environment

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Froud et al[24]	[I] Contrary opinions about the necessary/desirable support: People expressed a paradoxical need/desire for support from those closest to them. On the other hand, they simultaneously wanted to avoid those close to them while in pain.	➢ Support or lack of support/being a burden
	[II] People emphasized that the price of engaging in activities they thought likely to exacerbate their symptoms could be a loss of credibility since participation could be perceived as evidence that there was nothing wrong (this cognition was related with behavior [II]).	➢ The legitimacy of the illness
	[III] The absence of sexual activity due to low back pain was associated with the perception of a damaged relationship.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IV] Contrary opinions associated with social interactions: A cognitive dissonance was evident in accounts of social interaction. On the one hand, people described themselves as social, or formerly social, and wanted to be able to go out with friends. On the other hand, they recounted uncomfortable feelings associated with social activities.	➢ Perceptions about obligations with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] Contrary opinions about how pain was perceived in the workplace: Younger people tended to perceive back pain as more threatening to their careers. On the other hand, older workers or those closer to retirement appeared to find it easier to ask for help.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] People described that the absence of disclosure of their back pain was responsible for the dismissal from work or transfer.	➢ Perceptions about hiding the symptoms
	[VII] Some people began to question their worth as an employee.	➢ Changes of selves
	[VIII] People emphasized the need to modify work tasks.	➢ Cognitive strategies to manage the symptoms
	[IX] People perceived they were unsupported.	➢ Support or lack of support/being a burden
	[X] Marital relationships suffered such that cohabitation became unviable.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XI] Activity limitations were considered to have negative implications for relationships, especially in terms of interacting with children or grandchildren.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XII] Allowing sufficient time to recover was considered important; however, it was emphasized that this sometimes resulted in time off work.	➢ Cognitive strategies to manage the symptoms
	[XIII] People not eligible for sick pay are often described as not being able to afford to take the time off.	➢ Perceptions about priorities
	[XIV] Some people pointed out reduced pay due to sick leave could be insufficient.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XV] Some people thought their employers may be unwilling to accommodate their need or might terminate their employment.	➢ Support or lack of support/being a burden

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Lin et al[34]	[I] People changed their view on their relationship with problems and the judgment of others. They also became empowered to respond to their needs.	➢ Empowerment ➢ Changes of selves
	[II] People are unable to achieve a sense of confidence to face their changing roles in work and family life.	➢ Changes of selves
	[III] People frequently use the downward comparative strategy, comparing themselves with people in a worse physical state of mind and body.	➢ Cognitive strategies to manage the symptoms
	[IV] As people could no longer function in the same manner in their social and occupational roles, they learned to adjust expectations and modify standards. In addition to accepting limitations related to their performance, these people wrestled with accepting limitations in their relational roles regarding controlling others and accepting dependence on others.	➢ Cognitive strategies to manage the symptoms ➢ Support or lack of support/being a burden ➢ Expectations
	[V] People repeatedly described authenticity as awareness of self and others. […] Concretely, an author described that, as a corollary to accepting physical limitations, people expressed increasing comfort with relying on others for help with daily tasks. They also said that accepting limitations involved overcoming denial.	➢ Cognitive strategies to manage the symptoms ➢ Support or lack of support/being a burden
	[VI] People are unable to achieve a sense of calm to face their changing roles in work and family life.	➢ A lack of calm
MacNeela et al[37]	[I] Workers believed they were less productive than before.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] Back pain devastated economic security through disruptions and threats to the ability to work.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[III] For those in manual jobs, continued duties […] were perceived to be causing damage through "wear and tear."	➢ The causes of the symptoms
	[IV] Supervisor behaviors were typically cited as unsupportive.	➢ Support or lack of support/being a burden
	[V] Occupational status was, in most cases, a marker of the ability to cope with the demands of a job.	➢ Perceptions about markers that facilitate to cope with the environment
	[VI] A person […] identified the loss of the worker role to undermine self-esteem.	➢ Changes of selves
	[VII] Bleak visions of the future included frightening images of dependency.	➢ Support or lack of support/being a burden
	[VIII] One motive for social withdrawal was to avoid actual or anticipated rejection and suspicions of malingering. A further reason for withdrawal was the sense of social invisibility […].	➢ The causes of developing a determined behavior
	[IX] The result of the condition was a severe threat to the person's lifestyle and undermined the ability to carry out essential daily activities. In turn, such losses impacted valued roles and routines, such as parenting, gardening, exercise, and driving.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[X] Back pain […] compromised the ability to perform expected roles.	➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Expectations
	[XI] The spousal and parental relationships were highly stressed by back pain, with reports of diminished trust and mutual understanding.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XII] Back pain was described as a stigmatized illness lacking in authenticity and legitimacy.	➢ Stigma
	[XIII] Some people felt unable to perform familiar and necessary tasks.	➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Perceptions about obligations with the environment
Parenti et al[53]	[I] The need for improvements regarding people's psychological support […] was derived from elements such as […] low self-confidence.	➢ Changes of selves

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APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Primdahl et al[57]	[I] Fatigue is related to experiences of […] loss of control concerning other people.	➢ Perceptions about the control or not of the symptoms
	[II] It is essential for people not to be perceived as grumpy or whining, but to manage fatigue on their own.	➢ Empowerment
	[III] People perceived other individuals, who are familiar with "normal" tiredness, are only able to understand fatigue on an intellectual level.	➢ The legitimacy of the illness
	[IV] People described not having enough energy to take care of their families.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] People described fatigue as a great barrier to being with other people.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] People described a sense of being dependent on others as detrimental.	➢ Support or lack of support/being a burden
	[VII] It is hard to fulfill social expectations, which led to different emotions (this cognition was related to emotion [III]).	➢ Expectations
	[VIII] Fatigue affected several cognitive aspects of the individual: the engagement with others.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IX] People found it hard to reciprocate help and describe fatigue as exhausting, which limits their relationships with other people.	➢ Perceptions about obligations with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[X] People accepted help from others.	➢ Support or lack of support/being a burden ➢ Cognitive strategies to manage the symptoms
	[XI] People can feel too tired to entertain others or fall asleep.	➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Perceptions about obligations with the environment
Riggs and Killingback[59]	[I] Contrary opinions about being belonged to a group: While social interaction facilitated most people, others described that being part of a rheumatoid arthritis group labeled them as a patient and took away their identity.	➢ Changes of selves
	[II] People highlighted the need for support.	➢ Support or lack of support/being a burden
	[III] Social connection was a key factor to undertake physical activity. A reported sense of "belonging to a community" and "sharing the same struggles" indicated that acceptance and understanding were important.	➢ Cognitive strategies to manage the symptoms
	[IV] Lifestyle constraints, such as children and employment, affected people's activities. They preferred activities that fitted into their daily routines.	➢ Perceptions about obligations with the environment
	[V] Regarding location, community settings were preferred as they removed the stigma of being a patient, rather than a person with rheumatoid arthritis.	➢ Stigma
	[VI] The fundamental incentive for people was to counteract disease progression and preserve independence, maintaining their role within society.	➢ Motivation

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Robart and Boyle[60]	[I] People […] described the benefits of working, such as contributing to positive self-identity and offering a welcome distraction from back pain.	➢ Changes of selves ➢ Perceptions about the control or not of the symptoms
	[II] Contrary opinions about how workers/nonworkers were perceived by relatives: Those who were working were perceived as "stoical" and "heroic," whereas relatives in the nonworking sample were perceived as "blameless victims" and were more likely to be labeled "disabled."	➢ The legitimacy of the illness
	[III] Modified duties were described to be socially inappropriate in one instance in which male workers were expected to undertake duties ordinarily done by female workers.	➢ The legitimacy of the illness
	[IV] Workers who were more competent in their roles saw themselves as assertive and were proactive in their care.	➢ Empowerment
	[V] Factors such as […] "taking responsibility for oneself" positively influenced the ability to return to work.	➢ Empowerment
	[VI] People perceived an increase or a decrease of the ability to return to work (this cognition was related to emotions [I] and [II]).	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VII] The experience of modified duties led to the possibility of being a burden to colleagues.	➢ Support or lack of support/being a burden
	[VIII] Self-doubt, lack of control, and lack of confidence emerged and influenced people's beliefs about their ability to return to work.	➢ Changes of selves ➢ Perceptions about the control or not of the symptoms
	[IX] How workers perceived themselves may limit their ability to engage with the rehabilitation process.	➢ Changes of selves
	[X] Some people perceived pessimism over their ability to return to work.	➢ Pessimistic thoughts
	[XI] People described that some factors (ie, jobs that permitted to find a balance between sedentary positions and physical movement) facilitated that they could modify their work duties.	➢ The causes of developing a determined behavior
	[XII] A lack of modified duties was considered a barrier to return to work.	➢ The causes of developing a determined behavior
	[XIII] People described that their low back pain could be seen as "bogus" in the workplace.	➢ The legitimacy of the illness
	[XIV] People could be negatively appraised by others due to the invisibility of low back pain (this cognition relates to emotion [IV]).	➢ The legitimacy of the illness
	[XV] People with low back pain could be perceived as being to blame by others.	➢ The legitimacy of the illness ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[XVI] People reappraised their point of view about others to mediate work-condition conflict.	➢ Cognitive strategies to manage the symptoms
	[XVII] People described some uncertainties that could emerge related to their process when they felt their employers do not understand the difficulties they experience or how best to support them.	➢ The legitimacy of the illness ➢ Support or lack of support/being a burden
Sim and Madden[63]	[I] People described the difficulty of clearly and accurately talking about pain to others, reflecting the inadequacy of language in expressing a subjective experience (ie, pain is invisible).	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] Fatigue and lack of strength affected personal relationships.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[III] Cognitive difficulties were reported (eg, limitations with problem solving and abstract thinking), affecting the presence of opportunities in the workplace.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IV] The intention for maintaining a normal role caused that family relationships became strained.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] People involved in redefining their social obligations.	➢ Perceptions about obligations with the environment ➢ Cognitive strategies to manage the symptoms

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APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Snelgrove and Liossi[65]	[I] People described their integrity as threatened due to the presence of stigmatizing judgments and unsympathetic social contexts in which chronic low back pain was experienced (this made difficult family interactions).	➢ Stigma ➢ Changes of selves ➢ Perceptions about obligations with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] People reported being a burden to their families.	➢ Support or lack of support/being a burden
	[III] Gender differences were described regarding people's roles (ie, opportunities for control and influence in the workplace benefited the self-esteem of men more than women with chronic low back pain).	➢ Changes of selves
	[IV] Perceptions of lowered self-esteem were related to impaired social, family, and work roles.	➢ Changes of selves
	[V] Friends and family could offer emotional and tangible support [...]. However, any disruption to social roles could result in problems maintaining a normal social life.	➢ Support or lack of support/being a burden
	[VI] People described the presence of low self-esteem, which was offset with several behaviors (see behavior [II]).	➢ Changes of selves
	[VII] People described reestablishing a valued identity but found difficulties replacing valued roles (ie, unfavorable work context – unemployment).	➢ Changes of selves ➢ Cognitive strategies to manage the symptoms
	[VIII] Illness and cultural beliefs mediated coping strategies. Biomedical beliefs were determinant to people's experiences. These beliefs were related to [...] less successful rehabilitation to work.	➢ Perceptions about markers that facilitate to cope with the environment
	[IX] People described cognitive problem-solving processes such as the development of downward comparisons.	➢ Cognitive strategies to manage the symptoms
	[X] People described cognitive problem-solving processes such as the assertion of oneself in the face of stigma.	➢ Stigma ➢ Cognitive strategies to manage the symptoms
	[XI] People found alternative meanings in life to offset the reduction of self-esteem (eg, joining support groups).	➢ Changes of selves ➢ Support or lack of support/being a burden
Söderlund et al[66]	[I] People perceived other individuals without whiplash and pain labeled them negatively because there was no visible evidence of their pain.	➢ The legitimacy of the illness
	[II] The invisibility of pain also contributed to the people's belief that others thought they were malingering.	➢ The legitimacy of the illness
	[III] The combination of expectations regarding recovery and daily experiences of fluctuating symptoms decreased people's confidence concerning their return to work.	➢ Expectations ➢ Changes of selves
	[IV] Perceived work-related stress and aggravated symptoms decreased their confidence in their ability to return to work.	➢ Changes of selves ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[V] Supportive [...] colleagues and employers were of great importance in increasing people's confidence in their ability to return to work. Different adaptations of working conditions and acceptance of their physical and psychological limitations increased the people's confidence regarding return to work.	➢ Changes of selves ➢ Support or lack of support/being a burden ➢ Cognitive strategies to manage the symptoms
	[VI] People described pain and other symptoms interfered in their social roles.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VII] Support from significant others was an important part of being able to control the situation.	➢ Support or lack of support/being a burden ➢ Perceptions about the control or not of the symptoms
	[VIII] People perceived returning to work was a challenge.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IX] People are described to be stigmatized due to the changes in their image.	➢ Stigma ➢ Changes of selves

Table continues on next page.

APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Stack et al[67]	[I] People described the disruption to normal roles and daily activities could drive to help-seeking behavior.	➢ Perceptions about markers that facilitate to cope with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] Causal beliefs associated with rheumatoid arthritis symptoms included work.	➢ The causes of the symptoms
	[III] Changes in symptoms, experiences, and explanations helped people to determine when help should be sought.	➢ Perceptions about markers that facilitate to cope with the environment
	[IV] Contrary opinions about when seeking help: While few people recognized their symptoms as indicative of their illness, those that did suggested that they sought help when the pain spread to multiple joints.	➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Perceptions about markers that facilitate to cope with the environment
	[V] People described the severity, intensity, and duration of symptoms at the onset of rheumatoid arthritis influenced if they sought help.	➢ Perceptions about markers that facilitate to cope with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] People mentioned if they had more knowledge about their illness, they would have sought help earlier.	➢ Perceptions about markers that facilitate to cope with the environment
	[VII] People described the public had a greater awareness of conditions, such as cancer and heart disease, and the public did not perceive joint symptoms could be indicative of a serious illness.	➢ The legitimacy of the illness
	[VIII] People believed their illness affected older people or was caused by "wear and tear" (this hindered rapid help-seeking).	➢ The causes of the symptoms
Stack et al[68]	[I] A rapid onset of pain was often associated with the onset of additional symptoms.	➢ The causes of the symptoms ➢ The impact of the symptoms in the interaction of the individuals with the environment ➢ Perceptions about markers that facilitate to cope with the environment
Stewart et al[69]	[I] Being physically intimate during flares was described as difficult or impossible (this cognition was related to emotion [III]).	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[II] People described gout flares affected their ability to participate in social events (ie, going to the cinema).	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[III] Many people mentioned that the unpredictability of gout flares affected their ability to plan social activities and engagements.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[IV] People described the presence of pressure to go to work even if they were in pain due to financial stress and the need to support their families.	➢ Perceptions about obligations with the environment
	[V] The lack of intimacy due to gout flares negatively affected relationships.	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] Some people felt unable to move or participate in normal daily activities.	➢ The impact of the symptoms in the interaction of the individuals with the environment

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APPENDIX B (CONTINUED)

Cognitions in Table 3 (continued)

Author	Statement	Categories
Toye et al[74]	[I] "I feel others' disbelief threatens my integrity."	➢ Changes of selves
	[II] Contrary opinions about being part of a community: Being part of a community describes a sense of sharing, being valued, and becoming credible. However, despite the benefits […], there is a sense of ambivalence; "although I am like the others, at the same time I am not like them, and I need to be valued as an individual."	➢ Support or lack of support/being a burden
	[III] "I no longer need to gain the approval of others."	➢ Empowerment
	[IV] "My loss of roles that made me who I am undermined my self-worth."	➢ Changes of selves
	[V] "I cannot meet people's expectations."	➢ Expectations
	[VI] People described how hiding pain could affect their credibility.	➢ The legitimacy of the illness ➢ Perceptions about hiding the symptoms
	[VII] "I am learning to limit demands from others and manage my resources."	➢ Cognitive strategies to manage the symptoms
	[VIII] "I perceived my situation as a discrepancy between culturally accepted explanations and personal experience."	➢ Perceptions about obligations with the environment
Toye et al[75]	[I] The losses to self that accompany changes in work roles.	➢ Changes of selves
	[II] Work is described as adding value to the self (eg, work makes us what we are; work gives recognition, approval, self-realization, and self-respect).	➢ Changes of selves
	[III] People perceived a necessity of limiting the support that they could expect from colleagues (ie, in a harsh financial environment).	➢ Support or lack of support/being a burden
	[IV] People perceived employers could fail to support them in continued work. Some people felt as if they were "being treated like a number," although their work had been valued before pain. This led to a sense of betrayal.	➢ Support or lack of support/being a burden ➢ Betrayal
	[V] People perceived they could not continue at work (this cognition was related to emotion [III]).	➢ The impact of the symptoms in the interaction of the individuals with the environment
	[VI] A minority perceived the possible benefits of flexible working arrangements, although these might not be available.	➢ Cognitive strategies to manage the symptoms ➢ Perceptions about markers that facilitate to cope with the environment
	[VII] Some people described a lack of understanding by others.	➢ Support or lack of support/being a burden
	[VIII] People perceived letting the employer down threatened their image as a worker.	➢ Perceptions about obligations with the environment
	[IX] Some people perceived poor workplace policies.	➢ Support or lack of support/being a burden
	[X] Some people generally described staying at work had many benefits. Disbenefits included fewer opportunities for social life and to pursue hobbies.	➢ Perceptions about markers that facilitate to cope with the environment ➢ The impact of the symptoms in the interaction of the individuals with the environment

Behaviors in Table 3

Author	Statement	Categories
Bunzli et al[8]	[I] Withdrawal from social contact to avoid "letting others down" (this behavior was also related to cognition [V]).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
Climent-Sanz et al[14]	[I] People must wake up in the morning despite feeling tired to fulfill their working schedules.	➢ Practicing activities despite the symptoms
	[II] People described a constant movement in bed that ended up impacting the quality of sleep of their bedfellows (this behavior was related to emotion [I]).	➢ Constant movements in bed
Daker-White et al[17]	[I] People faced the problems of "being believed" concerning pain and the fluctuating nature of the condition.	➢ Fighting against the illegitimacy of the symptoms
	[II] People faced stigmatizing threats relating to the exposure (or visibility) of bodily deformities.	➢ Fighting against potential stigma

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APPENDIX B (CONTINUED)

Behaviors in Table 3 (continued)

Author	Statement	Categories
Donnelly et al[21]	[I] Concealing deformity was important to some people, especially in work and social situations.	➢ Hiding symptoms
	[II] Taking sick leave was often avoided if it was felt that colleagues or employers did not recognize their illness as legitimate.	➢ Sick leave avoidance ➢ Fighting against the illegitimacy of the symptoms
	[III] People could reduce their social outings and physical activities if they perceived limited means (this behavior was related to emotion [I]).	➢ Activity avoidance or restrictions/social withdrawal/social isolation
	[IV] People struggled to convince family, friends, and colleagues that they were legitimately ill.	➢ Fighting against the illegitimacy of the symptoms
	[V] People are socially isolated, particularly during a flare.	➢ Activity avoidance or restrictions/social withdrawal/social isolation
Feddersen et al[23]	[I] Some people tried to hide symptoms of illness at work (this behavior was related to cognition [XII]).	➢ Hiding symptoms
	[II] Some women ignored symptoms and limitations caused by their rheumatoid arthritis so they could carry on the previous activities with their children and in their paid work. When symptoms and limitations were ignored, it was often with full awareness of the consequences of overloading themselves and the probable worsening of symptoms.	➢ Ignoring symptoms
Froud et al[24]	[I] Some people avoided family activities and showed social withdrawal and isolation (these behaviors were related to emotion [II]).	➢ Activity avoidance or restrictions/social withdrawal/social isolation
	[II] Some people engaged in activities they thought likely to exacerbate their symptoms, simply to maintain relations.	➢ Practicing activities despite the symptoms
	[III] Some people did not disclose their back problems to their employers (this behavior was related to emotion [VI]).	➢ Hiding symptoms
	[IV] An individual preferred to use the holidays for recovery rather than taking time off work due to the belief that sick leave would pose a risk to the job.	➢ Sick leave avoidance
	[V] People battled to be believed, making efforts to perform tasks despite the pain.	➢ Fighting against the illegitimacy of the symptoms ➢ Practicing activities despite the symptoms
Lin et al[34]	[I] People stretched the limits of their ability to perform activities, especially at work, to be able to keep their jobs.	➢ Practicing activities despite the symptoms
	[II] The most valuable element to find meaning was the reevaluation of positive values in one's life and the provision of feedback. People may adhere to altruism, remain supportive of public welfare services, show concern about the needs of others, and use their experiences to help others make sense of their purpose and significance.	➢ Approaches to find meaning in life
MacNeela et al[37]	[I] Withdrawal from others and avoid interaction (these behaviors were related to emotion [IV] and cognition [VIII]).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[II] In a study, most people were still working.	➢ Practicing activities despite the symptoms
	[III] People struggled to meet expectations in the workplace.	➢ Fighting against the necessity of meeting people's expectations
Parenti et al[53]	[I] Some strategies (ie, exchanging social support) were adopted to increase resilience in facing rheumatoid arthritis challenges.	➢ Exchanging social support/use social groups
	[II] People applied self-care behaviors (this behavior was related to behavior [II]).	➢ Unspecified behaviors

Table continues on next page.

APPENDIX B (CONTINUED)

Behaviors in Table 3 (continued)

Author	Statement	Categories
Primdahl et al[57]	[I] People reduced their social activities to a minimum. […] Days with high levels of fatigue led to isolation at home either because it was difficult to go out or people deliberately chose to be by themselves and stayed home (this behavior was related to cognition [V]).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[II] People strived to avoid showing fatigue at work or in public.	➢ Hiding symptoms
	[III] People communicated their fatigue differently depending on the context, and they expected a reaction from those they talked to.	➢ Communication of the symptoms
	[IV] Contrary behaviors about how to face daily tasks: People broke down tasks over one or several days, or they consciously decided to carry on regardless of the consequences.	➢ Practicing activities despite the symptoms
	[V] People with rheumatoid arthritis did not share their illness with others (this behavior was related to emotion [IV]).	➢ Hiding symptoms
	[VI] People with fatigue constantly prioritized and planned activities according to their capacity to manage fatigue at home and work.	➢ Planning or prioritizing activities
Robart and Boyle[60]	[I] Making changes in working duties (ie, advice on ergonomics) was a further way injured workers may be enabled to continue in their work.	➢ The adaptation of strategies
	[II] Some people anticipated discrimination in the workplace.	➢ Hypervigilance/anticipation
Sim and Madden[63]	[I] People established their priorities, leading to certain activities, such as paid work or social relationships, being lost. This facilitated that people were socially isolated.	➢ Planning or prioritizing activities ➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[II] People used social/family networks and support groups.	➢ Exchanging social support/use social groups
Snelgrove and Liossi[65]	[I] People restricted their leisure time in retirement (this behavior was related to emotion [III]).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[II] People maintained social roles to offset the reduction of self-esteem.	➢ Practicing activities despite the symptoms
	[III] People […] developed anticipation toward negative social judgments with little reestablishment of behavioral activity (this behavior was related to emotion [IV] of Table 2).	➢ Hypervigilance/anticipation
	[IV] Those coping strategies that may be viewed as inhibiting any long-term adaptation included prolonged periods of rest and excessive use of alcohol (these strategies could disrupt family lives and spousal relationships).	➢ Alcohol ➢ Resting
	[V] People learned to live with pain in different situations (ie, an increase of functional capacity in work situations).	➢ Practicing activities despite the symptoms
	[VI] People socially isolated (this behavior was associated with emotions [I] and [III] in Table 3 and behavior [VI] in Table 2).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[VII] People adjusted priorities to offset the reduction of self-esteem (ie, joining support groups).	➢ Planning or prioritizing activities
Stack et al[67]	[I] People rapidly searched for help when the symptoms appeared rapid.	➢ Help-seeking behaviors
	[II] People initially sought help for symptom relief.	➢ Help-seeking behaviors
	[III] People sought help when the anticipated or real level of disruption became a concern or previous strategies for dealing with symptoms failed.	➢ Help-seeking behaviors
	[IV] People probably increased their visits to the consult due to the increase in the severity of the symptoms and impacted activities.	➢ Help-seeking behaviors
Stack et al[68]	[I] Some people adopted rapid help-seeking behaviors (this behavior was related to cognition [I]).	➢ Help-seeking behaviors

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APPENDIX B (CONTINUED)

Behaviors in Table 3 (continued)

Author	Statement	Categories
Stewart et al[69]	[I] People avoided eating out with family and friends (this behavior was related to emotion [VIII]).	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
	[II] People reported changing the nature of their jobs due to frequent gout flares, from less physical to more sedentary jobs, or choosing jobs with greater flexibility, such as self-employment or volunteering.	➢ The adaptation of strategies
	[III] Some people avoided leaving the house as they did not want to be seen walking with a limp or felt self-conscious about their feet being swollen. This facilitated that people were socially isolated.	➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation ➢ Hiding symptoms
	[IV] Several people avoided telling their friends and family that they were suffering from a gout flare (this behavior was related to emotion [IX]).	➢ Hiding symptoms ➢ Communication of the symptoms
	[V] A person slept in a different bed than its partner during a flare (this behavior was related to emotion [III]).	➢ The adaptation of strategies ➢ Activity avoidance or restrictions/ ➢ social withdrawal/social isolation
Toye et al[74]	[I] "I am encouraged to hide pain" (this behavior was related to emotion [III]; hiding pain can be a double-edged sword because people do not necessarily believe what they cannot see).	➢ Hiding symptoms
	[II] "I find it liberating to tell others about my pain. This permits me to avoid hiding my pain and allowing them to know my limitations."	➢ Communication of the symptoms ➢ Hiding symptoms
	[III] "I strive to present a picture of myself as a 'good' person who is not to blame for my pain" (this behavior was related to cognition [VI]).	➢ Fighting against the illegitimacy of the symptoms
Toye et al[75]	[I] "I struggle to affirm my credibility as a 'good worker' (ie, maintaining a positive image)."	➢ Fighting against the illegitimacy of the symptoms
	[II] Employees […] struggled to maintain a positive image. […] To avoid […] negative image, they used various strategies: struggling on at work and relying on colleagues despite pain, taking annual leave rather than taking the time of "off sick," or finally leaving work.	➢ Sick leave avoidance ➢ Practicing activities despite the symptoms
	[III] Some people left work voluntarily (this behavior was related to emotion [VI]).	➢ Giving up the job
	[IV] People went to great lengths to find employment and often hid back pain from their employers.	➢ Hiding symptoms
	[V] Contrary behaviors: Workers struggled to balance work commitments with other essential roles, leisure, and social activities (ie, some people generally described staying at work had many benefits; disbenefits included fewer opportunities for social life and to pursue hobbies).	➢ Practicing activities despite the symptoms
	[VI] Adjustment latitude […] involves a range of crucial adaptation strategies around prioritizing work, being flexible in execution of tasks […], adapting ways of working with colleagues […], and working in partnership with families […]. Not everyone at work experiences this latitude at work.	➢ The adaptation of strategies ➢ Planning or prioritizing activities

APPENDIX C

EMOTIONS, COGNITIONS, AND BEHAVIORS THAT APPEAR IN EACH INCLUDED REVIEW

Emotions Regarding Table 2

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013
Insecurity/uncertainty/ambivalence/indecision	7	X		X	X							X			X	X	X		
Short-tempered/anger/irritation/emotional upset/aggravation/snappy	7	X		X					X		X			X			X	X	
Anxiety/agitation	5	X	X						X									X	X
Distress/worry/concerns/preoccupied	10	X	X	X	X	X			X	X			X	X				X	
Depression	8	X		X	X				X				X	X			X	X	
Shame/embarrassment	6	X		X	X				X	X									X
Loathing/hate/denigration	3	X	X											X					
Grief/sadness/mourn/cried	6	X			X									X	X			X	X
Despair/hopeless or hope/frustration/overwhelm/helpless or help/fluctuations between hope and despair	11	X	X	X	X				X	X	X		X	X	X			X	
Fear/afraid	11	X	X	X	X		X					X		X		X	X	X	X
Pity	1			X															
Feeling of injustice	1				X														
Guilt	5			X	X				X					X					X
Feeling satisfied or dissatisfied/pleasant or unpleasant/happy or unhappy/well-being	6			X				X		X		X		X	X				
Dismay	1								X										
Feeling unmotivated/unenthusiastic	2										X	X							
Loneliness	1										X								
Pride	1											X							
Mood state	2									X								X	
Mentally draining	1																	X	
Desire	2							X											X
Bewilderment	1								X										
Emotional fragility	1																	X	
Unspecified negative emotions	1												X						

Cognitions Regarding Table 2

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al.	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013
The description of symptoms	14	X	X	X	X			X	X	X	X		X	X	X		X	X	X	
Changes of selves	12	X		X	X			X	X	X	X	X		X	X	X				X
Suicidal ideation thoughts	4	X			X				X									X		
Cognitive strategies to manage the symptoms	13	X	X	X	X		X	X		X	X	X		X	X	X				X

Table continues on next page.

APPENDIX C (CONTINUED)

Cognitions Regarding Table 2 (continued)

Table continues on next page.

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al.	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013
The impact of the symptoms in other variables and/or factors believed to cause them	17	X	X	X	X	X	X		X	X	X	X		X	X	X	X	X	X	X
Perceptions about the control or not of the symptoms	11		X	X	X		X		X	X	X			X	X	X	X			
Ruminating thoughts	1		X																	
Confusion and conflicting thoughts	1															X				
Expectations	3			X												X				X
Motivational situations	1											X								
Recall symptoms	1																X			
Lack of spontaneity	4				X						X					X				X
Honesty	1							X												
Calmness	1							X												
The relationship between positive outcomes and other variables	7		X	X							X	X		X	X	X				
The description of other factors rather than symptoms	1											X								
Lack of knowledge about the condition	2				X												X			

Behaviors Regarding Table 2

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stewart et al	Toye et al, 2013
Hypervigilance/anticipation	3	X					X							X				
Stoicism	1													X				
Activity avoidance/restrictions	8	X	X	X					X		X		X	X			X	
Seeking information and understanding	1												X					
Ignoring or disregarding the symptoms	2													X		X		
Planning/prioritizing/pacing activities	7				X	X	X				X		X	X	X			
Denying/hiding symptoms	3			X												X		X
Normalizing the symptoms	1															X		
Adopting a new identity or image	1												X					
Listening to and respecting the body	1																	X
Derived postural adjustments	1													X				
Topical treatments	1													X				
Positive approaches (optimism, humor, positive thinking)	5				X			X		X			X	X				
Spiritual approaches	1												X					
The use of earplugs	1		X															
Relaxation	2		X								X							
Resting/staying in bed	5		X		X						X			X			X	
Alcohol	1													X				
Prescribed medication	1													X				

Table continues on next page.

Behaviors Regarding Table 2 (continued)

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stewart et al	Toye et al, 2013
Adaptation to the condition	5									X			X	X		X	X	
Giving up with the condition	1												X					
Fighting against the symptoms/continuing with normal activities	7	X								X			X	X	X		X	X
The use of lavender scent	1		X															
The use of structured routines	2		X										X					
Stretching their limits	1				X													
Praying	1							X										
Pace	1										X							
The use of physical activity to take control	1											X						
Refusing to give in to the condition	1							X										
Unspecified behaviors	3			X	X				X									

Emotions Regarding Table 3

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stewart et al	Toye et al, 2013	Toye et al, 2016
Insecurity/uncertainty	3	X										X						X
Fear/dread/intimidation	12	X		X	X	X	X			X	X	X		X		X	X	X
Dependence	7	X		X	X	X	X	X								X		
Help or helplessness/frustration/despair/hope or hopelessness/despondency/ overwhelm/thwarted	10	X		X	X			X		X		X		X	X	X	X	
Anger/irritability/grump/aggravation	6	X			X			X		X				X		X		
Guilt/resentment/blame	7	X				X				X		X		X			X	X
Depression	3	X			X											X		
Loneliness/loss	4				X					X		X	X					
Concerns/distress/worry/self-absorbed	8		X	X			X	X		X		X				X		X
Anxiety/agitation	3		X					X				X						
Feelings of constant failure	1		X															
Desire or not	4			X	X						X					X		
Negativity toward others	1													X				
Well-being	2					X			X									
Gratitude	1					X												
Antagonism	1							X										
Lack of patience	1									X								
Overly sensitive	1									X								
Misunderstood	1									X								
Useless	1									X								
Lazy	1									X								

Table continues on next page.

APPENDIX C (CONTINUED)

Emotions Regarding Table 3 (continued)

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stewart et al	Toye et al, 2013	Toye et al, 2016
Whining	1									X								
Boredom	2									X						X		
Embarrassment/shame	4								X	X				X		X		
Feeling of being hard to live with	1									X								
Motivation	2										X	X						
Grief/sadness	2												X		X			
Mood states	2								X					X				
Feelings of vulnerability	1															X		
Feelings of being dispensable	1																	X
Feeling responsible	1																	X
Unspecified emotions	1													X				

Cognitions Regarding Table 3

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
The description of the symptoms	1			X																	
Changes of selves	13			X	X	X	X	X	X	X		X	X		X	X				X	X
The causes of the symptoms	3								X								X	X			
The causes of developing a determined behavior	2								X				X								
Support or lack of support/being a burden	13			X	X	X	X	X	X		X	X	X		X	X				X	X
Cognitive strategies to manage the symptoms	13	X		X	X		X	X			X	X	X	X	X	X				X	X
The impact of the symptoms in the interaction of the individuals with the environment	16	X	X	X	X	X	X		X		X		X	X	X	X	X	X	X		X
Perceptions about the control or not of the symptoms	4			X							X		X			X					
Expectations	6			X				X	X		X					X				X	
Motivation	1											X									
Pessimistic thoughts	1												X								
The legitimacy of the illness	8				X	X	X				X		X			X	X			X	
Perceptions about priorities	2					X	X														
Perceptions about obligations with the environment	10					X	X		X		X	X		X	X				X	X	X
Perceptions about hiding the symptoms	2						X													X	
Empowerment	4							X			X		X							X	
Perceptions about markers that facilitate to cope with the environment	5								X						X		X	X			X
Stigma	6	X		X					X			X			X	X					
A lack of calm	1							X													
Betrayal	1																				X

APPENDIX C (CONTINUED)

Behaviors Regarding Table 3

	Number of times	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donnelly et al	Feddersen et al	Froud et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Practicing activities despite the symptoms	7		X				X	X	X		X			X					X
Planning or prioritizing activities	4										X		X	X					X
The adaptation of strategies	3											X					X		X
Constant movements in bed	1		X																
Hiding symptoms	7				X	X	X				X						X	X	X
Ignoring symptoms	1					X													
Sick leave avoidance	3				X		X												X
Activity avoidance or restrictions/ social withdrawal/social isolation	8	X			X		X		X		X		X	X			X		
Fighting against the illegitimacy of the symptoms	5			X	X		X											X	X
Fighting against potential stigma	1			X															
Fighting against the necessity of meeting people's expectations	1								X										
Communication of the symptoms	3										X						X	X	
Unspecified behaviors	1									X									
Exchanging social support/use social groups	2									X			X						
Approaches to find meaning in life	1							X											
Hypervigilance/anticipation	2											X		X					
Alcohol	1													X					
Resting	1													X					
Help-seeking behaviors	2														X	X			
Giving up the job	1																		X

APPENDIX D

CITATION MATRIX

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Ashby S, Richards K, James C. The effect of fear of movement on the lives of people with chronic low back pain. *Int J Ther Rehabil*. 2010;17:232-243.	X							X												
Bowman J. Reactions to chronic low back pain. *Issues Ment Health Nurs*. 1994;15:445-453.	X				X			X												
Bowman J. The meaning of chronic low back pain. *AAOHN J*. 1991;39:381-384.	X				X															
Busch H. Appraisal and coping processes among chronic low back pain patients. *Scand J Caring Sci*. 2005;19:396-402.	X				X			X						X						
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;12:641-652.	X				X			X						X					X	
Coole C, Drummond A, Watson P, et al. What concerns workers with low back pain? Findings of a qualitative study of patients referred for rehabilitation. *J Occup Rehabil*. 2010;20:472-480.	X				X			X				X							X	X
Corbett M, Foster N, Ong B. Living with low back pain—stories of hope and despair. *Soc Sci Med*. 2007;65:1584-1594.	X				X			X						X						
Crowe M, Whitehead L, Gagan M, 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;47:585-592.	X				X			X						X					X	
de Souza L, Frank A. Experiences of living with chronic low back pain: the physical disabilities. *Disabil Rehabil*. 2007;29:587-596.	X				X			X											X	
de Souza L, Frank A. Patients' experiences of the impact of chronic back pain on family life and work. *Disabil Rehabil*. 2011;33:310-318.	X				X			X												
Holloway I, Sofaer B, Walker J. The transition from well person to "pain afflicted" patient: the career of people with chronic back pain. *Illn Crisis Loss*. 2000;8:372-387.	X																			
Holloway I, Sofaer B, Walker J. The stigmatisation of people with chronic back pain. *Disabil Rehabil*. 2007;29:1456-1464.	X				X			X											X	X
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;80:621-628.	X				X			X						X					X	X
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;10:199-207.	X				X			X						X					X	X
May C, Rose M, Johnstone F. Dealing with doubt: how patients account for non-specific chronic low back pain. *J Psychosom Res*. 2000;49:223-225.	X				X			X						X						
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.	X				X			X						X					X	

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Osborn M, Smith J. 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.	X				X			X						X					X	
Smith J, 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;22:517-534.	X				X			X						X					X	
Raak R, Wahren L. Health experiences and employment status in subjects with chronic back pain: a long-term perspective. *Pain Manag Nurs*. 2006;7:64-70.	X													X						
Satink T, Winding K, Jonsson H. Daily occupations with or without pain: dilemmas in occupational performance. *OTJR*. 2004;24:144-150.	X																		X	
Snelgrove S, Liossi C. An interpretative phenomenological analysis of living with chronic low back pain. *Br J Health Psychol*. 2009;14:735-749.	X				X			X						X					X	
Strunin L, Boden L. Family consequences of chronic back pain. *Soc Sci Med*. 2004;58:1385-1393.	X							X						X						
Toye F, Barker K. "Could I be imagining this?"—the dialectic struggles of people with persistent unexplained back pain. *Disabil Rehabil*. 2010;32:1722-1732.	X																		X	
White S, Seibold C. Walk a mile in my shoes: an autoethnographic study. *Contemp Nurse*. 2008;30:57-68.	X																			
Young A, Wasiak R, Phillips L, et al. Workers' perspectives on low back pain recurrence: "It comes and goes and comes and goes, but it's always there." *Pain*. 2011;152:204-211.	X				X			X												
Theadom A, Cropley M. "This constant being woken up is the worst thing"—experiences of sleep in fibromyalgia syndrome. *Disabil Rehabil*. 2010;32:1939-1947.		X																		
Ramlee F, Afolalu EF, Tang NKY. Do people with chronic pain judge their sleep differently? A qualitative study. *Behav Sleep Med*. 2018;16:259-271.		X																		
Russell D, Álvarez Gallardo IC, Wilson I, et al. "Exercise to me is a scary word": perceptions of fatigue, sleep dysfunction, and exercise in people with fibromyalgia syndrome—a focus group study. *Rheumatol Int*. 2018;38:507-515.		X																		
Vincent A, Whipple MO, Rhudy LM. Fibromyalgia flares: a qualitative analysis. *Pain Med*. 2015;17:463-468.		X																		
Kleinman L, Mannix S, Arnold LM, et al. Assessment of sleep in patients with fibromyalgia: qualitative development of the fibromyalgia sleep diary. *Health Qual Life Outcomes*. 2014;12:1-11.		X																		
Kengen Traska T, Rutledge DN, Mouttapa M, Weiss J, Aquino J. Strategies used for managing symptoms by women with fibromyalgia. *J Clin Nurs*. 2012;21:626-635.		X																		

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M. "I'm tired of being tired"—fatigue as experienced by women with fibromyalgia. *Adv Physiother*. 2011;13:11-17.		X																		
Humphrey L, Arbuckle R, Mease P, Williams DA, Samsoe BD, Gilbert C. Fatigue in fibromyalgia: a conceptual model informed by patient interviews. *BMC Musculoskelet Disord*. 2010;11:1-10.		X																		
Martin S, Chandran A, Zografos L, Zlateva G. Evaluation of the impact of fibromyalgia on patients' sleep and the content validity of two sleep scales. *Health Qual Life Outcomes*. 2009;7:1-7.		X																		
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;10:1-11.		X																	X	X
Arnold LM, Crofford LJ, Mease PJ, et al. Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns*. 2008;73:114-120.		X																	X	X
Crooks VA. Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: a mixed-method approach. *Soc Sci Med*. 2007;64:577-588.		X																		
Cunningham MM, Jillings C. Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res*. 2006;15:258-273.		X											X						X	
Söderberg S, Lundman B, Norberg A. The meaning of fatigue and tiredness as narrated by women with fibromyalgia and healthy women. *J Clin Nurs*. 2002;11:247-255.		X											X							
Cudney SA, Butler MR, Weinert C, Sullivan T. Ten rural women living with fibromyalgia tell it like it is. *Holist Nurs Pract*. 2002;16:35-45.		X											X							
Sturge-Jacobs M. The experience of living with fibromyalgia: confronting an invisible disability. *Res Theory Nurs Pract*. 2002;16:19-31.		X											X						X	
Raymond M, Brown J. Experience of fibromyalgia: qualitative study. *Can Fam Physician*. 2000;46:1100-1106.		X											X						X	
Hush J, Refshauge K, Sullivan G, Souza L, Maher C, McAuley J. Recovery: what does this mean to patients with low back pain? *Arthritis Rheum*. 2009;61:124-131.					X			X												
Hush JM, Refshauge KM, Sullivan G, de Souza L, McAuley JH. Do numerical rating scales and the Roland-Morris Disability Questionnaire capture changes that are meaningful to patients with persistent back pain? *Clin Rehabil*. 2010;24:648-657.					X															
Keen S, Dowell A, Hurst K, Klaber Moffett J, Tovey P, Williams R. Individuals with low back pain: how do they view physical activity? *Fam Pract*. 1999;16:39-45.					X															
Ong BN, Hooper H. Involving users in low back pain research. *Health Expect*. 2003;6:332-341.					X															
Ong BN, Hooper H. Comparing clinical and lay accounts of the diagnosis and treatment of back pain. *Sociol Health Illn*. 2006;28:203-222.					X									X						

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Tarasuk T, Eakin J. The problem of legitimacy in the experience of work-related back injury. *Qual Health Res*. 1995;5:204-221.					X															
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Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
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Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
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Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
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Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. *Arthritis Rheum*. 1995;8:290-297.			X	X												X	X			
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Mitton DL, Treharne GJ, Hale ED, et al. The health and life experiences of mothers with rheumatoid arthritis: a phenomenological study. *Musculoskelet Care*. 2007;5:191-205.				X			X													
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Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Feldthusen C, Bjork M, Forsblad-d'Elia H, Mannerkorpi K. Perception, consequences, communication, and strategies for handling fatigue in persons with rheumatoid arthritis of working age—a focus group study. *Clin Rheumatol*. 2013;32:557-566.						X			X	X										
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Plach S, Stevens PE, Moss VA. Social role experiences of women living with rheumatoid arthritis. *J Fam Nurs*. 2004;10:33-49.			X			X														
Stephens M, Yoshida KK. Independence and autonomy among people with rheumatoid arthritis. *Can J Rehabil*. 1999;12:229-243.			X			X														
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Coole C, Watson PJ, Drummond A. Low back pain patients' experiences of work modifications: a qualitative study. *BMC Musculoskelet Disord*. 2010b;11:277. https://doi.org/10.1186/1471-2474-11-277								X											X	X
Cooper K, Smith BH, Hancock E. Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient. *Physiotherapy*. 2008;94:244-252. https://doi.org/10.1016/j.physio.2007.10.006								X						X					X	
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Hewlett S, Cockshott Z, Byron M, et al. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis Rheum*. 2005;53:697-702.			X							X							X			
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Dures E, Kitchen K, Almeida C, et al. "They didn't tell us, they made us work it out ourselves": patient perspectives of a cognitive behavioral program for rheumatoid arthritis fatigue. *Arthritis Care Res*. 2012;64:494-501.										X										
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Buijs PC, Lambeek LC, Koppenrade V, et al. Can workers with chronic back pain shift from pain elimination to function restore at work? *J Back Musculoskelet Rehabil*. 2009;22:65-73.												X								
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Ryan CG, 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;49:433-444.												X								
Soeker MS, Wegner L, Pretorius B. South African clients' perceptions and experiences of adapting to their worker roles after rehabilitation. *Work*. 2009;32:133-143.												X								
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Mannerkorpi K, Kroksmark T, Ekdahl C. How patients with fibromyalgia experience their symptoms in everyday life. *Physiother Res Int*. 1999;4:110-122.													X						X	X
Mengshoel AM, Heggen K. Recovery from fibromyalgia—previous patients' own experiences. *Disabil Rehabil*. 2004;26:46-53.													X						X	X
Paulson M, Danielson E, Larsson K, Söderberg S. Men's descriptions of their experience of nonmalignant pain of fibromyalgia type. *Scand J Caring Sci*. 2001;15:54-59.													X						X	
Paulson M, Danielson E, Söderberg S. Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qual Health Res*. 2002;12:238-249.													X						X	
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;40:87-95.													X						X	
Raheim M, Håland W. Lived experience of chronic pain and fibromyalgia: women's stories from daily life. *Qual Health Res*. 2006;16:741-761.													X						X	
Schaefer KM. Struggling to maintain balance: a study of women living with fibromyalgia. *J Adv Nurs*. 1995;21:95-102.													X							
Schaefer KM. Health patterns of women with fibromyalgia. *J Adv Nurs*. 1997;26:565-571.													X							
Schaefer KM. The lived experience of fibromyalgia in African American women. *Holist Nurs Pract*. 2005;19:17-25.													X						X	
Söderberg S, Lundman B. Transitions experienced by women with fibromyalgia. *Health Care Women Int*. 2001;22:617-631.													X						X	X
Söderberg S, Lundman B, Norberg A. Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qual Health Res*. 1999;9:575-587.													X						X	
Söderberg S, Norberg A. Metaphorical pain language among fibromyalgia patients. *Scand J Caring Sci*. 1995;9:55-59.													X							
Thorne S, McGuinness L, Con A, Cunningham M, Harris SR. Health care communication issues in fibromyalgia: an interpretive description. *Physiother Can*. 2004;56:31-38.													X							
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. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3121659/pdf/1471-2474-12-126.pdf. Accessed May 14, 2015.																			X	X
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;15:169-174.																			X	X
Johansson EE, Hamberg K, Westman G, Lindgren G. The meanings of pain: an exploration of women's descriptions of symptoms. *Soc Sci Med*. 1999;48:1791-802.																			X	X

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Lofgren M, Ekholm J, Ohman A. A constant struggle: successful strategies of women in work despite fibromyalgia. *Disabil Rehabil*. 2006;28:447-455.																			X	X
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;11:831-840.																			X	X
Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M. Women's narratives on experiences of work ability and functioning in fibromyalgia. *Musculoskelet Care*. 2010;8:18-26.																			X	X
Glenton C. Chronic back pain sufferers—striving for the sick role. *Soc Sci Med*. 2003;57:2243-2252.														X						
Lillrank A. Back pain and the resolution of diagnostic uncertainty in illness narratives. *Soc Sci Med*. 2003;57:1045-1054.														X						
Crowe M, Whitehead L, Gagan MJ, et al. Self-management and chronic low back pain: a qualitative study. *Int J Nursing Stud*. 2010;66:1478-1486.														X					X	
Mason B. A relational approach to the management of chronic pain. *Clin Psychol*. 2004;35:17-20.														X						
Harding G, Parsons S, Rahman A, et al. It struck me that they didn't understand pain: the specialist pain clinic experience of patients with chronic musculoskeletal pain. *Arthritis Care Res*. 2005;53:691-696.														X					X	
Vroman K, Warner R, Chamberlain K. Now let me tell you in my own words: narratives of acute and chronic low back pain. *Disabil Rehabil*. 2009;31:976-987.														X						
Snelgrove S, Liossi C, Edwards S. A longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: changes and consistencies. *Psychol Health*. 2013;28:121-138.														X						
Sofaer Bennett B, Walker J, Moore A, et al. The social consequences for older people of neuropathic pain: a qualitative study. *Pain Med*. 2007;8:263-270.														X						
Laerum E, Indahl A, Skouen JS. What is "the good back consultation?" A combined qualitative and quantitative study of chronic low back pain patients' interaction with and perceptions of consultations with specialists. *J Rehabil Med*. 2006;38:255-262.														X						
Townsend A, Adam P, Cox SM, et al. Everyday ethics and help-seeking in early rheumatoid arthritis. *Chronic Illn*. 2010;6:171-182.																X	X			
Schneider M, Manabile E, Tikly M. Social aspects of living with rheumatoid arthritis: a qualitative descriptive study in Soweto, South Africa—a low resource context. *Health Qual Life Outcomes*. 2008;6:54.			X													X	X			
Yoshida K. Uncertainty in the lives of people with spinal cord injury and rheumatoid arthritis. *Can J Rehabil*. 1997;10:5-14.																X	X			
Bury M. Chronic illness as biographical disruption. *Sociol Health Illn*. 1982;4:167-182.			X													X	X			

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Sheppard J, Kumar K, Buckley CD, et al. 'I just thought it was normal aches and pains': a qualitative study of decision-making processes in patients with early rheumatoid arthritis. *Rheumatology (Oxford)*. 2008;47:1577-1582.			X													X	X			
Neill J. Transcendence and transformation in the life patterns of women living with rheumatoid arthritis. *Adv Nurs Sci*. 2002;24:27-47.			X													X	X			
Kumar K, Daley E, Khattak F, et al. The influence of ethnicity on the extent of, and reasons underlying, delay in general practitioner consultation in patients with RA. *Rheumatology (Oxford)*. 2010;49:1005-1012.																X	X			
Bernatsky S, Feldman D, De Civita M, et al. Optimal care for rheumatoid arthritis: a focus group study. *Clin Rheumatol*. 2010;29:645-657.																X	X			
Li LC, Townsend AF, Adam PM, et al. Crossing the threshold: help-seeking for early symptoms in people with rheumatoid arthritis. *Arthritis Rheum*. 2009;60:2027.																X				
Zhang J, Verhoef MJ. Illness management strategies among Chinese immigrants living with arthritis. *Soc Sci Med*. 2002;55:1795-1802.																X				
Nyman CS, Lützen K. Caring needs of patients with rheumatoid arthritis. *Nurs Sci Q*. 1999;12:164-169.																X	X			
Bury M. Meanings at risk: the experience of arthritis. In: Anderson R, Bury M, eds. *Living with Chronic Illness*. London, UK: Unwin Hyman; 1988:89-116.			X													X	X			
Griffith J, Carr A. What is the impact of early rheumatoid arthritis on the individual? *Best Pract Res Clin Rheumatol*. 2001;15:77-90.																X	X			
Williams G. The genesis of chronic illness: narrative re-construction. *Sociol Health Illn*. 1984;6:175-200.			X													X	X			
Sakalys JA. Illness behavior in rheumatoid arthritis. *Arthritis Care Res*. 1997;10:229-237.																X	X			
Ashe B, Taylor M, Dubouloz CJ. The process of change: listening to transformation in meaning perspectives of adults in arthritis health education groups. *Can J Occup Ther*. 2005;72:280-288.																X				
Hay MC, Cadigan RJ, Khanna D, et al. Prepared patients: internet information seeking by new rheumatology patients. *Arthritis Rheum*. 2008;59:575-582.																X				
Wiener CL. The burden of rheumatoid arthritis: tolerating the uncertainty. *Soc Sci Med*. 1975;9:97-104.			X														X			
Backman CL, Smith LF, Smith S, Montie PL, Suto M. Experiences of mothers living with inflammatory arthritis. *Arthritis Rheum*. 2007;57:381-388.			X														X			
Dildy SP. Suffering in people with rheumatoid arthritis. *Appl Nurs Res*. 1996;9:177-183.			X														X			

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Williams AE, Graham AS. 'My feet—visible, but ignored. . . .' A qualitative study of foot care for people with rheumatoid arthritis. *Clin Rehabil*. 2012;26:952-959.																	X			
Fair BS. Contrasts in patients' and providers' explanations of rheumatoid arthritis. *J Nurs Scholarsh*. 2003;35:339-344.																	X			
Tatlock S, Rüdell K, Panter C, et al. What outcomes are important for gout patients? In-depth qualitative research into the gout patient experience to determine optimal endpoints for evaluating therapeutic interventions. *Patient*. 2017;10:65-79. https://doi.org/10.1007/s40271-016-0184-x																		X		
Singh JA. Facilitators and barriers to adherence to urate-lowering therapy in African-Americans with gout: a qualitative study. *Arthritis Res Ther*. 2014;16:R82. https://doi.org/10.1186/ar4524																		X		
Singh JA. The impact of gout on patient's lives: a study of African-American and Caucasian men and women with gout. *Arthritis Res Ther*. 2014;16:R132. https://doi.org/10.1186/ar4589																		X		
Te Karu L, Bryant L, Elley CR. Maori experiences and perceptions of gout and its treatment: a kaupapa Maori qualitative study. *J Prim Health Care*. 2013;5:214-222.																		X		
Chandratre P, Mallen CD, Roddy E, Liddle J, Richardson J. "You want to get on with the rest of your life": a qualitative study of health-related quality of life in gout. *Clin Rheumatol*. 2016;35:1197-1205. https://doi.org/10.1007/s10067-015-3039-2																		X		
Brenton-Rule A, Dalbeth N, Edwards NL, Rome K. Experience of finding footwear and factors contributing to footwear choice in people with gout: a mixed methods study using a web-based survey. *J Foot Ankle Res*. 2019;12:3. https://doi.org/10.1186/s13047-018-0313-y																		X		
Singh JA. Gout and sexual function: patient perspective of how gout affects personal relationships and intimacy. *BMC Rheumatol*. 2019;3:8. https://doi.org/10.1186/s41927-019-0056-9																		X		
Lindsay K, Gow P, Vanderpyl J, Logo P, Dalbeth N. The experience and impact of living with gout: a study of men with chronic gout using a qualitative grounded theory approach. *J Clin Rheumatol*. 2011;17:1-6. https://doi.org/10.1097/RHU.0b013e318204a8f9																		X		
Dowell A, Morris C, MacDonald L, Stubbe M. "I can't bend it and it hurts like mad": direct observation of gout consultations in routine primary health care. *BMC Fam Pract*. 2017;18:1-11. https://doi.org/10.1186/s12875-017-0662-9																		X		
Frecklington M, Williams A, Dalbeth N, McNair P, Gow P, Rome K. The footwear experiences of people with gout: a qualitative study. *J Foot Ankle Res*. 2019;12:38. https://doi.org/10.1186/s13047-019-0349-7																		X		

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Howren A, Cox SM, Shojania K, Rai SK, Choi HK, De Vera MA. How patients with gout become engaged in disease management: a constructivist grounded theory study. *Arthritis Res Ther*. 2018;20:110. https://doi.org/10.1186/s13075-018-1608-x																		X		
Liddle J, Roddy E, Mallen CD, et al. Mapping patients' experiences from initial symptoms to gout diagnosis: a qualitative exploration. *BMJ Open*. 2015;5:e008323. https://doi.org/10.1136/bmjopen-2015-008323																		X		
Richardson JC, Liddle J, Mallen CD, et al. "Why me? I don't fit the mould...I am a freak of nature": a qualitative study of women's experience of gout. *BMC Women Health*. 2015;15:122. https://doi.org/10.1186/s12905-015-0277-z																		X		
Singh JA. Gout and comorbidity: a nominal group study of people with gout. *Arthritis Res Ther*. 2017;19:204. https://doi.org/10.1186/s13075-017-1416-8																		X		
Singh JA. Any sleep is a dream far away: a nominal group study assessing how gout affects sleep. *Rheumatology (Oxford)*. 2018;57:1925-1932. https://doi.org/10.1093/rheumatology/kex535																		X		
ten Klooster PM, Vonkeman HE, Voshaar MA, Bode C, van de Laar MA. Experiences of gout-related disability from the patients' perspective: a mixed methods study. *Clin Rheumatol*. 2014;33:1145-1154.																		X		
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;48:1189-1203.																			X	
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 Illn*. 2002;24:227-254.																			X	
Werner A, Steihaug S, Malterud K. Encountering the continuing challenges for women with chronic pain: recovery through recognition. *Qual Health Res*. 2003;13:491-509.																			X	
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;57:1409-1419.																			X	
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.																			X	
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;5:276-288.																			X	

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
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;41:768-774.																			X	
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;10:1280-1290.																			X	
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;22:383-390.																			X	
Dragesund T, Råheim M. Norwegian psychomotor physiotherapy and patients with chronic pain: patients' perspective on body awareness. *Physiother Theory Pract*. 2008;24:243-255.																			X	
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;13:498-503.																			X	
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;42:35-46.																			X	
Lundberg M, Styf J, Bullington J. Experiences of moving with persistent pain—a qualitative study from a patient perspective. *Physiother Theory Pract*. 2007;23:199-209.																			X	
Skuladottir H, Halldorsdottir S. The quest for well-being: self-identified needs of women in chronic pain. *Scand J Caring Sci*. 2011;25:81-91.																			X	
Dickson GL, Kim JI. Reconstructing a meaning of pain: older Korean American women's experiences with the pain of osteoarthritis. *Qual Health Res*. 2003;13:675-688.																			X	
Aegler B, Satink T. Performing occupations under pain: the experience of persons with chronic pain. *Scand J Occup Ther*. 2009;16:49-56.																			X	
Afrell M, Biguet G, Rudebeck CE. Living with a body in pain—between acceptance and denial. *Scand J Caring Sci*. 2007;21:291-296.																			X	
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;10:521-530.																			X	
Toye 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.																			X	
Toye 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;34:894-903.																			X	

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
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;13:201-210.																			X	
Gullacksen AC, Lidbeck J. The life adjustment process in chronic pain: psychosocial assessment and clinical implications. *Pain Res Manage*. 2004;9:145-153.																			X	
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;36:97-103.																			X	
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:e126-e130.																			X	
Undeland M, Malterud K. The fibromyalgia diagnosis: hardly helpful for the patients? A qualitative focus group study. *Scand J Primary Health Care*. 2007;25:250-255.																			X	
Lambert BL, Butin DN, Moran D, et al. Arthritis care: comparison of physicians' and patients' views. *Semin Arthritis Rheum*. 2000;30:100-110.			X																	
Bjørner JB, Hansen IR. Reumatoid artrit og samliv: en kvalitativ undersøgelse (Rheumatoid arthritis and partner relationships: a qualitative study). *Nordisk Sexol*. 1993;11:101-111. [Danish]			X																	
Locker D. *Disability and Disadvantage: The Consequences of Chronic Illness*. London, UK: Tavistock Publications; 1983.			X																	
Williams B, Barlow JH. Falling out with my shadow: lay perceptions of the body in the context of arthritis. In: Nettleton S, Watson J, eds. *The Body in Everyday Life*. London, UK: Routledge; 1998:124-141.			X																	
Pinder R. Bringing back the body without the blame: the experience of ill and disabled people at work. *Soc Health Illn*. 1995;17:605-631.			X																	
Donovan JL, Blake DR, Fleming WG. The patient is not a blank sheet: lay beliefs and their relevance to patient education. *Br J Rheum*. 1989;28:58-61.			X																	
Williams GH, Wood PHN. Coming to terms with chronic illness: the negotiation of autonomy in rheumatoid arthritis. *Int Disabil Stud*. 1988;10:128-133.			X																	
Grant M. Mothers with arthritis, childcare and occupational therapy: insight through case studies. *Br J Occup Ther*. 2001;64:322-329.			X																	
Rao JK, Arick R, Mihaliak K, Weinberger M. Using focus groups to understand arthritis patients' perceptions about unconventional therapy. *Arthritis Care Res*. 1998;11:253-260.			X																	
Gilworth G, Woodhouse A, Tennant A, Chamberlain MA. The impact of rheumatoid arthritis in the workplace. *Br J Ther Rehabil*. 2001;8:342-347.			X																	

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Moss P. Negotiating spaces in home environments: older women living with arthritis. *Soc Sci Med*. 1997;45:23-33.			X																	
Archenholtz B, Burckhardt CS, Segesten K. Quality of life of women with systemic lupus erythematosus or rheumatoid arthritis: domains of importance and dissatisfaction. *Qual Life Res*. 1999;8:411-416.			X																	
Coady DA, Armitage C, Wright D. Rheumatoid arthritis patients' experiences of night pain. *J Clin Rheumatol*. 2007;13:66-69.			X																	
Ward V, Hill J, Hale C, et al. Patient priorities of care in rheumatology outpatient clinics: a qualitative study. *Musculoskelet Care*. 2007;5:216-228.			X																	
McPherson KM, Brander P, Taylor WJ, McNaughton HK. Consequences of stroke, arthritis and chronic pain—are there important similarities? *Disabil Rehabil*. 2004;26:988-999.			X																	
Ryan S, Hassell A. Perceptions of control in patients with rheumatoid arthritis. *Nurs Times*. 2003;99:36-38.			X																	
Stamm T, Wright J, Machold K, et al. Occupational balance of women with rheumatoid arthritis: a qualitative study. *Musculoskelet Care*. 2004;2:101-112.			X																	
Goodacre LJ, Goodacre JA. Factors influencing the beliefs of patients with rheumatoid arthritis regarding disease-modifying medication. *Rheumatology*. 2004;43:583-586.			X																	
Shariff F, Carter J, Dow C, et al. Mind and body management strategies for chronic pain and rheumatoid arthritis. *Qual Health Res*. 2009;19:1037-1049.			X																	
Radford S, Carr M, Hehir M, et al. 'It's quite hard to grasp the enormity of it': perceived needs of people upon diagnosis of rheumatoid arthritis. *Musculoskelet Care*. 2008;6:155-167.			X																	
Bergström M, Sverker A, Larsson Ranada A, et al. Significant others' influence on participation in everyday life—the perspectives of persons with early diagnosed rheumatoid arthritis. *Disabil Rehabil*. 2019;42:385-393. https://doi.org/10.1080/09638288.2018.1499825									X											
Carr A, Hewlett S, Hughes R, et al. Rheumatology outcomes: the patient's perspective. *J Rheumatol*. 2003;30:880-883.									X											
Flurey C, White A, Rodham K, Kirwan J, Noddings R, Hewlett S. 'Everyone assumes a man to be quite strong': men, masculinity and rheumatoid arthritis: a case-study approach. *Sociol Health Illn*. 2018;40:115-129. https://doi.org/10.1111/1467-9566.12628									X											
Josefsson KA, Gard G. Women's experiences of sexual health when living with rheumatoid arthritis—an explorative qualitative study. *BMC Musculoskelet Disord*. 2010;11:240. https://doi.org/10.1186/1471-2474-11-240									X											
Lack S, Noddings R, Hewlett S. Men's experiences of rheumatoid arthritis: an inductive thematic analysis. *Musculoskelet Care*. 2011;9:102-112. https://doi.org/10.1002/msc.203									X											

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APPENDIX D (CONTINUED)

Study	Bunzli et al	Climent-Sanz et al	Daker-White et al	Donelly et al	Froud et al	Feddersen et al	Lin et al	MacNeela et al	Parenti et al	Primdahl et al	Riggs and Killingback	Robart and Boyle	Sim and Madden	Snelgrove and Liossi	Söderlund et al	Stack et al, 2011	Stack et al, 2013	Stewart et al	Toye et al, 2013	Toye et al, 2016
Lyyra TM, Heikkinen RL. Experienced health in older women with rheumatoid arthritis. *J Women Aging*. 2006;18:67-81. https://doi.org/10.1300/J074v18n04_06									X											
Orbai A-M, Smith KC, Bartlett SJ, De Leon E, Bingham CO, III. "Stiffness has different meanings, I think, to everyone": examining stiffness from the perspective of people living with rheumatoid arthritis. *Arthritis Care Res*. 2014;66:1662-1672. https://doi.org/10.1002/acr.22374									X											
Oshotse C, Zullig LL, Bosworth HB, Tu P, Lin C. Self-efficacy and adherence behaviors in rheumatoid arthritis patients. *Prev Chronic Dis*. 2018;15:180218. https://doi.org/10.5888/pcd15.180218									X											
Ostlund G, Bjork M, Thyberg I, et al. Emotions related to participation restrictions as experienced by patients with early rheumatoid arthritis: a qualitative interview study (the Swedish TIRA project). *Clin Rheumatol*. 2014;33:1403-1413. https://doi.org/10.1007/s10067-014-2667-2									X											
Shaw Y, Bradley M, Zhang C, et al. The development of resilience among rheumatoid arthritis patients: a qualitative study. *Arthritis Care Res*. 2020;72:1257-1265. https://doi.org/10.1002/acr.24024									X											
Squire R. Living well with rheumatoid arthritis. *Musculoskelet Care*. 2012;10:127-134. https://doi.org/10.1002/msc.1004									X											
Sverker A, Thyberg I, Ostlund G, Waltersson E, Thyberg M. Participation in work in early rheumatoid arthritis: a qualitative interview study interpreted in terms of the ICF. *Disabil Rehabil*. 2014;36:242-249. https://doi.org/10.3109/09638288.2013.7890									X											

APPENDIX E

LIST OF EXCLUDED STUDIES

B1. Experiences and perspectives of patients or professionals related to interventions, professional care, or diagnostic or other topics not directly associated with the objective of this review:

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B7. No systematic reviews or meta-summaries (meta-synthesis, meta-aggregation, or meta-ethnographies) of qualitative research:

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B8. Article published in other languages rather than English or Spanish:

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5. Smith TO, Purdy R, Lister S, Salter C, Fleetcroft R, Conaghan P. Living with osteoarthritis: a systematic review and meta-ethnography. *Scand J Rheumatol*. 2014;43:441-452. https://doi.org/10.3109/03009742.2014.894569
6. Wallis JA, Taylor NF, Bunzli S, Shields N. Experience of living with knee osteoarthritis: a systematic review of qualitative studies. *BMJ Open*. 2019;9:e030060. https://doi.org/10.1136/bmjopen-2019-030060
7. Wride JM, Bannigan K. "If you can't help me, so help me God I will cut it off myself…" The experience of living with knee pain: a qualitative meta-synthesis. *Physiotherapy*. 2018;104:299-310. https://doi.org/10.1016/j.physio.2018.04.002
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4. Eastway J, Lizarondo L. Experiences of adult patients with chronic non-communicable disease using electronic personal health records for self-management: a qualitative systematic review protocol. *JBI Database Syst Rev Implement Rep*. 2019;17:2334-2342. https://doi.org/10.11124/JBISRIR-2017-003941
5. Egerton T, Diamond L, Buchbinder R, Bennell K, Slade SC. Barriers and enablers in primary care clinicians' management of osteoarthritis: protocol for a systematic review and qualitative evidence synthesis. *BMJ Open*. 2016;6:e011618. https://doi.org/10.1136/bmjopen-2016-011618
6. Hurley M, Dickson K, Walsh N, et al. Exercise interventions and patient beliefs for people with chronic hip and knee pain: a mixed methods review. *Cochrane Database Syst Rev*. 2013;12. https://doi.org/10.1002/14651858.CD010842
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11. Rash JA, Buckley N, Busse JW, et al. Healthcare provider knowledge, attitudes, beliefs, and practices surrounding the prescription of opioids for chronic non-cancer pain in North America: protocol for a mixed-method systematic review. *Syst Rev*. 2018;7:189. https://doi.org/10.1186/s13643-018-0858-7
12. Small S, de Boer C, Swab M. Perceived barriers to and facilitators of labor market engagement for individuals with chronic physical illness in their experience with disability policy: a systematic review of qualitative evidence protocol. *JBI Database Syst Rev Implement Rep*. 2016;13:59-69. https://doi.org/10.11124/jbisrir-2015-2493
13. Traeger AC, Reed BJ, O'Connor DA, et al. Clinician, patient and general public beliefs about diagnostic imaging for low back pain: protocol for a qualitative evidence synthesis. *BMJ Open*. 2018;8:e019470. https://doi.org/10.1136/bmjopen-2017-019470
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APPENDIX F

EMOTIONS, COGNITIONS, AND BEHAVIORS IN THE INCLUDED THEMES RELATED TO THE EXPERIENCE OF MUSCULOSKELETAL SYMPTOMS

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Bunzli et al (2013)[8]	[I] Fluctuations in pain caused continuous adjustments, leaving people with feelings of insecurity and uncertainty. [II] People […] describing themselves as "short-tempered." [III] Fluctuations in pain were directly related to fluctuations between hope and despair. [IV] People felt anxiety and distress, considering an uncertain future. [V] Changes in behavior and mood were reported to result in feelings of depression. [VI] People had feelings of shame (this emotion was associated with cognition [IX]). [VII] The new "me but not me" was associated with feelings of distress and grief. This battle was more distressing than the pain itself. [VIII] People felt fearful about their mundane activities of daily living (this emotion was associated with cognition [VIII]). [IX] People expressed despair at the thought of pain always being present. [X] People felt self-denigration and self-loathing (these emotions were related to cognition [IX]). [XI] People felt from a trajectory of despair to one of hope for the future (these emotions were related to cognition [XII]).	[I] Pain was described as omnipresent, salient, and characterized by unpredictable fluctuations in intensity. [II] People described a lack of sleep and disrupted sleep because of pain. [III] People described a battle lost, where a new, altered identity emerged because of pain. [IV] This new "me but not me" was met with […] suicidal ideation thoughts, in a study. [V] People held biomedical beliefs about their back pain. [VI] Contrary opinions associated with the acceptance to live with pain: Although in many studies people described a "battle" or "fight" to control the pain and the assault on the self, people also acknowledged the need to learn to live with the pain. [VII] People described a dichotomy between the past and the present self. [VIII] The most mundane activities of daily living […] had gone from being unconscious and thoughtless to planned and threatening. [IX] Perceived changes in identity resulted in self-denigration and self-loathing. [X] People described the ability of pain to disrupt even the smallest and most mundane activities of daily living. [XI] People highlighted difficulties in accepting pain when fluctuations in pain meant continuous adjustment. [XII] Learning to live with the pain facilitated the turning point from a trajectory of despair to one of hope for the future.	[I] Physically centered strategies were widely cited, the most common being hypervigilance to painful or threatening movements. [II] Activity restriction or avoidance was also a common strategy. [III] Persistent strategies were cited whereby people exceeded their perceived functional capacities to fight back against the pain.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Climent-Sanz et al (2020)[14]	[I] People felt frustration and hatred toward life and usually developed feelings of [...] despair (these emotions were perceived to be associated with poor sleep quality). [II] People could develop a fear of not sleeping. People also developed a fear of the bedroom and fear of going to bed. [III] People felt anxiety (this emotion was related to behavior [I]). [IV] Concerns about poor sleep quality were reported to manifest constantly, generating fear of going to bed. [V] People felt fear of not being able to meet their sleep needs.	[I] People sometimes described poor sleep quality as the worst symptom of their health condition. [II] Poor sleep quality was perceived to affect the joints and muscles so that they do not "rest" properly, increasing pain intensity. [III] Being unable to sleep properly was perceived as a betrayal of the body, which may indicate that, at least in some cases, people suffering from fibromyalgia considered that they had no control over the symptom. [IV] Contrary opinions about most common sleep disturbances associated with the maintenance of sleep (ie, while people were arguing that their sleep problems were mainly related to sleep maintenance, others reported problems falling asleep). [V] People commonly identified poor sleep quality as one of the symptoms that had the greatest impact on fatigue, pain, cognitive functioning, ability to manage symptoms, eating behavior, and symptom flare-ups. [VI] Contrary opinions about the best solution to reduce fatigue: In some cases, people considered that the only solution to reduce the levels of fatigue was a good rest at night, whereas others indicated that fatigue maintained or appeared even when it was possible to have a satisfactory amount of sleep. [VII] Regarding the poor sleep-pain-fatigue cluster, it was described as a vicious circle in which insufficient sleep resulted in an increase in pain intensity the next day, which, at the same time, led to a state of fatigue that prevented a good rest at night. [VIII] Contrary opinions about the causes of the sleep problems: While there were people unable to identify a cause for their sleep problems, others pointed out that working night shifts during a long period resulted in problems initiating and maintaining sleep. [IX] People identified good sleep quality as the feeling of "disconnection" with the environment during the night. [X] People believed that there is no possible solution for their sleep problems. [XI] Concerns about poor sleep quality were reported to manifest constantly, generating ruminating thoughts. [XII] Sleep problems led people to consider motherhood (this cognition was related to emotion [V]). [XIII] People believed that lack of sleep was aging them. [XIV] Constantly waking up is the worst thing about their health condition. [XV] Good sleep quality was mainly related to feeling renewed upon waking and having the energy to face their daily tasks. [XVI] People considered that "sleep is such a gift" and that they "never take it for granted." [XVII] When people were very tired, they experience pain and small muscle cramps, being unable to fall asleep.	[I] People established regular sleep schedules (this was recognized as essential). [II] People also adopted other strategies such as the use of earplugs or relaxation techniques. However, these strategies were perceived as ineffective and, sometimes, unjustified. [III] Contrary opinions were associated with the behaviors toward to stay or not in bed (ie, while some people reported that they got out of bed to avoid developing behaviors of rejection toward the bed, others stayed in bed and tried to fall asleep again). [IV] The most generalized strategy was daytime rest. [V] The use of lavender scent while taking a hot bath helped people to decrease morning stiffness and better cope with the day.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Daker-White et al (2014)[17]	[I] People experiencing a flare-up would not only have to cope with the symptoms of the flare-up but also deal with worries that they might, despite the uncertainty, get worse rather than get better. [II] The root dissatisfaction for women with rheumatoid arthritis was related to cognition [XXV]. [III] Symptoms of arthritis led to secondary symptoms, largely related to pain: […] anger, depression, despair, self-pity, and […]. [IV] People felt fearful of exposure to their distorted bodies. [V] People felt distressed because of fatigue and pain. [VI] The fundamental issues faced by the person with rheumatoid arthritis were related to the unpredictable nature of symptoms and the uncertainty over the rate and the extent of disease progression. [VII] People felt a pervasive uncertainty and unpredictability of rheumatoid arthritis. [VIII] People felt insecurity (this emotion was related to cognition [XXII]). [IX] A person expressed feelings of embarrassment and guilt.	[I] Rheumatoid arthritis was perceived as an invisible, chronic, and incurable disease. [II] An individual identified fatigue as the most "pervasive" symptom. [III] The primary symptoms of arthritis led to secondary symptoms, largely related to pain: exhaustion […] and perception of loss of control. [IV] People commonly described themselves as either feeling "out of control" or less commonly as being controlled by arthritis. [V] People mentioned that their main symptoms were pain, stiffness, or immobility. A particular feature of these symptoms was that they were seen to vary or fluctuate in a manner that was unpredictable on a day-to-day basis. [VI] People noted an expectation of pain when moving following periods of inactivity. [VII] The role of the weather was mentioned as a factor in worsening or lessening symptoms. [VIII] How women perceived they looked also seemed to have an additional role in how they felt. [IX] People perceived a loss of the ability to engage in activities once seen as mundane (ie, people perceived taken-for-granted activities […] constituted a large measure of self-identity). [X] People described that tolerate variable uncertainty is the key concept in living with arthritis. [XI] Rheumatoid arthritis was shown to afford opportunities for growth and/or development of life in positive ways. [XII] People who successfully challenged their illness and its management do so according to a path that moves from dependent to "independent with help." [XIII] Once the grieving for their past life is over, disease "denial" is free to move from acknowledgment and on to acceptance. [XIV] Symptoms of arthritis led to secondary symptoms, largely related to pain: "low self-confidence," reduced libido, and difficulties reaching orgasm. [XV] Pain and fatigue provided considerable ambiguity as they are not visible forms of disability. [XVI] Apart from pain and fatigue, the only other typification of the condition of rheumatoid arthritis was a "crippling disease." [XVII] Fatigue found in rheumatoid arthritis was more dramatic or severe than "normal tiredness." [XVIII] Fatigue was mentioned as a separate symptom. [XIX] Pain in rheumatoid arthritis had a "circuitous" relationship with fatigue, such that "pain drains energy and fatigue produces more pain." [XX] People attempted to control a balance between energy and fatigue. [XXI] Activity, however minimal, required physical and psychological effort. The erstwhile, taken-for-granted world of everyday life became fraught with danger. [XXII] People suggested a form of a negative feedback loop, whereby "inflammation," "working the joints harder," and "unrefreshing sleep" were articulated as causes of symptoms. [XXIII] A person described himself as awkward and ugly. [XXIV] Control was related to fluctuations in symptoms. Typically, people described themselves as having a feeling "out of control." [XXV] Some women perceived "visible swollen and disfigured appearance of…painful body parts."	[I] One possible response to such dangers was to never leave the house, although this response might leave people feeling that they were "locked-in." [II] Concealing body parts became an important imperative. In extreme cases, people avoided going out of the house. [III] People never managed to master or "take charge" in rheumatoid arthritis (this behavior was related to emotion [VII]).

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Donnelly et al (2020)[21]	[I] People felt a sense of injustice toward developing the illness. [II] Feelings of sadness, despair, and depression were common. [III] Hopes and fears were often addressed. [IV] People were concerned about how they would manage their illness in the future. [V] Feelings of shame, embarrassment, and guilt were described around various aspects of self-managing the condition. These feelings were expressed, for example, concerning using visible aids, guilt around not being physically or emotionally available to others, and feelings of embarrassment around asking for help. [VI] People felt uncertainty (this emotion was related to cognition [XVI]). [VII] People felt hope (this emotion was related to cognition [IV]).	[I] Learning to accept the illness was an important part of managing life with rheumatoid arthritis. [II] In some instances, people expressed suicidal ideation thoughts. [III] This sense of injustice created a need to identify a cause (this cognition was related to emotion [I]). [IV] People described how religious beliefs and practices helped to maintain a positive outlook. [V] Rheumatoid arthritis was often experienced as a threat (or disruption) to self-identify. The predominant feature of the lived experience of self-managing rheumatoid arthritis related to "the self," a broad category constructed to reflect various dimensions of self-concept, self-esteem, and self-efficacy. Physical deformity played a role concerning self-identity, self-esteem, and self-confidence. [VI] Adjusting and adapting to an illness required resilience and the ability to draw from accumulated knowledge to employ effective self-management behaviors. [VII] The lack of a clear cause of a flare [...] reduced self-efficacy. [VIII] Rheumatoid arthritis was experienced as an invisible illness. [IX] Exposure to extreme hot or cold temperatures was thought to aggregate symptoms. [X] The perception of people as ill or not was intrinsic to how they approached their self-management and the role it played in their lives. [XI] People need to minimize the impact on their joints, preserve their energy, and avoid additional pain and fatigue (this cognition was related to behavior [IV]). [XII] Learning to listen to the body was recognized as an important tool of self-management. [XIII] People with rheumatoid arthritis perceived stairs or public transport could be particularly challenging. [XIV] Pain associated with rheumatoid arthritis could be particularly unbearable. [XV] A lack of spontaneity was perceived (this cognition was related to behavior [IV]). [XVI] Some people could not recognize a cause of a flare.	[I] People managed their illness under the perceived threat of immobilization, deformity, and dependence. To counter this, strategies of optimism, positivity, and humor were frequently adopted. [II] Self-management reduced spontaneity and created a cognitive burden (this behavior was related to cognition [XII]). [III] Behavioral adjustment included more rest, such as going to be earlier or taking a nap during or after work to be able to fulfill their duties. [IV] Pacing and planning daily activities are commonly featured in an individual's experiences. [V] Some participants took the risk of stretching their limits because they so dearly wanted to do special things or to just feel the pleasure of being "normal."
Feddersen et al (2017)[23]	[I] Some people were concerned (this emotion was related to cognition [XIII] in Table 3). [II] I felt preoccupied (this emotion was related to cognition [II]).	[I] People considered health effects were related to a potential worsening of the illness due to pregnancy. [II] The degree to which people were preoccupied with the illness was linked to the degree of symptom severity. [III] For some women, a lack of energy meant that they did not have enough strength to do the things they wanted for their benefit or pleasure.	[I] Women tried to consider the fluctuating course of the illness by planning and prioritizing to complete tasks ahead of time and be prepared for bad days.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Froud et al (2014)[24]	[I] People felt fearful of having to sit in pain for protracted periods.	[I] Modifying tasks, where possible, were thought to facilitate function. [II] People emphasized the need for vigilance […] to accommodate function and to enable activity and participation. [III] People described difficulties with gardening, housework, and shopping. Sleep, leisure activities, and outlets for stress that people had previously enjoyed were often no longer available. [IV] The inability to predict the onset of pain led to compromised ability to plan.	[I] The inability to predict the onset of pain led to anticipation of pain that compromised the ability to plan, leading to a convoluted mental decision-making process surrounding participation.
Lin et al (2011)[34]	[I] People felt satisfied with their present physical condition and desired to live only for themselves. [II] Sometimes I get to felt a sense of well-being (this emotion was related to behavior [II]).	[I] People perceived […] rethink and redefine what a so-called "normal life" should be to identify more practical criteria to suit their condition. [II] People related their attempts to accept their disease to soothe their minds from continued worry and pain. [III] People identified that the key to successfully maintain a positive behavior was to recognize the negative feelings and immediately pursue strategies that counteracted them. [IV] People accepted the ups and downs of the disease and the pain. [V] People perceived their self-esteem enhanced (this cognition was related to emotion [I]). [VI] People experienced the illness like any other unusual or disturbing event, and they attempted to make sense of such in terms of previous experiences. [VII] Reprioritizing values were also important to people to reflect on the positive changes that occurred in their lives due to living with rheumatoid arthritis and emphasize the personal growth obtained through adversity. [VIII] People altered the basis of their self-worth to understand the disease's progress (changing values). [IX] People showed honesty and calmness to face their condition.	[I] People can treat pain by changing their behavior […]. It includes developing […] optimism. [II] Maintaining positive behavior ([…] using humor […], doing things they enjoyed before, […] praying, and refusing to "give in" to the condition) was vital for gaining a sense of well-being.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
MacNeela et al (2015)[37]	[I] Heightened episodes of pain were debilitating and led to dismay. [II] A person felt despair alternating with hope. [III] The general hopelessness is illustrated more specifically by examples [...]. Feeling weak and overwhelmed set the context for strong emotional responses. The intensity of feelings of anger and depression, of being very upset, agitated, and angry with oneself. [IV] People felt [...] guilt or embarrassment about the label (back pain). [V] Concern emerged about further damage. Helps makes sense of this person's behavior of activity avoidance. [VI] Bewilderment was identified around the experience of chronic low back pain.	[I] The [...] back pain, its [...] consequences, and the prospect of future disability [...] undermined the person's capacity to remain independent as well as beliefs about personal control and sustainability. [II] Pain was usually described as an ever-present sensation of an impending threat, varying in severity between good and bad days. [III] Conceiving oneself as a back pain patient additionally impacted on personal self-worth. [IV] Dysfunctional and unreliable, the body was externalized and placed outside oneself. [V] People had suicidal ideation thoughts (this cognition was related to emotion [III]). [VI] Severe and intense sensations were illustrated by descriptors of pain, such as twisting, crippling, raw, red, shooting, aching, and burning. [VII] Pain was directly responsible for disrupted, unsatisfying sleep; reduced mobility; and impaired self-care. [VIII] The emerging pain identity represented an unwelcome intrusion. [IX] Some people considered the symptoms as an "assault on the self."	[I] People showed behaviors related to activity avoidance (this behavior was related to emotion [V]). [II] People endured a traumatizing challenge to personal identity (this behavior was related to cognition [IX]).

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Parenti et al (2020)[53]	[I] The sense of helplessness connected to the illness's deteriorating effects. [II] The need for improvements regarding people's physical health [...] was derived from elements such as the embarrassment of physical changes and mood disturbances. [III] The phase of resignation left people with a feeling of hopelessness. [IV] People with early-stage rheumatoid arthritis experienced less mental well-being (this emotion was related to cognition [III]). [V] People reported concerns over their physical and psychological health status.	[I] People reported a gradual loss of ability to function autonomously due to the illness progression. [II] Independence was perceived as being essential to conduct a normal life. [III] Contrary opinions about the most important aspects for health maintenance: People with long-stage rheumatoid arthritis tended to define health as an equilibrium, giving more importance to mental well-being [...] than the physical absence of pain [...]. People with early-stage rheumatoid arthritis tended to focus on physical limitations and how they negatively affected their life. [IV] People with long-stage rheumatoid arthritis perceived that the physical absence of pain appeared to be more under control thanks to a better understanding of the symptoms and the acceptance of the chronic illness. People with an early stage of rheumatoid arthritis tended to focus on physical limitations [...], which was related to [...] the absence of personal adjustments and the acceptance of the chronic condition. [V] Some people entered a phase of confrontation with the destruction of the self, as it was before for themselves and others. [VI] The need for improvements regarding people's physical health [...] was derived from elements such as [...] low self-confidence. [VII] Some strategies (acceptance, equanimity, flexibility, managing sense of control, pursuing valued goals, etc) were adopted to increase resilience in facing rheumatoid arthritis challenges, which promoted their psychological well-being and self-care behaviors. [VIII] Some people developed a passive resignation during the phase of resignation. [IX] People felt unable to exert any type of willpower over the future development of the disease during the phase of resignation. [X] Some people considered rheumatoid arthritis as a challenging stimulus (this cognition was related to behavior [I]). [XI] The phase of resignation left people unable to exert any type of willpower over the future development of the disease.	[I] The term "fighting behavior" indicated a form of proactive coping. [II] Some people forced an adaptation to the condition during the phase of resignation. [III] [Some authors] identified the importance of "cultivating resilience" as a positive approach. This approach permitted people to focus on recognizing their physical limitations and strengthen their remaining intact abilities.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Primdahl et al (2019)[57]	[I] Fatigue negatively influenced motivation and enthusiasm. [II] Fatigue led to a feeling of imbalance in everyday life, which was dominated by the experience of hopelessness and loneliness. [III] Physical activity was associated with irritability and anger (these emotions were related to cognition [XII]).	[I] People perceived fatigue as inexplicable, unpredictable, difficult to control, and with considerable consequences for all aspects of their everyday lives. It is different from the fatigue that people without rheumatoid arthritis experience. [II] Fatigue affected several cognitive aspects of the individual: concentration, memory, learning, solving problems, the assimilation of information, and participation in conversations. [III] People perceived themselves to be limited and always one step behind due to their cognitive problems. [IV] Fatigue also caused positive experiences: People learned to be more conscious about the choices in life, let things pass, and recognize the advantages of resting. [V] Fatigue is experienced as exhausting, negatively impacting the ability to take initiative and to get things done. [VI] People with fatigue described the importance to take good care of themselves and their bodies to feel good and try to restore the imbalance in life and ease fatigue. [VII] People described the chance to be spontaneous as reduced since it takes time to adjust plans. [VIII] Fatigue related to the illness reduced sleep quality, with episodes of being awake at night and feeling unrefreshed after sleep, and a body that feels heavy or as though they are ill. [IX] Some everyday tasks become slow and troublesome due to joint pain and physical limitations. [X] To be "tired" is not considered an appropriate word, and people use words such as "fatigued," "exhausted," and "lack of energy." People used metaphors such as "heaviness" or "weight." [XI] Some people could distract themselves from their fatigue by concentrating on something else. [XII] People perceived that physical activity became extremely exhausting.	[I] People divided their tasks over a day or several days to be able to manage bad days and save energy for later events and tasks. [II] Contrary behaviors about how to face poor sleep and the unpredictable nature of fatigue: Poor sleep and the unpredictable nature of fatigue require breaks and rest during the day. Some people set time aside, while others described this fact as impossible. [III] "I tried to pace, relax, and rest during the day to save energy for later events and tasks, and be able to manage bad days." [IV] Some people avoided energy-consuming activities.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Riggs and Killingback (2019)[59]	[I] Pain and fatigue caused uncertainty about the appropriateness of activity (this emotion was related to cognition [VII]). [II] Unpredictability of rheumatoid arthritis provoked safety fears. [III] Physical activity enhanced mental well-being, evoking feelings of pleasure and pride […]. Participation in physical activity gave people the satisfaction that they were accomplishing wellness rather than illness. [IV] Inactivity was associated with […] a fear of reduced mobility. [V] Some people felt a lack of motivation or discipline.	[I] Contrary opinions about what physical activity means for people: Some people described physical activity as a "duty," while others considered it as a part of the management plan. [II] Activity improved self-awareness, enabling people to acquire a better understanding of their symptoms and limitations. Consequentially, this fact enhanced self-efficacy and the ability to cope with unpredictable "flare-ups." [III] People accepted their role in managing their condition. [IV] Some people described more flexibility when practicing physical activity at home. However, they preferred prearranged activity over home-based programs (this cognition was related to emotion [V]). [V] People described pain and fatigue were barriers to staying active. [VI] The fundamental incentive for people was to counteract disease progression and preserve independence, maintaining their self-identity. [VII] Some people doubted whether activity was appropriate or would make symptoms worse.	[I] People used physical activity as a way of taking control.
Robart and Boyle (2021)[60]	(-)	[I] Lower back pain was described as an "invisible disability."	(-)

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APPENDIX F (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Sim and Madden (2008)[63]	[I] Some people […] found pain to be both worrying and non-worrying depending on its impact on function. [II] Negative feelings about the future emerged associated with the presence of the illness. [III] People […] were identified: […] to feel in despair […]. [IV] People felt depression (this emotion was related to cognition [VII]).	[I] Some people described the pain as being both bodily and mental or using words such as "burning" or "cutting." [II] The overall impression was that the pain was hard to reduce to a single description or a single quality. [III] People identified factors affecting their pain: their levels of activity or the weather. However, the intensity and the location of the pain in response to those factors were unpredictable. [IV] Pain brought the previously taken-for-granted body into conscious awareness and created a disjunction between the body and the self. [V] Pain was commonly reported as having a dramatic impact on daily life. [VI] Pain and fatigue were connected. Although the pain was […] reported as having a dramatic impact on daily life, some people described fatigue as more debilitating. [VII] Several factors were cited as causing depression, including pain, fatigue, a loss of control of the illness and life in general, and the feeling of loss of the former life. [VIII] Acceptance of the biomedical explanation of fibromyalgia could influence coping patterns. [IX] The ability of the self to understand fibromyalgia (eg, becoming aware of one's symptom patterns or gaining information about fibromyalgia) was essential to manage the condition. [X] Contrary opinions about the reevaluation of life due to the impact of the illness (loss of the previous life and identity): Some people described the changes as positive, as the illness allowed reevaluating and appreciating what is important in life […]. For others, the illness only produced negative feelings about the future. [XI] Contrary opinions about the course of pain: People described pain could have a specific location. However, pain is also perceived as diffuse and shifting and both constant and varying. The pain was also experienced when active or when resting. [XII] Symptoms were individually mundane but collectively devastating in their impact. [XIII] People described that they could feel ill and well at the same time or ill but looking well. [XIV] People also perceived pain could be elusive, although it feels powerful. [XV] People described the body became a burden and something against which one must struggle. [XVI] People described that the subjective and incommunicable nature of pain made it difficult to cope with. [XVII] People described that they felt weary and with sleep disturbances due to the consequences of pain and fatigue. [XVIII] Fatigue and lack of strength affected daily activities. [XIX] People described the importance to maintain a balance between battling against fibromyalgia ("struggling") and living with it ("adapting").	[I] People seek information and understanding to resist or accommodate bodily, activity, and identity constraints. [II] People engaged in positive thinking […]. More psychological or emotion-based methods of coping were also reported – such as […] adopting a new or modified self-identity or self-image to resist or accommodate bodily, activity, and identity constraints. [III] People resisted the dominance of symptoms or found distraction in pleasurable activities to resist or accommodate bodily, activity, and identity constraints. [IV] Contrary behaviors toward pacing or not daily activities: While some people continued with their normal activities, others severely limited their activity. Some people adapted successfully. They planned activities and used carefully structured daily routines. [V] Psychological or emotion-based coping approaches were reported, such as positive thinking, a new or a modified self-identity or self-image, and spirituality. [VI] Coping strategies identified were […] adapting, giving up, or struggling […].

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APPENDIX F (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Snelgrove and Liossi (2013)[65]	[I] People felt distressed during their pain experiences (this emotion was related to cognition [VIII]). [II] People had feelings of frustration, anger, self-loathing, self-denigration, and even depression (these emotions were related to cognition [IX]). [III] People continued to mourn the loss of the previous valued life. [IV] People mentioned a fearful self (this emotion was related to behavior [I]). [V] People felt a negative alteration of their well-being (this emotion was related to cognition [XI]). [VI] People could feel depression associated with behavior [VI]. [VII] People fluctuated although between hope and despair (this emotion was related to behavior [III]). [VIII] Feelings of guilt were reported (this emotion was related to cognition [XII]).	[I] Chronic low back pain was reported as debilitating and reduced a secure and positive sense of the self. [II] People perceived their dignity was threatened due to the impaired and awkward mobility that promoted perceptions of premature aging. [III] Changes in the self lagged the demands of chronic low back pain, not necessarily accommodating for a degree of acceptance or adaptation. [IV] A dualism of the self emerged, with people referring to a subject-object distinction (as a protective function) between their painful bodies (external and threatening object) and the valued sense of the self (subject). [V] Illness and cultural beliefs mediated coping strategies. Biomedical beliefs were determinant to people's experiences. These beliefs were related to [...] a reduction of well-being, psychological inflexibility, and comprehensive enmeshment with pain, with little engagement or acceptance and a loss-orientated focus. [VI] When the cause was not determined, people also identified other potential factors that hindered the rehabilitation efforts: genetic explanations or cultural-based idioms of stress. [VII] People described factors such as the degree of motivation and self-efficacy, the perceptions of control, or whether people had a primary or secondary relationship with pain influenced pain experiences. [VIII] Pain experiences were reported mainly as persistent and disruptive, causing a loss of the previous lifestyle and personality changes. [IX] People attributed the loss of the valued "self" to an increase of functional limitation accompanied by different emotions that have been described in emotion [II]. [X] People are described to be enmeshed in pain. [XI] Little causal explanation for the condition adversely affected female well-being more than male well-being. [XII] Contrary opinions about how to modulate self-efficacy: Some people described their efficacy could reduce by perceptions of uncontrolled and unpredictable pain, as well as guilty and lack of readiness to self-manage. On the other hand, others perceived their efficacy could increase with developed positive self-management strategies. [XIII] People described a period of resignation. [XIV] People found alternative meanings in life to offset the reduction of self-esteem (ie, listening to successful stories).	[I] People [...] developed anticipation toward a disabled future with little reestablishment of behavioral activity. [II] An increase of stoicism was employed to maintain a normal lifestyle and was related to a reduction of the levels of pain. [III] People remained determined to establish a legitimate cause of their illness; adjusted to their limitations and undertook achievable tasks; adopted lower, more realistic expectations about the future; and remained positive although fluctuating between hope and despair. All these behaviors were developed to try to preserve a valued self-identity. [IV] Physically centered coping strategies, such as personally derived postural adjustments and topical treatments, were adjunct to the use of prescribed medication. [V] Those coping strategies that may be viewed as inhibiting any long-term adaptation included prolonged periods of rest and excessive use of alcohol (these strategies could reduce self-esteem). [VI] Less useful were avoidance strategies than minimized exposure to situations where limitations could be exposed. [VII] People used cognitive-focused coping strategies such as [...] ignoring the pain or "disregarding" [...] to maintain normative lifestyles. [VIII] People recounted an initial response of resistance followed by resignation. [IX] People adjusted priorities to offset the reduction of self-esteem (ie, listening to successful stories).

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APPENDIX F (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Söderlund et al (2018)[66]	[I] People felt a loss of hope [...] (this emotion was related to cognition [XIV]). [II] People felt an existential uncertainty due to the changes in their image. [III] People felt hope and happiness (these emotions were related to behavior [II]). [IV] People felt insecurity (this emotion was related to cognition [II]). [V] People felt sad and helpless (these emotions were related to cognitions [XVI] and [XIX]).	[I] People described their previous image as difficult to reestablish. [II] Low perceived control appeared to lead to low confidence regarding the ability to manage injury-related problems and the future. [III] The perceived severity, manageability, and realistic expectations of symptom development also influenced how people perceived the control of the condition. [IV] People perceived severe symptoms were difficult to tolerate and manage. [V] Severe symptoms [...] decreased the people's beliefs and confidence regarding their ability to control the situation. [VI] People believed knowledge of how [...] pain and other symptoms were associated made the situation more understandable and could lead to the development of better strategies for coping with the situation. [VII] Understanding the pain was believed to contribute to its elimination. [VIII] When the expectations of recovery were not fulfilled quickly enough, confusion and conflicting thoughts emerged about the results. [IX] Knowledge about and experiences of participation in physical activity were perceived to be beneficial. However, physical activity was not always a priority. [X] People believed that an optimistic outlook on life would help improve the situation. [XI] People interpreted an emotional improvement as getting better even when the pain and other symptoms did not necessarily decrease. [XII] People described the importance of being optimistic despite the pain and other symptoms (this was reinforced when people perceived improvements in their symptoms). [XIII] Some people believed that they needed to take responsibility for their situation to increase their ability to control it. [XIV] People described pain and other symptoms interfered in their lives (eg, autonomy, ability, or spontaneity). [XV] People believed exercise was beneficial. However, they also described the difficulty to continue with it. [XVI] People believe they had lost the physical capacity they had previous the injury. [XVII] The confidence to manage pain and participate in daily activities decreased due to the lack of success in determining how to control the situation. [XVIII] The combination of expectations regarding recovery and daily experiences of fluctuating symptoms decreased people's confidence concerning the future. [XIX] People also perceived psychological losses that were consequences of whiplash.	[I] People needed to prioritize different commitments according to their beliefs about how pain and other symptoms would be aggravated. [II] People strived for normalcy. [III] People sought to resume the normalcy, autonomy, and spontaneity of life experienced before whiplash.

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APPENDIX F (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Stack et al (2011)[67]	[I] People felt fearful when symptoms appeared rapidly. [II] Uncertainty emerged about whether the illness existed and what action, if any, should be taken. [III] Fear of symptoms becoming more intense and permanent, and it could drive to behaviors [I] and [II]. [IV] Uncertainty emerged when the symptoms began slowly.	[I] People described a lack of knowledge about rheumatoid arthritis (eg, the significance of musculoskeletal symptoms, their own risk of the illness, or the causes of the condition). [II] Causal beliefs were associated with rheumatoid arthritis symptoms, including stressful life events, childbirth, an injury, or "overdoing it." [III] Attributing symptoms to external factors often meant that people believed their symptoms to be temporary (internal attributions were less likely). [IV] Some people did not want to think about themselves as being unhealthy. [V] People usually described their daily tasks were dramatically affected when the symptoms appeared rapid. [VI] Some people described they recalled mild symptoms that they had ignored or misattributed. [VII] People described the difficulty to pinpoint when their relevant symptoms began first when the onset of symptoms was slow, vague, or transitory. [VIII] As symptoms increased in severity and duration, people's explanations for their symptoms changed to match their symptom experience. [IX] Some people mentioned it was difficult to understand the causes of the illness. [X] People believed their illness affected older people or was caused by "wear and tear" (this hindered a correct interpretation of the symptoms). [XI] Some people with preexisting illnesses (ie, osteoarthritis) attributed the emergence of new symptoms to these preexisting illnesses. [XII] Some people did not consider that their symptoms were related to rheumatoid arthritis since they had no familiar history of this condition. [XII] People described symptoms as normal "aches and pains" or "normal" (for someone of their age, gender, life circumstance, etc). [XIV] Some people believed that they focused on other life events that they did not prioritize their symptoms.	[I] Ignoring symptoms allowed some people to continue with normal daily activities. However, when these activities were disrupted, symptoms could no longer be ignored, and perceptions changed. [II] Denial was used by those who did not want to deal with the stress of a possible chronic illness or additional morbidity for those with a preexisting condition. [III] People used a process of adaptation and accommodation to manage the disruption to normal roles and daily activities. [IV] Normalizing symptoms led some to explain away their early symptoms (this behavior was related to cognition [XIII]).

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APPENDIX F (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Stack et al (2013)[68]	[I] The symptoms were associated with feelings of depression [...], while others described anger or feelings of fearfulness. [II] When the onset of symptoms was rapid, feelings of fear were greater. [III] In the early stages of rheumatoid arthritis where the onset of symptoms was slow, the uncertainty about the significance of symptoms appeared. [IV] An insidious onset and fluctuating symptoms created ambivalence and indecision. [V] The ambiguity and vagueness of symptoms were related to uncertainty and, in some cases, emotional upset.	[I] Pain was often described as "mild," "vague," and "non-disabling." People who used this description made understanding the cause very difficult (with some people attributing their symptoms to exertion or minor trauma). [II] Severe pain was described with words such as "unbearable" or "overpowering" (the pain was related to "bone cancer" or believed to be originated from broken or chipped bone). [III] The symptoms were associated with [...] suicidal thoughts. [IV] Rapid-onset symptoms were described as "new resistant," "severe," "abnormal," and "debilitating." [V] Some people described the suddenness and extreme nature of the rheumatoid arthritis onset as a "light switch" or being "cut off." [VI] Swelling was described as severe and the joint becoming "puffed out." [VII] People described their symptoms as "diffuse," "gradual," or "episodic" when the onset of the illness was slow. [VIII] People also described their symptoms as "everyday aches and pains" or "twinges" that began as a nuisance but became severe and were related to functional impairment. [IX] At the onset, stiffness was a symptom that could be bothersome at night because it prevented sleep. [X] Some people described generalized "flu-like" symptoms but were not explicit about the specific symptoms that comprised this experience. [XI] People described fatigue as a very important symptom at the onset of the illness (a person reported that weariness was one of the most significant problems faced at the onset of symptoms). [XII] People associated that weakness increased after being unable to undertake routine daily activities. Others mentioned that weakness was a mild problem.	(-)

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Stewart et al (2020)[69]	[I] People felt frustration and desperation to relieve pain. [II] People also felt frustration with the duration of pain experienced during flares lasting multiple days. [III] Sleep disruptions due to the intensity of the pain affected the overall mood of some people. [IV] The unpredictable nature of gout flares was a concern for many people. [V] Many people […] became snappy and short-tempered during flares. [VI] Several people reported depression and cried […] during flares. [VII] People showed anxiety and fear related to not knowing when to expect a gout flare. [VIII] The overall psychological impact of gout flares was mentally draining, which resulted in emotional fragility. [IX] People felt fearful of triggering a flare.	[I] Gout flares were described as the worst pain ever experienced (ie, being worse than childbirth). [II] The location of the gout flare was also considered an important contributor to the perceived severity of the flare. [III] The intensity of the pain meant that people were unable to eat due to loss of appetite. [IV] People believed footwear contributed to the pain and swelling of a flare. [V] The pain was often described as intense, constant, and throbbing in nature with the sensation that the joint was burning or on fire. [VI] People commented on the quick onset of gout flares and preferred flares that came fast and went fast. [VII] People described 2 or 3 flares per year were "not too bad" while going for long periods without flares was perceived as "a miracle." [VIII] Contrary opinions about the location of the gout flares: Some people described a gout flare as more severe when affecting larger joints. On the other hand, others mentioned that flares that affected the feet were more serious than in other joints (ie, hands), due to their impacts on mobility. [IX] People described the difficulty to find shoes that they could wear comfortably during a flare. [X] People mentioned the presence of sleep disruptions because of the intensity of the pain.	[I] Many people resorted their assistive devices to move around their homes, including wheelchairs and crutches. [II] Other people reported holding on to walls to walk, hopping on one leg, or shuffling around to relieve pain. [III] Others had no choice but to stay in bed. [IV] Many people completely avoided participating in sporting activities they previously enjoyed (this behavior was related to emotion [IX]). [V] A person avoided daily activities such as eating or drinking to avoid the necessity of going to the bathroom during a flare. [VI] Many people chose to go barefoot during this time (this behavior was related to cognition [IV]). [VII] During gout flares, people resorted to wearing shoes that were wider and loose fitting or chose shoes of a larger size. [VIII] Some people opted to sleep in a chair or recliner or sleep with their foot out of the bed. [IX] Some people struggled to conduct household chores and yard work (ie, cleaning).
Toye et al (2013)[74]	[I] "I feel afraid, agitated, ashamed, and guilty." These were associated with the discrepancy between culturally accepted explanations and personal experience. [II] People were aware that they had changed, but they felt grief for the old "real self." [III] "I want to feel like my old self." [IV] Some people felt shame at having medically unexplained pain (this emotion was related to behavior [III]).	[I] "My body has become alienated from me and has become something bad." [II] "I am no longer a person, but I have a body." [III] "Although I struggle to prevent the erosion of my old 'real self' and I am not 'giving in' to my painful body, I face the fact that I am irreparably altered." [IV] "I am no longer at the mercy of my body, but I am a co-expert." [V] People believed that recovery is becoming someone different from what you once were. [VI] "I am coming to know my body and gain the confidence to experiment and make my choices." [VII] The ability to redefine oneself, or psychological flexibility, might help people move forward with pain and reduce its impact. [VIII] "The day-to-day unpredictability of my pain creates an endless timeless present where my life has become dominated by caution and the emergence of a lack of spontaneity." [IX] Plans, expectations, and dreams of the future are irreparably altered, and life focuses inward.	[I] "I listen to and respect my body to align and integrate it. This shows a developing relationship of trust and cooperation with my body." [II] "I am encouraged to hide my pain" (this behavior was related to emotion [III]; hiding pain can be a double-edged sword because people do not necessarily believe what they cannot see). [III] "I struggle to find the right balance between hiding and showing pain." The pull to hide pain and appear "normal" was related to emotion [IV].
Toye et al (2016)[75]	(-)	(-)	(-)

(-) indicates that the corresponding review does not report information for that theme (emotions, cognitions or behaviors).

APPENDIX G

EMOTIONS, COGNITIONS, AND BEHAVIORS IN THE INCLUDED THEMES RELATED TO THE INTERACTION WITH THE ENVIRONMENT

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Bunzli et al (2013)[8]	[I] People expressed fear about job loss and future financial insecurity. [II] People mentioned unreciprocated dependency on family members associated with feelings of helplessness. [III] People experienced disbelief at why they were suffering. This prompted feelings of frustration, anger, guilt, and despair. [IV] People acknowledged that isolation exacerbated feelings of depression.	[I] People described recurrent flare-ups disrupted the consistency of workability. [II] People partook in cost analysis or risk assessment where contextual demands influenced whether or not to engage in activities with or without pain. [III] The challenge of coping with pain daily and making plans had a significant impact on daily functioning, particularly in the workplace and family context. [IV] People described their roles in the family environment changed. [V] People perceived stigmatization.	[I] Withdrawal from social contact to avoid "letting others down" (this behavior was also related to cognition [V]).
Climent-Sanz et al (2020)[14]	[I] Concerns emerged about the inability to find a comfortable sleep position. [II] People felt anxiety and a feeling of constant failure (these emotions were related to cognition [I]).	[I] Sleep problems and fatigue affected the functional capacity in the workplace. [II] Sleep problems caused people to barely share the bed with their partners.	[I] People must wake up in the morning despite feeling tired to fulfill their working schedules. [II] People described a constant movement in bed that ended up impacting the quality of the sleep of their bedfellows (this behavior was related to emotion [I]).

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Daker-White et al (2014)[17]	[I] Rheumatoid arthritis engendered a "dread of [future] dependency [on others]." [II] People felt frustration and distress (these emotions were related to cognition [XI]). [III] People wished to "be believed" regarding the invisibility of their painful symptoms. [IV] Concerns emerged to fulfill social obligations. [V] People with rheumatoid arthritis lost their independence and did not relish dependency.	[I] Many expectations emerged to govern physical functioning or the ability to do things. [II] The support people received from their partners was perceived as "too much" because it was felt to be eroding their social roles. [III] Rheumatoid arthritis was perceived as a chronic and incurable disease. The effect of these symptoms led to changes and losses in social roles. [IV] Control was related to the levels of social support. Typically, people described themselves as either (more commonly) feeling "out of control." [V] Contrary opinions about the ability to achieve control of the illness: Some women suggested that it was easier for older women to achieve control in this context because they had fewer social role obligations than their younger counterparts. [VI] "The onset and development of arthritis is simultaneously an assault on the body and a disruption of social life." The best term to capture these issues in the context of rheumatoid arthritis is probably "biographical disruption." This biographical disruption centered on the loss of previous life and work identities. [VII] The success in coping with rheumatoid arthritis seemed to hinge upon the degree of flexibility possible in both formal structures and informal relationships. [VIII] Within social relationships, "control" referred to reciprocity (ie, "giving-receiving"). [IX] Informal structures like families contain unstated norms of reciprocity or give-and-take, and for many people, the experience of disablement is one of having these norms upset. [X] Whether for worker or homemaker, it was precisely taken-for-granted activities that constituted a large measure of self-identity. [XI] Some people described a lack of appreciation by others.	[I] People faced the problems of "being believed" concerning pain and the fluctuating nature of the condition. [II] People faced stigmatizing threats relating to the exposure (or visibility) of bodily deformities.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Donnelly et al (2020)[21]	[I] People felt loss and loneliness, particularly during a flare (these emotions were related to behavior [V]). [II] Some people did not wish to reveal their illness for fear (this emotion was related to cognition [IV]). [III] Some people felt a potential dependency on family and friends (this emotion was related to cognition [VI]). [IV] As part of the emotional work of self-management, individuals were required to deal with feelings of frustration, anger, and depression.	[I] Some men reported that relying on others to help with domestic tasks, such as chopping wood, could undermine their sense of masculinity. [II] Maintaining caring roles could mean a physical and emotional challenge: "I could not tie his [child's] little boots and had to call a neighbour, this was traumatic… I could not take my baby in my arms." [III] Social comparison was a common strategy across the studies. Downward comparisons […]. Upward comparisons […]. Self-comparison […]. [IV] Some people believed that they would be perceived as less productive or competent if they revealed their illness. [V] […] people perceived they were unsupported by family, friends, and colleagues. [VI] Contrary opinions about seeking help: People described how they felt about seeking help. Support, particularly from family and friends, was widely regarded as having positive effects concerning self-management. However, they perceived that they could be a burden. [VII] People perceived themselves to be a burden (this cognition was related to emotion [IV]). [VIII] The illness affected the ability to work and how a loss of employment impacted self-identity.	[I] Concealing deformity was important to some people, especially in work and social situations. [II] Taking sick leave was often avoided if it was felt that colleagues or employers did not recognize their illness as legitimate. [III] People could reduce their social outings and physical activities if they perceived limited means (this behavior was related to emotion [I]). [IV] People struggled to convince family, friends, and colleagues that they were legitimately ill. [V] People are socially isolated, particularly during a flare.

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First Author and Year of Publication	Emotions	Cognitions	Behaviors
Feddersen et al (2017)[23]	[I] Performing paid work contributed to general well-being. [II] Some women increased their dependency when continuing work became impossible. [III] Others felt gratitude when they received help from their children and partner. [IV] People felt fear (this emotion was related to cognition [X]). [V] Some people could self-blame (this emotion was related to cognition [XI]).	[I] People described paid work seemed to be given a higher priority than being a mother and living with rheumatoid arthritis. [II] Participation in the labor market was seen as a positive identity marker. [III] Some women perceived themselves to be a burden to their families because of their lack of capabilities in the house. [IV] The unpredictability of fatigue, the fluctuating course of the illness, and how the illness developed over time were described as some of the greatest challenges of having rheumatoid arthritis concerning motherhood and paid work. [V] Pain and reduced mobility were noted as limiting factors that further impacted their paid work and being a mother. [VI] Social positions in the family changed: Children and partners took over some household tasks. [VII] Some people did not have sufficient personal resources to perform anything other than their paid work, rest, and sleep. [VIII] The ability to continue working was dependent on support and recognition from the woman's partner, employer, and coworkers. This included opportunities to work flexibly, reductions in working hours and duties, or changes to tasks. [IX] It was considered very worthwhile to stay connected to the labor market. [X] Some people perceived they couldn't cope with daily life with children because of the illness. [XI] Some people perceived they can't provide for their family and to live up to social norms in society. [XII] When the illness meant that a woman had to give up work, it could be seen as a "biographical disruption" or a loss of identity. [XIII] "I thought the illness could be passed on to the child."	[I] Some people tried to hide symptoms of illness at work (this behavior was related to cognition [XII]). [II] Some women ignored symptoms and limitations caused by their rheumatoid arthritis so they could carry on the previous activities with their children and in their paid work. When symptoms and limitations were ignored, it was often with full awareness of the consequences of overloading themselves and the probable worsening of symptoms.

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Froud et al (2014)[24]	[I] People felt worried about how they were seen by others. [II] People felt fearful of spoiling the experience for loved ones (family). [III] People emphasized [...] the fear associated with losing a job. [IV] Concerns emerged about performing tasks despite the pain. If this was seen as a sign of competence by their coworkers, this could serve to further fuel the delegitimization of their pain. [V] Some worries emerged about job security or the stigma from coworkers that could result from taking sick leave. Many were concerned about the ability to maintain bill payments (this emotion was related to cognition [XIV]). [VI] Some people felt fearful (this emotion was related to cognition [XV]). [VII] Some people described a high degree of dependence on others.	[I] Contrary opinions about the necessary/desirable support: People expressed a paradoxical need/desire for support from those closest to them. On the other hand, they simultaneously wanted to avoid those close to them while in pain. [II] People emphasized that the price of engaging in activities they thought likely to exacerbate their symptoms could be a loss of credibility since participation could be perceived as evidence that there was nothing wrong (this cognition was related with behavior [II]). [III] The absence of sexual activity due to low back pain was associated with the perception of a damaged relationship. [IV] Contrary opinions associated with social interactions: A cognitive dissonance was evident in accounts of social interaction. On the one hand, people described themselves as social, or formerly social, and wanted to be able to go out with friends. On the other hand, they recounted uncomfortable feelings associated with social activities. [V] Contrary opinions about how pain was perceived in the workplace: Younger people tended to perceive back pain as more threatening to their careers. On the other hand, older workers or those closer to retirement appeared to find it easier to ask for help. [VI] People described that the absence of disclosure of their back pain was responsible for the dismissal from work or transfer. [VII] Some people began to question their worth as an employee. [VIII] People emphasized the need to modify work tasks. [IX] People perceived they were unsupported. [X] Marital relationships suffered such that cohabitation became unviable. [XI] Activity limitations were considered to have negative implications for relationships, especially in terms of interacting with children or grandchildren. [XII] Allowing sufficient time to recover was considered important; however, it was emphasized that this sometimes resulted in time off work. [XIII] People not eligible for sick pay are often described as not being able to afford to take the time off. [XIV] Some people pointed out reduced pay due to sick leave could be insufficient. [XV] Some people thought their employers may be unwilling to accommodate their need or might terminate their employment.	[I] Some people avoided family activities and showed social withdrawal and isolation (these behaviors were related to emotion [II]). [II] Some people engaged in activities they thought likely to exacerbate their symptoms, simply to maintain relations. [III] Some people did not disclose their back problems to their employers (this behavior was related to emotion [VI]). [IV] An individual preferred to use the holidays for recovery rather than taking time off work due to the belief that sick leave would pose a risk to the job. [V] People battled to be believed, making efforts to perform tasks despite the pain.

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Lin et al (2011)[34]	(-)	[I] People changed their view on their relationship with problems and the judgment of others. They also became empowered to respond to their needs. [II] People are unable to achieve a sense of confidence to face their changing roles in work and family life. [III] People frequently use the downward comparative strategy, comparing themselves with people in a worse physical state of mind and body. [IV] As people could no longer function in the same manner in their social and occupational roles, they learned to adjust expectations and modify standards. In addition to accepting limitations related to their performance, these people wrestled with accepting limitations in their relational roles regarding controlling others and accepting dependence on others. [V] People repeatedly described authenticity as awareness of self and others. […] Concretely, an author described that, as a corollary to accepting physical limitations, people expressed increasing comfort with relying on others for help with daily tasks. They also said that accepting limitations involved overcoming denial. [VI] People are unable to achieve a sense of calm to face their changing roles in work and family life.	[I] People stretched the limits of their ability to perform activities, especially at work, to be able to keep their jobs. [II] The most valuable element to find meaning was the reevaluation of positive values in one's life and the provision of feedback. People may adhere to altruism, remain supportive of public welfare services, show concern about the needs of others, and use their experiences to help others make sense of their purpose and significance.

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
MacNeela et al (2015)[37]	[I] Some people felt very distressed (this emotion was related to cognition [XIII]). [II] The feeling that pain had taken over severely tested hopes for the future. [III] Continued manual duties were worrying (this emotion was related to cognition [III]). [IV] Irritability arising from pain was the final motivating factor to the behaviors mentioned as [I]. [V] Depictions of spousal relationships emphasized […] dependence on help from the partner. [VI] People developed a sense of agitation and antagonism toward other people.	[I] Workers believed they were less productive than before. [II] Back pain devastated economic security through disruptions and threats to the ability to work. [III] For those in manual jobs, continued duties […] were perceived to be causing damage through "wear and tear." [IV] Supervisor behaviors were typically cited as unsupportive. [V] Occupational status was, in most cases, a marker of the ability to cope with the demands of a job. [VI] A person […] identified the loss of the worker role to undermine self-esteem. [VII] Bleak visions of the future included frightening images of dependency. [VIII] One motive for social withdrawal was to avoid actual or anticipated rejection and suspicions of malingering. A further reason for withdrawal was the sense of social invisibility […]. [IX] The result of the condition was a severe threat to the person's lifestyle and undermined the ability to carry out essential daily activities. In turn, such losses impacted valued roles and routines, such as parenting, gardening, exercise, and driving. [X] Back pain […] compromised the ability to perform expected roles. [XI] The spousal and parental relationships were highly stressed by back pain, with reports of diminished trust and mutual understanding. [XII] Back pain was described as a stigmatized illness lacking in authenticity and legitimacy. [XIII] Some people felt unable to perform familiar and necessary tasks.	[I] Withdrawal from others and avoid interaction (these behaviors were related to emotion [IV] and cognition [VIII]). [II] In a study, most people were still working. [III] People struggled to meet expectations in the workplace.
Parenti et al (2020)[53]	[I] People felt an increase in their well-being (this emotion was related to behavior [I]). [II] The need for improvements regarding people's psychological support [...] was derived from elements such as the embarrassment of physical changes and mood disturbances.	[I] The need for improvements regarding people's psychological support […] was derived from elements such as […] low self-confidence.	[I] Some strategies (ie, exchanging social support) were adopted to increase resilience in facing rheumatoid arthritis challenges. [II] People applied self-care behaviors (this behavior was related to behavior [II]).

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Primdahl et al (2019)[57]	[I] Physical activity […] is associated with irritability and anger. […] A reduced energy to participate in social activities leads to negative feelings such as anger. [II] The emotional impact of fatigue is related to experiences of frustration, hopelessness, fear […], and lack of patience […] concerning other people. [III] Younger women with many social roles felt overly sensitive and misunderstood. Other women felt useless. It is hard to fulfill social expectations, which lead to a feeling of being viewed as lazy, boring, and self-absorbed. Feelings of guilt and embarrassment can also arise (these emotions were related to cognition [XI]). [IV] The emotional and social consequences of fatigue can result in a particular type of loneliness. [V] People had a feeling of being hard to live with (this emotion was related to cognition [IV]). [VI] Emotions such as grump or whining could emerge (these emotions were related to cognition [II]).	[I] Fatigue is related to experiences of […] loss of control concerning other people. [II] It is essential for people not to be perceived as grumpy or whining, but to manage fatigue on their own. [III] People perceived other individuals, who are familiar with "normal" tiredness, are only able to understand fatigue on an intellectual level. [IV] People described not having enough energy to take care of their families. [V] People described fatigue as a great barrier to being with other people. [VI] People described a sense of being dependent on others as detrimental. [VII] It is hard to fulfill social expectations, which led to different emotions (this cognition was related to emotion [III]). [VIII] Fatigue affected several cognitive aspects of the individual: the engagement with others. [IX] People found it hard to reciprocate help and describe fatigue as exhausting, which limits their relationships with other people. [X] People accepted help from others. [XI] People can feel too tired to entertain others or fall asleep.	[I] People reduced their social activities to a minimum. […] Days with high levels of fatigue led to isolation at home either because it was difficult to go out or people deliberately chose to be by themselves and stayed home (this behavior was related to cognition [V]). [II] People strived to avoid showing fatigue at work or in public. [III] People communicated their fatigue differently depending on the context, and they expected a reaction from those they talked to. [IV] Contrary behaviors about how to face daily tasks: People broke down tasks over one or several days, or they consciously decided to carry on regardless of the consequences. [V] People with rheumatoid arthritis did not share their illness with others (this behavior was related to emotion [IV]). [VI] People with fatigue constantly prioritized and planned activities according to their capacity to manage fatigue at home and work.
Riggs and Killingback (2019)[59]	[I] Meeting people who had more advanced stages of rheumatoid arthritis evoked mixed emotions: intimidation, fear, and motivation. [II] A desire to limit disease progression, alongside seeing the benefits in others with rheumatoid arthritis, endorsed participation.	[I] Contrary opinions about being belonged to a group: While social interaction facilitated most people, others described that being part of a rheumatoid arthritis group labeled them as a patient and took away their identity. [II] People highlighted the need for support. [III] Social connection was a key factor to undertake physical activity. A reported sense of "belonging to a community" and "sharing the same struggles" indicated that acceptance and understanding were important. [IV] Lifestyle constraints, such as children and employment, affected people's activities. They preferred activities that fitted into their daily routines. [V] Regarding location, community settings were preferred as they removed the stigma of being a patient, rather than a person with rheumatoid arthritis. [VI] The fundamental incentive for people was to counteract disease progression and preserve independence, maintaining their role within society.	(-)

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Robart and Boyle (2021)[60]	[I] People felt motivated. [II] Others felt fear of pain or re-injury. [III] The experience of modified duties led to feelings of guilt. [IV] The fear of disclosing a lower back injury can be related to behavior [II]. [V] People felt fear and uncertainty about the future. These emotions were related to the discriminatory practices that could appear in the workplace. [VI] Several uncertainties were reported regarding the return-to-work process and future work capacity. Some people described feeling lost, anxious, and insecure about the future. [VII] Others showed concerns about earlier-than-anticipated retirement and future work capacity. [VIII] Some of these uncertainties are driven by fears of being discriminated (in the workplace). [IX] Fear of re-injury and despair emerged and influenced people's beliefs about their ability to return to work. [X] Some uncertainties could emerge related to the process (this emotion was related to cognition [XVII]).	[I] People [...] described the benefits of working, such as contributing to positive self-identity and offering a welcome distraction from back pain. [II] Contrary opinions about how workers/non-workers were perceived by relatives: Those who were working were perceived as "stoical" and "heroic," whereas relatives in the nonworking sample were perceived as "blameless victims" and were more likely to be labeled "disabled." [III] Modified duties were described to be socially inappropriate in one instance in which male workers were expected to undertake duties ordinarily done by female workers. [IV] Workers who were more competent in their roles saw themselves as assertive and were proactive in their care. [V] Factors such as [...] "taking responsibility for oneself" positively influenced the ability to return to work. [VI] People perceived an increase or decrease of the ability to return to work (this cognition was related to emotions [I] and [II]). [VII] The experience of modified duties led to the possibility of being a burden to colleagues. [VIII] Self-doubt, lack of control, and lack of confidence emerged and influenced people's beliefs about their ability to return to work. [IX] How workers perceived themselves may limit their ability to engage with the rehabilitation process. [X] Some people perceived pessimism over their ability to return to work. [XI] People described that some factors (ie, jobs that permitted to find a balance between sedentary positions and physical movement) facilitated that they could modify their work duties. [XII] A lack of modified duties was considered a barrier to return to work. [XIII] People described that their low back pain could be seen as "bogus" in the workplace. [XIV] People could be negatively appraised by others due to the invisibility of low back pain (this cognition relates to emotion [IV]). [XV] People with low back pain could be perceived as being to blame by others. [XVI] People reappraised their point of view about others to mediate work-condition conflict. [XVII] People described some uncertainties that could emerge related to their process when they felt their employers do not understand the difficulties they experience or how best to support them.	[I] Making changes in working duties (ie, advice on ergonomics) was a further way injured workers may be enabled to continue in their work. [II] Some people anticipated discrimination in the workplace.

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Sim and Madden (2008)[63]	[I] People felt loneliness and grief (these emotions were related to behavior [I]).	[I] People described the difficulty of clearly and accurately talking about pain to others, reflecting the inadequacy of language in expressing a subjective experience (ie, pain is invisible). [II] Fatigue and lack of strength affected personal relationships. [III] Cognitive difficulties were reported (eg, limitations with problem solving and abstract thinking), affecting the presence of opportunities in the workplace. [IV] The intention for maintaining a normal role caused that family relationships became strained. [V] People involved in redefining their social obligations.	[I] People established their priorities, leading to certain activities, such as paid work or social relationships, being lost. This facilitated that people were socially isolated. [II] People used social/family networks and support groups.
Snelgrove and Liossi (2013)[65]	[I] Despondency, shame, and helplessness were related to impaired social, family, and work roles. [II] People could feel anger and guilt (these emotions were related to cognition [V]). [III] Fear of pain and a loss of function in older individuals restricted leisure time in retirement, promoting lowered mood. [IV] People had feelings of negativity toward others (this emotion was related to cognition [IX] in Table 2). [V] Some people remain positive reestablishing a valued identity. However, others felt thwarted by difficulties replacing valued roles (these emotions were related with cognition [VII]).	[I] People described their integrity as threatened due to the presence of stigmatizing judgments and unsympathetic social contexts in which chronic low back pain was experienced (this made difficult family interactions). [II] People reported being a burden to their families. [III] Gender differences were described regarding people's roles (ie, opportunities for control and influence in the workplace benefited the self-esteem of men more than women with chronic low back pain). [IV] Perceptions of lowered self-esteem were related to impaired social, family, and work roles. [V] Friends and family could offer emotional and tangible support […]. However, any disruption to social roles could result in problems maintaining a normal social life. [VI] People described the presence of low self-esteem, which was offset with several behaviors (see behavior [II]). [VII] People described reestablishing a valued identity but found difficulties replacing valued roles (ie, unfavorable work context – unemployment). [VIII] Illness and cultural beliefs mediated coping strategies. Biomedical beliefs were determinant to people's experiences. These beliefs were related to [...] less successful rehabilitation to work. [IX] People described cognitive problem-solving processes such as the development of downward comparisons. [X] People described cognitive problem-solving processes such as the assertion of oneself in the face of stigma. [XI] People found alternative meanings in life to offset the reduction of self-esteem (ie, joining support groups).	[I] People restricted their leisure time in retirement (this behavior was related to emotion [III]). [II] People maintained social roles to offset the reduction of self-esteem. [III] People […] developed anticipation toward negative social judgments with little reestablishment of behavioral activity (this behavior was related to emotion [IV] of Table 2). [IV] Those coping strategies that may be viewed as inhibiting any long-term adaptation included prolonged periods of rest and excessive use of alcohol (these strategies could disrupt family lives and spousal relationships). [V] People learned to live with pain in different situations (ie, an increase of functional capacity in work situations). [VI] People socially isolated (this behavior was associated with emotions [I] and [III] in Table 3 and behavior [VI] in Table 2). [VII] People adjusted priorities to offset the reduction of self-esteem (ie, joining support groups).

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Söderlund et al (2018)[66]	[I] People felt sad and helpless about all social losses that were consequences of whiplash.	[I] People perceived other individuals without whiplash and pain labeled them negatively because there was no visible evidence of their pain. [II] The invisibility of pain also contributed to the people's belief that others thought they were malingering. [III] The combination of expectations regarding recovery and daily experiences of fluctuating symptoms decreased people's confidence concerning their return to work. [IV] Perceived work-related stress and aggravated symptoms decreased their confidence in their ability to return to work. [V] Supportive […] colleagues and employers were of great importance in increasing people's confidence in their ability to return to work. Different adaptations of working conditions and acceptance of their physical and psychological limitations increased the people's confidence regarding return to work. [VI] People described pain and other symptoms interfered in their social roles. [VII] Support from significant others was an important part of being able to control the situation. [VIII] People perceived returning to work was a challenge. [IX] People are described to be stigmatized due to the changes in their image.	(-)

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Stack et al (2011)[67]	(-)	[I] People described the disruption to normal roles and daily activities could drive to help-seeking behavior. [II] Causal beliefs associated with rheumatoid arthritis symptoms included work. [III] Changes in symptoms, experiences, and explanations helped people to determine when help should be sought. [IV] Contrary opinions about when seeking help: While few people recognized their symptoms as indicative of their illness, those that did suggested that they sought help when the pain spread to multiple joints. [V] People described the severity, intensity, and duration of symptoms at the onset of rheumatoid arthritis influenced if they sought help. [VI] People mentioned if they had had more knowledge about their illness, they would have sought help earlier. [VII] People described the public had a greater awareness of conditions, such as cancer and heart disease, and the public did not perceive joint symptoms could be indicative of a serious illness. [VIII] People believed their illness affected older people or was caused by "wear and tear" (this hindered rapid help-seeking).	[I] People rapidly searched for help when the symptoms appeared rapid. [II] People initially sought help for symptom relief. [III] People sought help when the anticipated or real level of disruption became a concern or previous strategies for dealing with symptoms failed. [IV] People probably increased their visits to the consult due to the increase in the severity of the symptoms and impacted activities.
Stack et al (2013)[68]	(-)	[I] A rapid onset of pain was often associated with the onset of additional symptoms.	[I] Some people adopted rapid help-seeking behaviors (this behavior was related to cognition [I]).
Stewart et al (2020)[69]	[I] Dependency emerged on family members for basic care. [II] Financial worry emerged associated with the loss of incomes. [III] People desired not to be touched for fear of exacerbating the pain. [IV] Shame and embarrassment of a gout flare harmed social participation. [V] Some people felt depression, anger, frustration, and feelings of vulnerability (these emotions were related to cognition [V]). [VI] Physical isolation caused frustration, irritability, and aggravation. [VII] Some people developed feelings of boredom (this emotion was related to cognition [VI]). [VIII] People felt fearful of triggering a flare with certain foods. [IX] Some people felt embarrassed about the negative connotations associated with gout.	[I] Being physically intimate during flares was described as difficult or impossible (this cognition was related to emotion [III]). [II] People described gout flares affected their ability to participate in social events (ie, going to the cinema). [III] Many people mentioned that the unpredictability of gout flares affected their ability to plan social activities and engagements. [IV] People described the presence of pressure to go to work even if they were in pain due to financial stress and the need to support their families. [V] The lack of intimacy due to gout flares negatively affected relationships. [VI] Some people felt unable to move or participate in normal daily activities.	[I] People avoided eating out with family and friends (this behavior was related to emotion [VIII]). [II] People reported changing the nature of their jobs due to frequent gout flares, from less physical to more sedentary jobs, or choosing jobs with greater flexibility, such as self-employment or volunteering. [III] Some people avoided leaving the house as they did not want to be seen walking with a limp or felt self-conscious about their feet being swollen. This facilitated that people were socially isolated. [IV] Several people avoided telling their friends and family that they were suffering from a gout flare (this behavior was related to emotion [IX]). [V] A person slept in a different bed than its partner during a flare (this behavior was related to emotion [III]).

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APPENDIX G (CONTINUED)

First Author and Year of Publication	Emotions	Cognitions	Behaviors
Toye et al (2013)[74]	[I] "I feel guilty" (this emotion was related to cognition [VI]). [II] "Overwhelming doubt permeated my experience at work, social life, […] and family." [III] "I feel fear of overburdening others."	[I] "I feel others' disbelief threatens my integrity." [II] Contrary opinions about being part of a community: Being part of a community describes a sense of sharing, being valued, and becoming credible. However, despite the benefits […], there is a sense of ambivalence; "although I am like the others, at the same time I am not like them, and I need to be valued as an individual." [III] "I no longer need to gain the approval of others." [IV] "My loss of roles that made me who I am undermined my self-worth." [V] "I cannot meet people's expectations." [VI] People described how hiding pain could affect their credibility. [VII] "I am learning to limit demands from others and manage my resources." [VIII] "I perceived my situation as a discrepancy between culturally accepted explanations and personal experience."	[I] "I am encouraged to hide pain" (this behavior was related to emotion [III]; hiding pain can be a double-edged sword because people do not necessarily believe what they cannot see). [II] "I find it liberating to tell others about my pain. This permits me to avoid hiding my pain and allowing them to know my limitations." [III] "I strive to present a picture of myself as a 'good' person who is not to blame for my pain" (this behavior was related to cognition [VI]).
Toye et al (2016)[75]	[I] Employees […] were particularly concerned not to be seen as "bad workers" or as letting the side down. [II] Chronic pain threatened the sense of being integral in the workplace, and some people felt easily dispensable or feared that employers saw them as too risky to keep on. [III] Uncertainty about the unpredictability and relentlessness of symptoms, along with a fear of symptom progression emerged. [IV] "I feel […] worried about gaining a reputation for being 'work-shy.'" This feeling could be increased by a culture of skepticism and mistrust regarding chronic pain (this emotion was related to cognition [VIII]). [V] Feelings of guilt in the workplace are compounded by judgments by colleagues (this emotion was related to cognition [X]). [VI] Fear of letting employers down or not being seen as a good worker. [VII] Guilt and resentment at losing/not finding suitable employment emerged. [VIII] People were concerned that employers would not tolerate the unpredictability and relentlessness of symptoms. [IX] Many people felt responsible for back injuries (this emotion was related to cognition [IX]).	[I] The losses to self that accompany changes in work roles. [II] Work is described as adding value to the self (eg, work makes us what we are; work gives recognition, approval, self-realization, and self-respect). [III] People perceived a necessity of limiting the support that they could expect from colleagues (ie, in a harsh financial environment). [IV] People perceived employers could fail to support them in continued work. Some people felt as if they were "being treated like a number," although their work had been valued before pain. This led to a sense of betrayal. [V] People perceived they could not continue at work (this cognition was related to emotion [III]). [VI] A minority perceived the possible benefits of flexible working arrangements, although these might not be available. [VII] Some people described a lack of understanding by others. [VIII] People perceived letting the employer down threatened their image as a worker. [IX] Some people perceived poor workplace policies. [X] Some people generally described staying at work had many benefits. Disbenefits included fewer opportunities for social life and to pursue hobbies.	[I] "I struggle to affirm my credibility as a 'good worker' (ie, maintaining a positive image)." [II] Employees […] struggled to maintain a positive image. […] To avoid […] negative image, they used various strategies: struggling on at work and relying on colleagues despite pain, taking annual leave rather than taking the time of "off sick," or finally leaving work. [III] Some people left work voluntarily (this behavior was related to emotion [VI]). [IV] People went to great lengths to find employment and often hid back pain from their employers. [V] Contrary behaviors: Workers struggled to balance work commitments with other essential roles, leisure, and social activities (this behavior was related to cognition [X]). [VI] Adjustment latitude […] involves a range of crucial adaptation strategies around prioritizing work, being flexible in execution of tasks […], adapting ways of working with colleagues […], and working in partnership with families […]. Not everyone at work experiences this latitude at work.

(-) *indicates that the corresponding review does not report information for that theme (emotions, cognitions or behaviors).*

LETTER TO THE EDITOR-IN-CHIEF

This is a letter to the Editor-in-Chief in response to JOSPT article "When treating coexisting low back pain and hip impairments, focus on the back: adding specific hip treatment does not yield additional benefits—a randomized controlled trial" by Burns et al. J Orthop Sports Phys Ther. 2021;51(12):581-601. https://doi.org/10.2519/jospt.2021.10593

TREATING THE HIPS FOR LOW BACK PAIN MAY BE EFFECTIVE: FOR THE RIGHT PATIENT

J Orthop Sports Phys Ther 2022;52(5):300. doi:10.2519/jospt.2022.0202

We read with great interest the aforementioned study by Burns et al[4] focusing on the treatment of patients with low back pain and concurrent hip impairments. This is an important area of study, and we anticipate that this line of research will help shed light on the most effective approaches for treating low back pain, which is a major financial burden on US health systems. However, we have concerns with the methodology of this study and feel that the results should be interpreted with caution.

Hip-spine syndrome, as coined by Offierski and MacNab,[6] was originally used to describe patients with low back pain associated with hip osteoarthritis, a condition that primarily affects hip mobility. Since that time, several studies (including those referenced by Burns et al) have reported a high rate of hip impairments among those with low back pain.[1,7] Upon closer inspection, we find that most of the impairments reported by these studies are related to hip mobility (ie, range of motion). However, the study performed by Burns and colleagues included patients in their study with impairments potentially unrelated to hip mobility, such as hip strength deficits and positive special tests for intra-articular hip conditions. Moreover, a limitation in hip strength was the most frequent finding among eligible patients in this study.

It is possible that the inclusion of patients with impairments unrelated to mobility may have affected the results of this study. As stated by the authors, previous studies have shown that including interventions targeting the hips is beneficial for those with low back pain.[2,3,5] There are important differences between these studies and the study by Burns and colleagues. One of these studies only included patients with concurrent hip mobility impairments.[5] The other study showed that hip interventions were most effective for those who also reported hip pain.[2,3] While the reason (ie, diagnosis) for hip pain was not included in the previous studies, the presence of hip pain indicates a greater involvement of the hip than asymptomatic hip weakness, which was used as an inclusion criterion in the study by Burns et al. It should also be noted that manual muscle testing has questionable interrater reliability and that asymptomatic hip weakness is likely common among healthy adults without hip or low back pain.

Further research is needed to identify patients with low back pain that will benefit from interventions directed toward the hip region. While the study by Burns et al provides important information on this approach, the reported results should not be viewed as conclusive, and we caution those who may abandon this treatment approach based on the results of this study. Larger studies on this topic are needed that allow for statistical approaches that identify subgroups of patients with low back pain that respond to physical therapy treatment of the hips.

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RESPONSE TO THE LETTER TO THE EDITOR-IN-CHIEF

J Orthop Sports Phys Ther 2022;52(5):300-302. doi:10.2519/jospt.2022.0202-R

We thank the Editor for allowing us to respond and the authors for their thoughtful critique. The authors of the letter highlight important discussion points related to the results of this trial. We agree that the results should be interpreted cautiously, and additional research is needed to provide clarification regard-

ing the role of the hip impairments in individuals with low back pain LBP. We agree that clinicians should not abandon treatment of the hip(s) in patients with (LBP) until further research provides clarification.

The authors argue that having hip weakness alone (without hip range of motion limitations or hip pain) may not constitute a hip impairment that would benefit from interventions to the hip. Thus, in our trial, including participants with hip weakness only may have reduced our ability to demonstrate a significant effect from adding hip interventions to the treatment of LBP. We considered hip weakness to be an impairment because it is commonly observed in the LBP population, and physical therapists often render treatments to improve hip muscle strength in patients with LBP.[3,6] Further, hip muscle strengthening exercises in addition to low back exercise in people with LBP have been shown to produce greater reductions pain and disability compared to sham manual therapy.[6] Addressing hip weakness with muscle strengthening interventions has the potential to contribute to reducing LBP symptoms and is commonly performed by physical therapists.[3,6] Therefore, hip muscle weakness was included as one possible hip impairment that met our inclusion criteria for participation. We intentionally had a broad set of possible hip impairments that met our inclusion criteria because we wanted to mimic clinical practice and typical patient populations that are seen by physical therapists thus making it more generalizable to clinical practice. We used manual muscle testing (MMT) to test for hip muscle weakness as it is commonly used in clinical practice. While we acknowledge that interrater reliability is poor to moderate for assigning a specific grade (0-5) of weakness using MMT, MMT can detect the presence or absence of weakness,[2] and that is how it was used in our study.

The wide range of possible hip impairments included in our trial, rather than specifically the inclusion of participants with hip weakness only, likely led to heterogeneity across the sample and is a more probable reason for the similar outcomes observed in each treatment group. It is likely that our trial captured individuals who may have different responses to hip interventions.[7,8]

Subgroups of hip-spine syndrome have been described[7] as (1) simple: coexisting hip pathology (eg, hip osteoarthritis); (2) secondary: hip impairments that preceded and reproduce LBP; and (3) complex: hip impairments that overlap between the low back and hip. Our study likely included participants from each category, resulting in a heterogeneous sample that diluted any possible differences between groups. Some participants may have had coincidental findings that were not directly related to their LBP symptoms.

We did not differentiate potential subgroups at baseline because they lack strict definitions. It would be unreliable for clinicians to try to differentiate these groups using clinical measures, and it was not ethically appropriate or financially viable to conduct additional imaging that was not clinically indicated. In addition, our inclusion criteria only noted the presence of a hip impairment and did not determine the relationship of the hip impairment to the LBP symptoms, which would have provided information about whether the hip impairment was clinically related to the LBP symptoms.

Perhaps only including participants with a hip impairment that was related to their LBP symptoms through physical examination tests, measures, and/or symptom responses may have identified a sample that was less heterogeneous and changed the results.[1,4,5] If the hip impairment was a coincidental finding, it may be less likely to respond to treatment directed at the hip. Future studies should determine if there are subgroups of individuals with LBP and concurrent hip impairment(s) that may respond more favorably to the inclusion of hip interventions in the treatment approach to LBP. Additionally, more research is needed to determine the nature of the relationships between hip impairments and LBP symptoms in people with a primary complaint of LBP. These future studies will assist in clarifying whether hip interventions are a useful addition to the treatment of LBP when a hip impairment is identified.

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Measurement Properties of the Patient-Specific Functional Scale and Its Current Uses: An Updated Systematic Review of 57 Studies Using COSMIN Guidelines

OBJECTIVE: To systematically review measurement properties, including acceptability, feasibility, and interpretability, and current uses of the Patient-Specific Functional Scale (PSFS).

DESIGN: Systematic review of a patient-reported outcome measure using the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) guidelines.

LITERATURE SEARCH: We searched 11 databases from January 2010 to July 2020 for articles on measurement properties or use of PSFS.

STUDY SELECTION CRITERIA: Published primary articles without language restrictions.

DATA SYNTHESIS: Two independent reviewers screened all records, extracted data, and performed risk of bias assessments using COSMIN guidelines. We qualitatively synthesized findings for each measurement property in musculoskeletal and nonmusculoskeletal conditions, and 2 reviewers independently performed Grading of Recommendations Assessment, Development and Evaluation assessments. This study was preregistered with the Open Science Framework (https://doi.org/10.17605/OSF.IO/42UZT).

RESULTS: Of the 985 articles screened, we included 57 articles on measurement properties and 255 articles on the use of PSFS. The PSFS had *sufficient* test-retest reliability in musculoskeletal (22 studies, 845 participants, low-to-moderate certainty) and nonmusculoskeletal conditions (6 studies, 197 participants, very low certainty), *insufficient* construct validity as a measure of physical function (21 studies, 2 945 participants, low-to-moderate certainty), and *sufficient* responsiveness (32 studies, 13 770 participants, moderate-to-high certainty). The standard error of measurement ranged from 0.35 to 1.5. The PSFS was used in 87 unique health conditions, some without prior evidence of validity.

CONCLUSION: The PSFS is an easy-to-use, reliable, and responsive scale in numerous musculoskeletal conditions, but the construct validity of PSFS remains uncertain. Further study of the measurement properties of the PSFS in nonmusculoskeletal conditions is necessary before clinical use. *J Orthop Sports Phys Ther 2022;52(5):262-275. Epub: 05 Feb 2022. doi:10.2519/jospt.2022.10727*

KEY WORDS: *clinical measurement (clinimetrics), outcome measures, reliability, systematic review/meta-analysis, validity*

Function is a key construct in physical therapy, often assessed using patient-reported outcome measures (PROMs).[9] The Patient-Specific Functional Scale (PSFS) is one such PROM developed by Stratford and colleagues in 1995.[77] It asks respondents to identify 3 to 5 activities they have difficulty with and rate them on a scale from 0 ("unable to do") to 10 ("able to do at the same level as before injury or problem"). A systematic review of 13 studies on measurement properties of the PSFS published before May 2010 concluded that the PSFS was *valid* (can assess what it is intended to assess), *reliable* (can produce reproducible results), and *responsive* (can detect the change when change has occurred) in a limited number of musculoskeletal conditions.[30]

The 2012 review also identified that the PSFS was used in several health conditions (eg, peripheral neuropathies) where it had not been validated.[30] For an outcome measure to inform clinical decisions, it is crucial that the measure is interpretable, acceptable, valid, reliable, and responsive in the *intended* patient population.[20] Use of outcome measures with unknown or insufficient measurement properties can inflate or deflate results by up to 68% and consequently lead to research waste and ineffective clinical decisions.[20,23,65] The PSFS needs to be further evaluated before clinical use in all health conditions.[30]

Since the publication of the 2012 systematic review,[30] the PSFS has been

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evaluated in nonmusculoskeletal conditions such as Parkinson's disease and snake envenomation.[12,24] Various guidelines now recommend the PSFS as a core outcome,[34,88] and it is mandated for use by organizations such as the national Accident Compensation Corporation in New Zealand and the Workplace Safety and Insurance Board of Ontario, Canada.[56] Guidelines for systematic reviews of PROMs and risk of bias assessment have also since been introduced by the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) initiative.[68] An updated systematic review[46] of the PSFS is therefore timely.

Our primary aim was to review the measurement properties, acceptability, feasibility, and interpretability of the PSFS in different health conditions using current best-practice reference standards. Our secondary aim was to review the current use of the PSFS in various health conditions to identify whether the PSFS was being used in novel health conditions without prior evaluation.

METHODS

We followed the COSMIN guideline on the systematic review of PROMs.[48,68] The guideline includes 10 distinct steps on how to perform a literature search, evaluate measurement properties and quality of the PROM, and formulate recommendations.[48] The protocol for this study was preregistered in the Open Science Framework.[64] We used updated Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA 2020) guideline to report this systematic review.[64]

Data Sources and Searches

We searched 11 databases including 4 grey-literature databases on July 4, 2020, from January 2010 onward (PubMed, Embase (via Ovid), AMED (via Ovid), PsycInfo (via Ovid), CINAHL (via EBSCOhost), SPORTDiscus (via EBSCOhost), Scopus, Google Scholar (limited to first 300 search results), TRIP, REHABDATA, and LILACS). We elected not to search the additional 3 databases we had originally planned due to a large number of duplicates. We used variations of the term "patient-specific functional scale" in each database. For example, our search strategy in PubMed was *Patient-Specific Function* Scale Filters: Humans, from 2010 – 2020*. We limited our search to studies published after 2009 since the previous review by Horn and colleagues had already conducted a comprehensive search of literature published until May 2010. All studies on measurement properties included by Horn and colleagues were automatically included. A full list of databases searched and the search terms are in the study protocol.[64]

Study Selection

The search results were imported into EndNote reference software[83] where we removed duplicates. Then, 2 reviewers

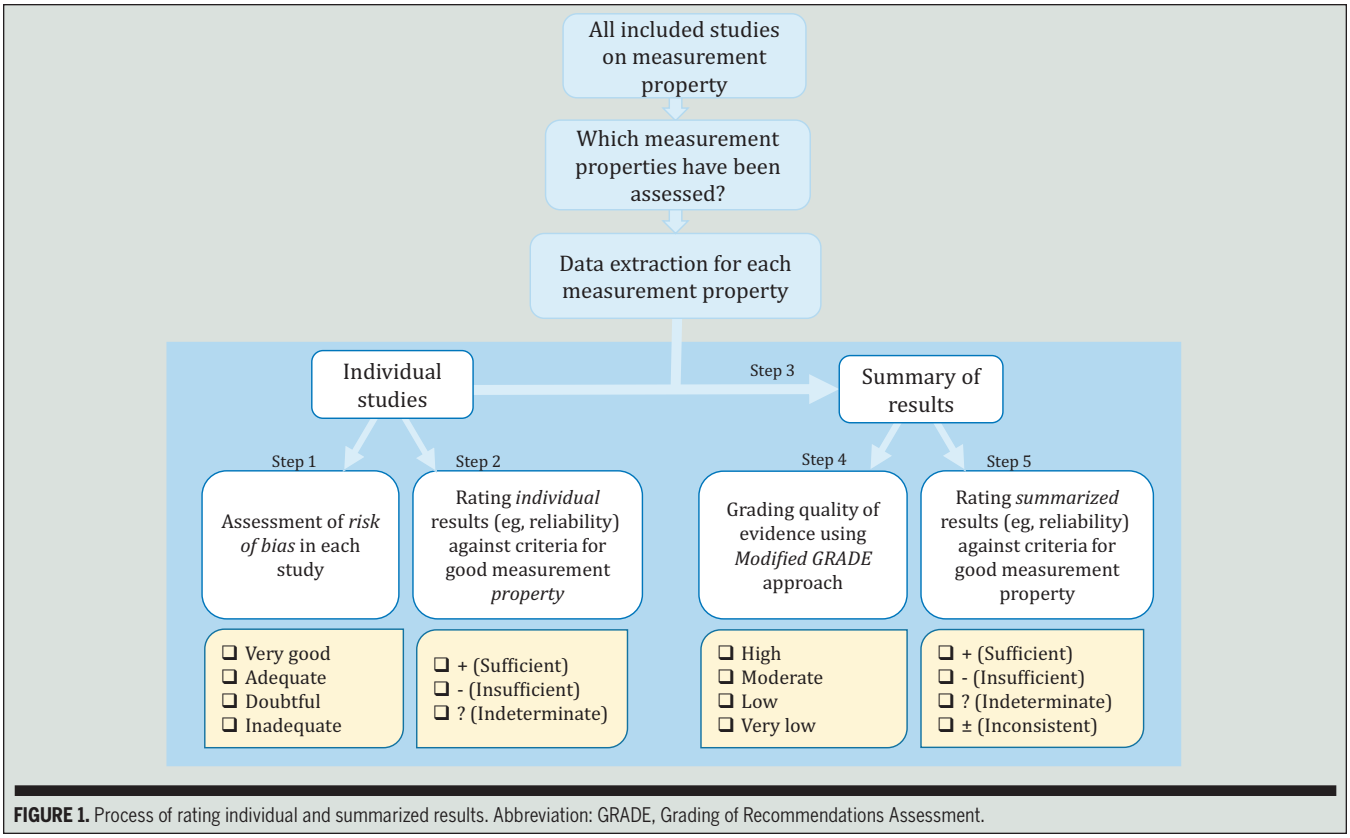

FIGURE 1. Process of rating individual and summarized results. Abbreviation: GRADE, Grading of Recommendations Assessment.

independently screened the title/abstract and then full text of articles using Rayyan web application (https://rayyan.qcri.org). We included *primary* studies on human participants that either used the PSFS or investigated its measurement properties (validity, reliability, or responsiveness), interpretability (eg, floor and ceiling effects and minimum important change (MIC)), acceptability (willing to complete PSFS and difficulty with completion), or feasibility (ease of application such as administration time). We excluded articles for which full text could not be found even after contacting authors. We did not exclude studies based on language; Google translation software was used to translate non-English studies when needed.[32]

The included articles were labeled as "measurement property" (including interpretability/acceptability/feasibility) or "use". If the PSFS was used to validate another instrument, this was classified as "use". Disagreements were resolved by consulting a third team member whose decision was considered final. Finally, we searched the reference list of all included articles on measurement properties. We planned to revise our search strategy if we found more than 5 new articles during reference screening.

Data Extraction and Quality Assessment

A pair of reviewers (AP with another team member) independently extracted data on measurement properties, interpretability, acceptability, and feasibility of the PSFS.[48] For studies on the use of PSFS, AP extracted all data. A full description of the data extraction plan is available in our protocol.[64] We extracted

TABLE 1 Summary of Measurement Properties Assessed and Criteria for Evidence Assessment

Property	Components/Approaches (Parameters)	Criteria for Good Measurement Property†	Examples of Standards Within ROB Assessment	Example(s) of Risk of Bias Assessment
Reliability	Reliability (ICC)	(+): ICC ≥ 0.70. (?): ICC is not reported. (-): ICC < 0.70.	(Total 8 standards) Were patients stable in the interim period? Was time interval appropriate? Were test conditions similar?	"Very good": Evidence provided that patients were stable. "Adequate": It is assumable that patients were stable. "Doubtful": It is unclear if patients were stable. "Inadequate": Patients were *not* stable.
	Measurement Error (SEM, SDC)	(+): SDC or LoA < MIC. (?): MIC values are not reported. (-): SDC or LoA value is larger than MIC.	(Total 6 standards) Was SEM, SDC, or LoA calculated? Was time interval appropriate?	"Very good": Time interval was appropriate (1-3 wk)*. "Inadequate": Time interval is not appropriate (< 24 h OR > 1 mo).
Hypothesis testing for construct validity	Comparison with other instruments (Correlation coefficient "r") Known-groups validity (mean difference between subgroups)	(+): Results match the hypothesis defined by the review team. (?): No hypothesis is defined by the review team. (-): Results are not in accordance with the hypothesis.	(Total 7 standards) Were the measurement properties of the comparator instrument(s) sufficient? Was adequate description of subgroups provided?	"Very good": Comparator instrument has sufficient measurement property in a population similar to study population.
Responsiveness	Comparison with *change* scores in other instruments (Correlation coefficient "r" s) Comparison between subgroups (Mean difference in *change* scores between subgroups, eg, "changed" versus "stable") Comparison before and after intervention (ES, SRM with prior hypothesis)	(+): Results match the hypothesis defined by the review team or AUC ≥ 0.70. (?): No hypothesis is defined by the review team. (-): Results are not in accordance with the hypothesis or AUC < 0.70.	(Total 10 standards) Is it clear what the comparator instrument measures? Was the statistical method appropriate for the hypotheses to be tested?	"Very good": Area under the ROC curve is calculated. "Doubtful": Poor or there is no description of characteristics of subgroups. "Inadequate": There is no description of intervention.

Abbreviations: AUC, area under the curve; ES, effect size; ICC, intraclass correlation coefficient; LoA, limits of agreement; MIC, minimum important change; ROC, receiver operating characteristic; SEM, standard error of measurement; SDC, smallest detectable change; SRM, standardized response mean.
†(+): Sufficient; (?): Indeterminate; (-): Insufficient.
**As there is no standard follow-up time, based on the review team's expertise, we decided 1-3 weeks was "very good"; less than 24 hours or more than 1 month was rated as "inadequate" due to risk of recall bias and potential for true change in patient status.*

data on the study population, sample size, intraclass correlation coefficients (ICCs) for reliability, standard error of measurement (SEM) for measurement error, correlation coefficients and AUC values for construct validity and responsiveness, distribution of scores, and for what purpose the PSFS was used.

Then, the team members used the COSMIN taxonomy of measurement properties[49] to classify which measurement properties were assessed in each included study (**FIGURE 1**). For example, even if studies reported a correlation of *change* scores on PSFS with a comparator instrument as evidence of validity,[35,96] we recorded this within responsiveness. Two reviewers then independently used the updated COSMIN Risk of Bias checklist to categorize the *methodological quality* of each study as "very good", "adequate", "doubtful", or "inadequate".[48] Next, 2 reviewers independently rated the *values* for each measurement property reported as sufficient (+), insufficient (-), or indeterminate (?) using COSMIN's "updated criteria for good measurement properties".[68] Criteria for these assessments are presented in **TABLE 1**. For construct validity and responsiveness, we specified *a priori* hypotheses for sufficient measurement properties (**TABLE 2**). Where a study reported data addressing multiple hypotheses, such as using multiple comparators, these were rated separately.

We did not assess the structural validity and internal consistency of PSFS because the scale is not based on a reflective model; activities within the PSFS do not need to be correlated.[47] We also did not assess content validity using the COSMIN methodology as most items within the COSMIN tools to evaluate content validity (eg, was each item tested in an appropriate number of patients?) did not apply to a flexible scale like the PSFS where items are self-selected.

Data Synthesis and Analysis

We qualitatively summarized the results for each measurement property and described the range and median values where appropriate. We also planned, if possible, to conduct a meta-analysis using pooled estimates for each measurement property.

We then compared the *summarized results* against the "updated criteria for good measurement properties". For each measurement property, if more than 75% of studies met the "sufficient" (or "insufficient") criteria such as ICC > 0.70, this was rated as "+" (or "-"). If less than 75% of studies met the "sufficient" (or "insufficient") criteria, this was rated as "inconsistent" (±) and no Grading of Recommendations Assessment, Development and Evaluation (GRADE) assessment was done.

Finally, we graded the *certainty* of summarized evidence using the modified GRADE approach.[47,48,68] The modified GRADE considers 4 factors to downgrade the certainty of evidence from high to moderate, low, or very low. The first factor is the *risk of bias* (-1 serious, -2 very serious, or -3 extremely serious). A serious risk of bias (-1 level) is present if there are multiple studies of doubtful quality or only 1 study of adequate quality; very serious (- 2 levels) if there are multiple studies of inadequate quality or only 1 study of doubtful quality; and extremely serious (- 3 levels) if there is only 1 study of inadequate quality. Second, *inconsistency* (-1 serious or -2 very serious) considers whether most of the data

TABLE 2 Review Team's Hypotheses for Validity and Responsiveness

Measurement Property	Hypothesis tested
Construct validity	1. Correlation of PSFS scores and instruments measuring function/disability would be ≥ 0.50.
	2. Correlation of PSFS scores with scores on instruments measuring related constructs (eg, pain, HRQOL) would be > 0.30.
	3. Correlation of PSFS scores with instruments measuring less/unrelated constructs (eg, mental function)would be < 0.30.
Responsiveness	1. Correlation of *change* scores in PSFS and instruments measuring function/disability would be ≥ 0.50.
	2. Correlation of *change* scores in PSFS and instruments measuring related constructs would be ≥ 0.30.
	3. Correlation of *change* scores in PSFS and instruments measuring unrelated constructs would be < 0.30.
	4. Mean change scores would be greater in "improved" patients than "stable" patients by at least SDC* (based on external criterion such as GROC scale).
	5. Effect sizes in "improved" groups would be higher than "stable" groups.
	6. AUC would be ≥ 0.70
	7. The correlation of PSFS with GROC scales would be greater than 0.3*

Abbreviations: GROC, Global Rating of Change; HRQOL, health-related quality of life; PROMIS, Patient-Reported Outcomes Measurement Information System; PSFS, Patient-Specific Functional Scale; SDC, smallest detectable change.
**These represent post hoc changes made to a priori hypothesis or additional hypothesis added during data extraction. We did not have hypotheses on the magnitude of difference in Effect Sizes between "changed" and "not changed" groups since there are no guidelines regarding this. We reviewed that correlation of PSFS with GROC scales would be greater than 0.3 since study authors did not report if GROC scales were specific to changes in physical function. We added that change scores should differ by at least SDC between changed and unchanged groups.*
Note: The review hypotheses were based on previous literature describing correlation of physical function measures in musculoskeletal conditions (including generic measures such as the PROMIS Physical function) with comparator measures of physical function, pain, and general health.[14,33,51,93]

support the summarized result. If there was 1 study with inconsistent results, we rated this as serious inconsistency; more than 1 study was considered very serious inconsistency. Third, *imprecision* refers to the total sample size of the included studies (-1 [Total n = 50-100], or -2 [Total n < 50]). The final factor *indirectness* (-1 serious or -2 very serious) is applied if study results are from another population but was not relevant to our study.

For studies that used the PSFS as an outcome measure, we qualitatively synthesized findings on patient population, frequency, and purpose of use of the PSFS.

Subgroup Analyses

Included articles were classified as musculoskeletal or nonmusculoskeletal based on the health conditions studied. More specific subgroups were also used where indicated (mixed musculoskeletal, upper extremity, neck, back, lower extremity, snake envenomation, Parkinson's disease, community-dwelling elderly, chronic obstructive pulmonary disease, and coronary artery disease).

RESULTS

We found a total of 2 014 articles, of which we included 299 articles (**FIGURE 2**). The supplementary material provides a list of articles excluded during full-text screening. We did not find any additional studies during reference screening. After adding the 13 studies from the previous system-

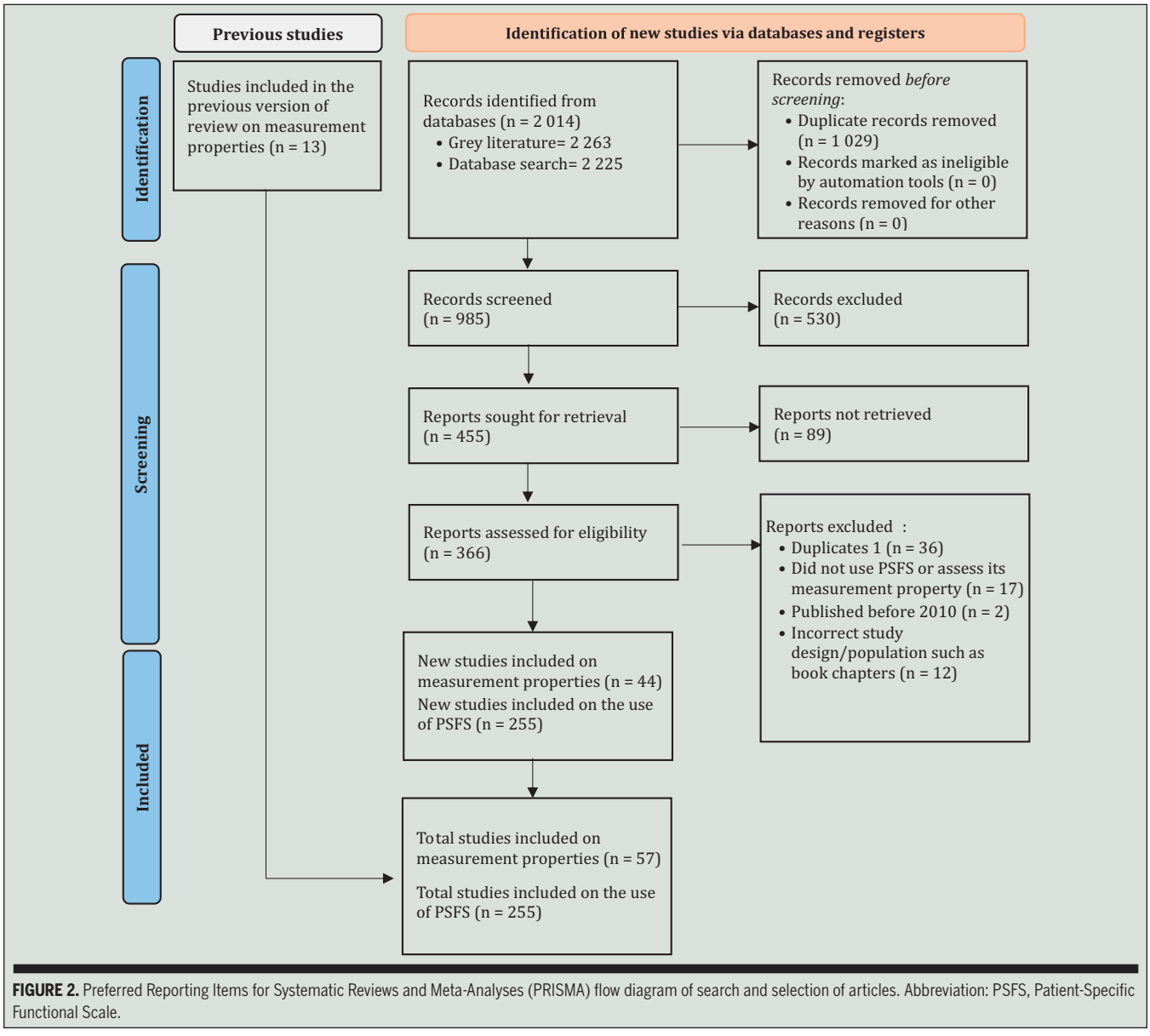

FIGURE 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of search and selection of articles. Abbreviation: PSFS, Patient-Specific Functional Scale.

TABLE 3 Summary of Results for Reliability, Measurement Error and Minimum Important Change of the PSFS

	Summarized Results for the Reliability of the PSFS				Summarized Results for the Measurement Error of the PSFS				MIC	
Patient Population With Subsamples	**Combined sample size**	**Median time interval (Range)**	**ICC (range of point estimates)**	**Rating and certainty of evidence (GRADE)**	**Sample size**	**SEM summarized results (range)**	**SDC summarized results (range)**	**Rating and certainty of evidence (GRADE)**	**Sample size**	**Median MIC value (range)**
Musculoskeletal problems **Mixed musculoskeletal problems**[1,53,75]	2 studies, 91 participants[53,75]	1 wk	ICC = 0.83-0.89	+ *Low*[a]	2 studies, 91 participants [53,75]	0.63 and 0.9	1.46 and 2.1	+ *Low*[a]	3 studies, 1799 participants[1,53,75]	2.0 (1.25-2.3)
Upper extremity conditions **Upper limb problems,**[7,28,60] **shoulder problems,**[35] **lateral epicondylitis**[57,58] **hand OA**[73,92]	8 studies, 339 participants[7,28,35,57,58,60,73,92]	5 d (1 d-3 wk)	ICC = 0.71-0.91	+ *Moderate*[b]	5 studies, 261 participants[7,28,35,60,92]	0.35-0.90	0.97-3.0	- *Moderate*[c]	4 studies, 383 participants[1,28,35,74]	1.3 (1.16-2.0)
Lower extremity conditions **Knee OA,**[10] **conditions of the knee,**[13] **amputations**[60]	3 studies, 113 participants[10,13,71]	6 d (2 d-1 wk)	ICC = 0.73-0.87	+ *Moderate*[b]	2 studies, 80 participants [13,71]	0.62 and 0.96	1.5 and 2.24* *Converted from 11.2 change on 50 point scale	+ *Low*[a]	1 study, 546 participants[1]	2.3 (1 study only)
Conditions of the spine: neck **Cervical radiculopathy,**[15,96] **neck pain with or without radiculopathy,**[54] **neck pain without radicular symptoms**[8,9,94]	5 studies, 152 participants	2 wk (1 d-4 wk)	ICC = 0.82-0.98* *1 study reporting 0.17[96]	+ *Moderate*[c]	2 studies, 60 participants[15,96]	1.4-1.5 (radiculopathy only)	2.1-3.3 samples with cervical radiculopathy	- *Very low*[d]	2 studies, 60 participants[15,96]	2.1 (2.0-2.2)
					2 studies, 62 participants[54,8,9]	0.28-0.43 (with or without radiculopathy)	0.64 and 0.99	+ *Low*[a]	1 study, 89 participants[1]	2.3 (1 study)
Conditions of the spine: back **Lumbar spinal stenosis,**[16] **low back pain**[77] **(acute**[17] **or chronic low back pain with or without radicular symptoms**[44]**)**	4 studies, 150 participants[16,17,44,77]	5 wk (24 h-6 wk)	ICC = 0.85-0.97* *0.59 reported in 1 study	+ *Low*[a]	2 studies, 45 participants[16,44]	0.5 and 1.03	1.4 and 2.40	± *NA*	7 studies, 516 participants[1,16,17,29,44,77,95]	2.0 (0.8-2.9)
Snake envenomation[24,84] ***Same participants**[24,84]	2 studies, 86 participants	8 d	ICC = 0.83 (0.72-0.79)	+ *Very low*[e]	(2 studies, 86 participants)	0.73 (1 study)	1.04 (1 study)	- *Very low*[e]		1 (1 study)
Parkinson's disease[12]	1 study, 26 participants	3-5 d	ICC = 0.72 (0.47-0.86)	+ *Very low*[f]	NR	NR	NR	NR	NR	NR
Community-dwelling elderly[42]	1 study, 31 participants	48 hours	ICC = 0.82 (0.67-0.91)	+ *Very low*[g]	1 study, 31 participants	1 (1 study)	2.8(1 study)	?	NR	NR
COPD[61]	1 study, 12 participants	3 wk	ICC = 0.55 (-0.27-0.85)	- *Very low*[g]	1 study, 12 participants	1 (1 study)	2 (1 study)	?	NR	NR

Table continues on page 268.

TABLE 3 Summary of Results for Reliability, Measurement Error and Minimum Important Change of the PSFS (continued)

	Summarized Results for the Reliability of the PSFS				Summarized Results for the Measurement Error of the PSFS				MIC	
Patient Population With Subsamples	Combined sample size	Median time interval (Range)	ICC (range of point estimates)	Rating and certainty of evidence (GRADE)	Sample size	SEM summarized results (range)	SDC summarized results (range)	Rating and certainty of evidence (GRADE)	Sample size	Median MIC value (range)
Stable coronary artery disease[91]	1 study, 42 participants	1 wk	ICC = 0.72	+ *Very low*[g]	NR	NR	NR	NR	NR	NR

Abbreviations: COPD, chronic obstructive pulmonary disease; GRADE, Grading of Recommendations Assessment; GROC, Global Rating of Change; ICC, intraclass correlation coefficient; MIC, minimum important change; NA, not applicable; NR, not reported; OA, osteoarthritis; PSFS, Patient-Specific Functional Scale; SDC, smallest detectable change; SEM, standard error of measurement.
GRADE assessments:
[a]*Evidence downgraded -1 due to Serious Risk of Bias and -1 Imprecision (multiple studies of doubtful quality or 1 study of adequate quality and total sample size between 50 and 100).*
[b]*Evidence downgraded -1 due to Serious Risk of Bias (multiple studies of doubtful quality or 1 study of adequate quality).*
[c]*Evidence downgraded -1 due to Inconsistency (1 study with inconsistent result).*
[d]*Evidence downgraded -1 due to Serious Risk of Bias, -1 due to Imprecision, and -1 due to Inconsistency (multiple studies of doubtful quality or 1 study of adequate quality, total sample size between 5 and 100, and 1 study with inconsistent result).*
[e]*Evidence downgraded -2 due to Very Serious Risk of Bias and -1 due to Imprecision (multiple studies of inadequate quality or only 1 study of doubtful quality, total sample size between 50 and 100).*
[f]*Evidence downgraded - 3 due to extremely serious Risk of Bias and -2 due to Imprecision (only 1 study of inadequate quality and total sample size < 50).*
[g]*Evidence downgraded -2 due to Very Serious Risk of Bias and -2 due to Imprecision (multiple studies of inadequate quality or only 1 study of doubtful quality, total sample size < 50).*
Note: MIC values are derived from "smallest change" group on GROC when multiple values were reported.

atic review,[30] we had a total of 57 studies on measurement properties of the PSFS and 255 articles on the use of the PSFS. Description of included studies on measurement properties is available in **SUPPLEMENTAL TABLE S1**.

Studies on Measurement Properties (Including Acceptability and Feasibility)

We had substantial to almost perfect agreement between reviewers for risk of bias and GRADE assessments (Cohen's kappa 0.61 and 0.81, respectively). We were unable to conduct the planned meta-analyses due to heterogeneity in patient population, comparator instruments used, retest durations, and quality of studies.

Reliability

Twenty-eight studies with sample sizes ranging from 6 to 99 participants studied the test-retest reliability of the PSFS. A summary of results for each subgroup is presented in **TABLE 3**, and data for individual studies with the risk of bias assessment are in **SUPPLEMENTAL TABLE S2**.

Based on qualitatively summarized data (**TABLE 3**), we found that test-retest reliability of the PSFS is sufficient (ie, ICC values > 0.70) in all conditions studied; however, this is only supported by evidence of low-to-moderate certainty (musculoskeletal conditions) and very low certainty (all other conditions).

Measurement Error

Twenty-one studies reported either the SEM or the smallest detectable change (SDC) values for the PSFS (**SUPPLEMENTAL TABLE S2**). Based on qualitative summary (**TABLE 3**), the SEM values of the PSFS were less than or equal to 1 for most reported conditions, except for cervical radiculopathy, where it was 1.5. The SDC values ranged from 1.5 points to about 3 points, but these were not consistently lower than MIC values (moderate to very low certainty).

Construct Validity

Twenty-two studies assessed the construct validity of the PSFS (**SUPPLEMENTAL TABLE S3**).

TABLE 4 Summary of Results for the Construct Validity of the PSFS Based on Hypothesis Testing (ie, Comparison With Other Outcome Measures)

Patient Population Subsamples	Sample Size	Construct Approach (Outcome Measures)	Summarized Correlation (Range)†	Review Team's Hypothesis	Criteria for Good Measurement Properties (+/-/±/?)	GRADE Assessment
Musculoskeletal conditions **Various conditions**[2,75]	2 studies, 1 278 participants[2,75]	**Pain** NPRS	0.26 and 0.32	Correlation > 0.30; Higher pain = lower function	±	*Not applicable*
Upper extremity conditions Upper limb disorders,[2,7] shoulder disorders,[60] hand OA,[73,92] proximal humeral fracture,[41] upper limb nerve injury,[59] snakebite on upper extremity[24]	9 studies, 748 participants[2,7,24,36,41,59,60,73,92]	**Function** QuickDASH, DASH, SPADI, WOOS, UEFI	0.08-0.51	Correlation > 0.50; Higher function on other scales = higher function on PSFS	-	*Moderate*[a]
	4 studies, 368 participants[41,59,60,73]	**Pain** NPRS, SPADI pain subscale, VAS	0.14-0.36	Correlation > 0.30; Higher pain = lower function	-	*Moderate*[a]
	3 studies, 146 participants[41,73,92]	**Strength** Grip strength, Pinch Strength	0.05-0.25	Correlation > 0.30; Greater strength = more function	-	*High*
	2 studies, 215 participants[59, 73]	**General Health Status** EQ-5D, SF-36 physical domain	0.20-0.33	Correlation > 0.30; Higher self-reported health = greater function	±	*Not applicable*
Lower extremity conditions Conditions of the knee,[13] lower limb conditions in older adults,[42] snake bite on lower extremity,[24] lower extremity problems,[2] knee OA[25]	4 studies, 769 participants[2,13,24,25]	**Function** SF-36 Physical Function, WOMAC function, LEFS	0.22-0.83	Correlation > 0.50; Higher function on other scales = higher function on PSFS	-	*Moderate*[a]
	2 studies, 120 participants[13,25]	**Mental Function/health** SF-36	0.16-0.23	Correlation < 0.30; Better mental health = higher physical function	+	*High*
Conditions of the spine: neck Acute/chronic neck pain[2,54,89,94]	4 studies, 342 participants[2,54,89,94]	**Function/Disability** Neck Disability Index	0.35-0.82	Correlation > 0.50; Higher function on other scales = higher function on PSFS	+	*Moderate*[a]
Conditions of the spine: back Low back pain irrespective of duration,[2,29,36,38,75,77] acute low back pain[17]	7 studies, 666 participants[2,17,29,36,38,75,77]	**Function** ODI, RMQ	0.28-0.67	Correlation > 0.50; Higher function on other scales = higher function on PSFS	±	*Not applicable*
Others Community-dwelling older adults	1 study, 31 participants[42]	**Balance and Function** ABC Scale and LEFS	0.68 (for ABC Scale) and 0.81 (for LEFS)	Correlation > 0.50; Greater balance = higher function	+	*Low*[b]
Others Adults with Parkinson's disease	1 study, 26 participants[12]	**Function** MDS-UPDRS, PDQ-39 GROC	At 4 mo: 0.001-0.23	Correlation > 0.50; Higher function on other scales = higher function on PSFS	-	*Very low*[c]
Others People 12 y or older envenomed by snake on extremity	1 study, 86 participants[24]	**Function** SF-36 physical function, PROMIS-10	0.68-0.83	Correlation > 0.50; Higher function on other scales = higher function on PSFS	+	*Low*[d]
Others Worker's compensation claimants	1 study, 294 participants[26]	**Function** SF-36 physical function, Pain Disability Index	0.44-0.53	Correlation > 0.50; Higher function on other scales = higher function on PSFS	±	*Not applicable*

Abbreviations: ABC, Activity Balance Confidence; DASH, Disabilities of the arm, shoulder and hand questionnaire; EQ-5D, EuroQOL 5D; GRADE, Grading of Recommendations Assessment, Development and Evaluation; GROC, Global Rating of Change; LEFS, Lower Extremity Functional Scale; MDS-UPDRS, Movement Disorders Society Modified Unified Parkinson's Disease Rating Scale; NPRS, Numeric Pain Rating Scales; OA, Osteoarthritis; ODI, Oswestry Disability Index; PDQ, Parkinson's Disease Questionnaire; PROMIS, Patient-Reported Outcomes Measurement Information System; RMQ, Roland-Morris Questionnaire; SF-36, Short Form 36 Health Survey; SPADI, Shoulder Pain and Disability Index; UEFI, Upper Extremity Functional Index; WOMAC, Western Ontario and McMaster Universities Osteoarthritis Index; WOOS, Western Ontario Osteoarthritis of the Shoulder Index.

†Summary correlations are presented as magnitude only without direction (ie, +ve or –ve correlation) since the direction of correlations differs based on which scale is used. The magnitude of correlation with direction for individual scales is available in the supplementary material. The Risk of Bias assessment and Criteria for good measurement property ratings are based on both magnitude and direction of correlation.

GRADE assessments:

[a]*Evidence downgraded -1 due to Inconsistency (1 study with inconsistent result not supporting the summary).*

[b]*Evidence downgraded -2 due to Imprecision (total sample size < 50).*

[c]*Evidence downgraded -3 due to Extremely serious risk of bias and -2 due to Imprecision (only 1 study of inadequate quality and total sample size < 50).*

[d]*Evidence downgraded -1 due to serious Risk of Bias (only 1 study of adequate quality).*

TABLE 5 SUMMARY OF RESULTS FOR RESPONSIVENESS OF PSFS

	Construct Approach (ROC Curves)				Construct Approach (Correlation With Change Scores on Comparator Instruments)				
Population group	**Sample size**	**Time Intervals**	**Summarized AUC (Range)**	**Rating and Certainty of Evidence**	**Sample Size**	**Time Intervals**	**Construct & Comparator Instruments**	**Summarized Correlation Coefficients (Range)**	**Rating and Certainty of Evidence**
Mixed musculoskeletal **5 studies (10 197 participants)**[1,2,53,56,75]	3 studies (1 346 participants)[1,53,75]	6-18 d[75] Variable[1,53]	0.70-0.88	+ *High*	3 studies (8 955 participants)[2,56,75]	6-18 d,[75] variable[2,56]	**Pain** NPRS	0.38-0.55	+ *High*
					2 studies (1 285 participants)[2,75]	6-18 d,[75] variable[2]	**Global Change** GROC/GPE	0.49-0.71	+ *High*
Upper extremity conditions **11 studies (1 563 participants)** Upper extremity problems,[1,2,28,38] Shoulder disorders,[35,36,60,74] Hand OA,[92] Humeral Fracture,[41] Dupuytren's disease,[87] Upper limb amputation,[71] Mastectomy patients,[19] Hand surgery[45]	5 studies (650 participants)[1,28,35,60,74]	4-6 wk[35,60], 3 mo[74] Variable[1,28],	0.67-0.89	+ *Moderate*[a]	6 studies (610 participants)[2,28,35,36,74,92]	1 week,[92] 4-6 wk,[35,36] 3 mo,[74] variable[2,28]	**Function** SPADI[35,36] UEFI[2,28] DASH[92] QuickDASH[74]	0.45-0.59* (1 study reporting 0.13 not included[92])	± *Not applicable*
					3 studies (364 participants)[28,35,74]	4-6 wk,[35] 3 mo,[74] variable[28]	**Pain** NPRS	0.32-0.55	+ *High*
					3 studies (284 participants)[35,60,74]	4 wk,[61] 4-6 wk,[35] 3 mo[74]	**Global Change** GROC/GPE	0.32-0.47	+ *High*
Lower extremity conditions **7 studies (1 892 participants)** Lower extremity problems,[1,55] Knee conditions,[13] Knee OA[10,25,50,78]	1 study (546 participants)[1]	Variable	0.88 (0.83-0.94)	+ *High*	3 studies (866 participants)[2,10,78]	1 month,[78] 3 mo[10] and 1 y[10], variable[2]	**Function** WOMAC,[10] LEFS[2,78]	0.12-0.54	- *Moderate*[a]
					2 studies (188 participants)[10,13]	2-3 wk,[13] 3 mo,[10] 1 y[10]	**Global Change** GROC/GPE	0.37-0.77	+ *High*
Spine: neck **7 studies (650 participants)** Neck pain,[1,2,54] Neck pain without radiculopathy,[89] Cervical radiculopathy,[15,96] Chronic whiplash[76]	4 studies, 425 participants[1,15,76,96]	3 wk,[15] 4 wk,[96] 6 wk,[76] Variable[1]	0.71-0.99	+ *High*	2 studies (122 participants)[2,89]	1-4 wk,[89] Variable[2]	**Function** NDI	0.57 and 0.83	+ *High*
					1 study (39 participants)[15]	3 wk	**Pain** NPRS	0.80	+ *Low*[b]
					3 studies (274 participants)[15,54,76]	3 wk,[15,54] 6 wk[76]	**Global Change** GROC/ GPE	0.40-0.82	+ *High*
Spine: back **13 studies (2 628 participants)** Low back pain,[1,2,27,29,38,77] Chronic thoracic or lumbar pain,[44,52,95] Lumbar stenosis, Acute or subacute low back pain[17,36,66]	7 studies (2 249 participants)[1,16,17,27,29,44,95]		0.72-0.88	+ *High*	4 studies (1 013 participants)[2,36,38,52]	2 wk,[38] 12 wk,[36] 1 y[36] Variable[2,52]	**Function** ODI[2] RMQ[36,38,52]	0.40-0.70	± *Not applicable*
					1 study, 78 participants[38]	1-15 d	**Pain** VAS	0.59	+ *Moderate*[c]
					5 studies, 1 242 participants[16,17,27,66,95]	2 wk,[17] 6 wk,[66] 3-6 mo,[27] 1 y[95]	**Global Change** GROC	0.34-0.69	+ *High*
Adults with Parkinson's disease **1 study (26 participants)**					1 study, 26 participants[12]	4 mo	**Function** MDS-UPDRS and PDQ-39	0.06-0.19	- *Very low*[d]
Snake bite **1 study (86 participants)**	1 study, 86 participants[24]	2 wk	0.70; (0.61-0.73)	+ *Moderate*[c]					

Abbreviations: AUC, area under the curve; DASH, Disabilities of the Arm, Shoulder and Hand Questionnaire; GRADE, Grading of Recommendations Assessment; GROC, Global Rating of Change; GPE, Global Perceived Effect; LEFS, lower extremity functional scale; MDS-UPDRS, Movement Disorders Society Modified Unified Parkinson's Disease Rating Scale; NPRS, Numeric Pain Rating Scales; OA, osteoarthritis; ODI, Oswestry Disability Index; PDQ, Parkinson's Disease Questionnaire; PROMIS, Patient-Reported Outcomes Measurement Information System; RMQ, Roland-Morris Questionnaire; ROC, receiver operating characteristic; SPADI, Shoulder Pain and Disability Index; UEFI, Upper Extremity Functional Index; WOMAC, Western Ontario and McMaster Universities Osteoarthritis Index.
GRADE assessments:
[a]Evidence downgraded -1 due to Inconsistency (1 study whose results do not meet the hypothesis).
[b]Evidence downgraded -2 due to Imprecision (total sample size < 50 to 100).
[c]Evidence downgraded -1 due to Imprecision (total sample size between 50 and 100).
[d]Evidence downgraded -3 due to extremely serious Risk of Bias and -2 due to Imprecision (only 1 study of inadequate quality and total sample < 50).
Note: Studies with values that appear as outliers have been reported separately without including in the range. We only considered studies that reported either ROC analysis or correlation of change scores with comparator instruments as evidence of responsiveness. Where authors reported effect sizes for groups based on the global rating of change scales (GROC), we treated this as subgroup comparison. In line with COSMIN recommendations, if authors reported effect sizes without a priori hypothesis, these were not included in final summary.

Only 29% of these studies met our hypotheses that PSFS would have correlations of greater than 0.50 with measures of physical function (**TABLE 4**). Hence, we found "insufficient" evidence for the validity of the PSFS as a measure of physical function (mostly moderate certainty).

Content Validity

Content validity of the PSFS was evaluated in 10 studies[3,6,11,12,21,41,53,73,85,87] by mapping patient-reported activities against the International Classification of Functioning, Disability and Health (ICF). A median of 95% (80%-100%) of all patient-reported activities fell within the "Activities and Participation" component of the ICF. Mannberg et al reported that 62% of the activities reported in the PSFS were common with those found in Western Ontario Osteoarthritis of the Shoulder index.[41]

Responsiveness

Thirty-nine studies evaluated the responsiveness of the PSFS (**SUPPLEMENTAL TABLE S4**). We found moderate-to-high certainty evidence suggesting that the PSFS had sufficient responsiveness in all studied musculoskeletal conditions and adults with snakebite on an extremity (**TABLE 5**). Several studies concluded that the PSFS demonstrates comparable responsiveness to region-specific outcome measures such as Upper Extremity Functional Index and Neck Disability Index (NDI).[1,2,28,61,74,76] The PSFS was more responsive than the NDI[15] and the Roland Morris Questionnaire (RMQ),[17,27,44] especially among those with low activity limitations.

Interpretability

Fifteen studies reported MIC values for the PSFS in different health conditions (**SUPPLEMENTAL TABLE S2**). A summary of MIC values for each health condition is presented in **TABLE 3**. Median MIC values ranged from 1 point to 3 points. These values are based on anchor-based longitudinal approach (as recommended by COSMIN).

Thirteen studies reported analysis of floor or ceiling effects (or both) for the PSFS. Four studies (33%) each found floor effects[36,41,55,84] and ceiling effects[2,24,41,84] at follow up, while 8 studies (67%) each reported no floor effects[2,17,35,54,60,70,74,87] or ceiling effects.[35,36,54,55,60,70,74,87]

Acceptability and Feasibility

The PSFS took participants and therapists approximately 4 minutes (SD = 1.9) to complete[13] and reduced participant burden compared to longer region-specific questionnaires.[59] Experts and patients reported no problem in understanding and responding to the PSFS and said it was comprehensive.[7,85] In some studies, participants had difficulty identifying activities: 40% could identify 5 activities[13]; 71% could nominate 3 activities[28]; and 5%-8% of patients were unable to identify problems.[10,87] To overcome these difficulties, researchers provided an example list which patients found helpful.[35,85] Other modifications included reversing response options (0 = "no difficulty" and 10 = "impossible to perform the activity"), which was preferred by 10 out of 11 participants.[87] Telephone-administered PSFS was as valid and reliable as in-person administered PSFS.[84]

Studies Using the PSFS as an Outcome Measure

The PSFS was used in 255 studies in participants presenting with 87 unique health conditions (**SUPPLEMENTAL TABLE S5**). It was mostly used in conditions of the back (n = 70) and lower extremity (n = 53). It was also used without prior validation in conditions including meralgia paresthetica,[69] Ehlers-Danlos Syndrome,[67] Juvenile Idiopathic Arthritis,[37] dizziness,[81,90] postpolio syndrome,[31] stroke,[8] whiplash disorder,[40,79] temporomandibular dysfunction,[18] complex regional pain syndrome,[63] muscle tension dysphonia,[86] and diabetes.[39,82] Five studies reported using the PSFS with children and adolescents, with some as young as 7 years old.[43,72,80,97,98] In 2 studies, the parents completed the PSFS as proxy for their child.[4,37]

DISCUSSION

We summarized results from 57 studies of the measurement properties of the PSFS and 255 studies in which the PSFS was used. We found that the PSFS has "sufficient" test-retest reliability (very low–to–moderate certainty), "insufficient" construct validity as a measure of physical function (low-to-moderate certainty), and "sufficient" responsiveness except in upper extremity and back conditions, where evidence was inconsistent (moderate-to-high certainty). While there is continued use of the PSFS in neurological populations such as stroke (and, less commonly, in children and adolescents), there is currently no evidence on its measurement properties in these populations.

Our findings regarding test-retest reliability and responsiveness are consistent with those in the 2010 systematic review.[30] In contrast with 2 systematic reviews,[30,49] we found that the construct validity of the PSFS is uncertain. One potential reason for this discrepancy is the difference in the definitions of validity (we used COSMIN guidelines to define construct validity). In addition, we defined an a priori hypothesis, making our results more transparent.

Given the patient-specific nature of the PSFS, the low correlations with comparator PROMs may not discount the PSFS as a valid tool but may instead demonstrate that the PSFS measures physical function in a different way than condition-specific measures. The PSFS maps primarily to the "Activities" component of the ICF (80%), but it also covers the impairment and participation domains of physical function (20%).[20] Also studies report that only around 60% of PSFS responses are found in comparator PROMs.[5,41] When completing the PSFS, people are likely to select activities that are highly *specific* to them and are *most* affected (eg, "pulling up an anchor" or "line dancing").[25] This may result in lower baseline scores on the PSFS and low-to-moderate correlations with fixed-item instruments (which include activities *most commonly* affected). This may explain why correlations are weak at baseline (0.08 to 0.56) but larger at follow-up (0.58-0.90) in the same studies, and why the PSFS has comparable and sufficient responsiveness.[2,24,29,41,78,92] Future studies may consider head-to-head comparisons of the PSFS with fixed-length instruments and computer-adaptive measures such as Patient-Reported Outcomes Measurement Information System (PROMIS)[22].

Limitations

We followed the latest international guidelines for conduct of systematic reviews and used an extensive search strategy. However our findings have limitations. First, we only considered *improvement* in respondents' functional status. Floor effects may be observed in the PSFS in progressive neurological diseases.[13] Second, there was a lack of clear guidelines for risk of bias assessment for some measurement properties. Where this was the case (such as selecting time cutoffs for reliability assessment), we made decisions based on the collective expertise of the research team.

Third, there is a lack of a clear distinction in the literature between the constructs of acceptability and feasibility. Some concepts, such as "time to complete" and "mode of administration", seem to contribute to both constructs. We have reported results for acceptability and feasibility together in the absence of stronger guidelines.

Fourth, we could only assess content validity descriptively because the COSMIN tool for assessing content validity is not applicable to flexible measures like the PSFS. Lastly, our conclusions are limited to the health conditions specified in the summary tables.

Clinical Implications

While the PSFS is a feasible, easy-to-use, reliable, and responsive measure, the underlying construct remains unclear. These findings are based on studies primarily in musculoskeletal conditions, and the scale needs further evaluation before clinical use in neurological and cardiopulmonary conditions.

CONCLUSION

The PSFS is reliable and responsive in most musculoskeletal conditions and is reliable in very few nonmusculoskeletal conditions such as Parkinson's disease and coronary artery disease (very low–to–moderate certainty). However its construct validity, i.e., the underlying construct measured, is uncertain. Future studies evaluating its psychometric properties in nonmusculoskeletal conditions are also warranted.

KEY POINTS

FINDINGS: There was very low–to–moderate certainty that the Patient-Specific Functional Scale (PSFS) is reliable and responsive in musculoskeletal conditions and reliable in very few nonmusculoskeletal conditions. However, its construct validity remains uncertain.

IMPLICATIONS: The PSFS has clinical utility in musculoskeletal conditions. However, what construct is assessed by the PSFS remains unclear. There is currently insufficient evidence to support use of PSFS in nonmusculoskeletal conditions.

CAUTION: Our findings are limited to selected health conditions we report (including several musculoskeletal conditions, coronary artery disease, Parkinson's disease, chronic obstructive pulmonary disease, and snake bite on extremity).

STUDY DETAILS

AUTHOR CONTRIBUTIONS: AP and JHA were involved in the conception of the study; all authors were involved in the design of the study. All authors were involved in screening, data extraction, risk of bias, and quality assessment of studies; AP and 1 other member of the review team performed each of these steps independently. AP synthesized the results, which were checked by JHA, RW, YP, DCR, and SS. AP drafted the manuscript. All authors provided feedback on

the manuscript and approved the final version.

DATA AVAILABILITY: Data from the systematic review can be requested from the corresponding author.

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Physical Activity Promotion: Moving From Talking the Talk to Walking the Walk

When a patient enters the treatment room, musculoskeletal clinicians expect to provide advice and interventions related to the specific health condition for which the patient is seeking care. However, do clinicians also see the larger picture related to the patient's overall health? We argue that most clinicians do *not*.[3]

Physical inactivity is a leading risk factor for mortality, and it is a modifiable contributor to morbidity and mortality.[10] In contrast, regular physical activity (PA) is associated with health benefits, particularly for those with musculoskeletal disorders.[1] Promoting PA is within the scope of physical therapists who position themselves as movement experts. National and international documents including the World Health Organization Global Action Plan on Physical Activity recognize the social imperative of clinicians to promote PA.[10] While over 90% of clinicians believe that promoting PA is a part of their professional role, data from around the globe reveal that PA promotion *is not routinely practiced by clinicians* (**APPENDIX 1**).

When it comes to patients' health, how do clinicians move from talking the talk to walking the walk? The roots of this problem are systemic, and cross-sector changes are needed. However, there are things that clinicians and clinical organizations can do to maximize physical therapists' impact on the health of society. Factors influencing clinicians' PA promotion are known, yet there is a lack of clear guidance for how best to implement PA promotion in routine practice. We discuss key theoretical domains and concrete behavior change techniques (BCTs) that clinicians and organizations can implement to facilitate more frequent and effective PA promotion. Our objective is to assist clinicians and organizations to think differently about PA promotion, incorporate PA promotion into clinical practice, and do better at promoting PA by improving the clinician-patient encounter.

SYNOPSIS: Despite its demonstrated efficacy, physical activity (PA) promotion is not routinely practiced by clinicians. We provide recommendations to improve PA promotion in routine clinical practice by (1) improving clinicians' capacity through enhancing knowledge, skills, and confidence and (2) improving organizations' capacity through building PA promotion pathways.

Promoting PA in routine clinical practice is urgently needed to maximize clinicians' impact on the health of society. *J Orthop Sports Phys Ther 2022;52(5):236-242. doi:10.2519/jospt.2022.10859*

KEY WORDS: *behavior change, health promotion, physical activity, physical therapy, social responsibility*

BUILDING CLINICIAN KNOWLEDGE

Across the PA promotion literature, three domains are identified as targets to improve the implementation of PA promotion into routine clinical practice: knowledge, skills, and confidence. We share strategies to assist the clinician in reframing how to incorporate PA into clinical practice.

Think of PA Promotion as Behavior Change Rather Than Patient Education

Because individuals generally do not respond positively to being told what to do, we recommend considering PA promotion as a behavior change conversation.[8] Doing so shifts the narrative from providing information to a patient-centered, action-oriented approach. Behavior change requires clinicians to understand that providing information alone is often insufficient to catalyze change.[8] Readiness to change is a modifiable state, and determining how ready a patient is to adopt regular PA is paramount to setting a goal and supporting a patient to change.[6] Finding a connection between PA and the individual's values, goals, strengths, and future desired state will promote readiness to change and the development of autonomy for the behavior, which can sustain the behavior long term.[6]

Recognize BCTs as Active Strategies to Use When Promoting PA

BCTs are observable, replicable, irreducible, and theory-based strategies that are

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the *active ingredients* in interventions to change behavior.[7] BCTs can increase PA (**TABLE 1**).[4] We recommend promoting PA while using multiple BCTs over using a single BCT in isolation. Particularly, including at least one BCT from the "Goals and planning" or the "Feedback and monitoring" domain is associated with greater success in PA promotion.

Understand PA Guidelines as Targets to Guide Goal Setting

Despite knowing that PA guidelines exist, clinicians have struggled to articulate specific targets around which to frame PA promotion. We recommend understanding local and global PA guidelines as a starting point to open a discussion and further tailor goals and strategies to improve PA by patients. Start where the patient currently is and build slowly toward the guidelines. Most guidelines recommend an average of 150-300 minutes of moderate-to-vigorous–intensity PA per week or 75-150 minutes of vigorous-intensity PA per week in addition to 2 days per week of resistance training to achieve substantial health benefits.[2] More recent guidelines have included the focused message "sit less, move more" to encourage reducing sedentary time as even modest changes to PA offer meaningful health benefits.[2]

BUILDING CLINICIAN SKILLS

Once a clinician agrees to implement PA promotion into clinical practice, they need to also adopt measures to improve its effectiveness and applicability for patients. Two key skills (communication and time management) can improve PA promotion.[9]

Communication Skills

Clinicians must get better at incorporating BCTs into interactions with patients. Person-centered and autonomy supporting counseling approaches are the most successful.[5] We recommend considering using motivational interviewing, nonviolent communication, and appreciative inquiry as they are all paradigms within which BCTs can be employed (**APPENDIX 2**).[4] **TABLE 2** provides a sample dialogue of a person-centered and autonomy supportive brief intervention to improve a patient's PA.[4] Clinicians can use this sample dialogue as a framework for incorporating PA promotion conversations in routine practice.

Time Management Skills

Lack of time is a consistent barrier to PA promotion. However, among those who regularly promote PA, time is not reported as a barrier. What explains this contrast? Qualitative data revealed that regular PA promoters weave conversations and BCTs into routine clinical practice through brief interventions that do not impede other clinical responsibilities or require additional time. Overcoming the perceived time barrier by clinicians may be achieved by discussing and demonstrating PA promotion methods that are compatible with the time constraints of typical practice. One approach is incorporating PA promotion conversations while engaging in hands-on techniques or while the patient is performing exercises.

BUILDING CLINICIAN CONFIDENCE

Clinicians say they want to build their own confidence in PA promotion. Two strategies show promise in this domain.

Seeing PA Promotion Modeled Will Improve Clinicians' Confidence

Clinicians who do not regularly promote PA may benefit from seeing it modeled by those who are experienced in promoting PA. Modeling how to incorporate PA promotion in the context of providing manual therapy or other exercise interventions is one way to demonstrate knowledge and skill acquisition. Observing successful incorporation of these skills into modeled routine encounters will demonstrate a paradigm in which PA promotion is seamlessly integrated to enhance patients' health and outcomes.

Practicing PA Promotion Will Improve Clinicians' Confidence

Role-playing PA promotion scenarios provide opportunities to practice behavior change conversations and on how to incorporate BCTs. Follow-up sessions with clear instructions, and written and verbal feedback can enhance the stickiness of the learning and can facilitate knowledge translation into clinical practice. Clinical managers can organize sessions to observe and practice peer modeling as one way to build confidence.

BUILDING CAPACITY IN ORGANIZATIONS

Because behaviors are influenced by complex systems that may be outside the clinician's control, strategies that account for organizational factors are also needed. Key approaches to improve organizational capacity to promote PA are listed below.

Integrate Screening for Baseline PA Into Every Clinical Consultation

Consistently screening for baseline PA is a strong predictor of PA promotion.[9] There are a number of PA screening tools that are not burdensome to incorporate into workflows, and just the act of screening for baseline PA may be a key avenue to increase PA promotion in routine clinical practice (**TABLE 3**). Clinical managers might consider integrating screening for baseline PA as a standard of care in every initial consultation.

Incorporate PA Promotion Audit and Feedback Mechanisms

Measuring clinicians' PA promotion frequency and quality, and reporting these results back to the clinician may be a key opportunity for organizations seeking to improve PA promotion. Audit and feedback is effective for changing clinician behavior and is most effective when it is delivered by a supervisor or a trusted colleague, is presented frequently, and includes specific goals and action plans.[5] Many organizations already include audit

TABLE 1 Recommended Behavior Change Techniques to Incorporate Into PA Promotion Interventions[7]

Cluster	BCT	Description	Example
Goals and planning	Goal setting (behavior)[a]	Provide opportunities to make choices from a collaboratively devised menu of behavioral options and autonomous goals. Agree to a SMART (specific, measurable, achievable, realistic, timebound) goal defined in terms of the behavior to be achieved.	Agree to a daily walking goal (eg, 20 min).
	Problem solving[a]	Analyze or prompt the person to analyze factors influencing the behavior and generate or select strategies that include overcoming barriers and/or increasing facilitators.	Prompt the patient to identify barriers preventing them from engaging in physical activity such as: What is getting in the way of being regularly physically active? How can you problem-solve to reduce these barriers?
	Action planning[a]	Prompt detailed planning of performance of the behavior (should include context, frequency, duration, and intensity).	Encourage planning the performance of physical activity at a particular time (eg, during lunch) on certain days of the week. The Commitment, Activation, Taking steps model can be useful: What do you intend to do specifically? (C) What would be a good first step? (A) When and how will that step be taken? (T)
	Commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behavior.	Ask the patient to use an "I will" statement to affirm a strong commitment (using words such as "strongly" or "committed") to engage in physical activity.
Feedback and monitoring	Feedback on behavior[a]	Monitor and provide information or evaluative feedback on performance of behavior.	Discuss the patient's experiences with physical activity and have them reflect on their successes.
	Self-monitoring of behavior[a]	Prompt monitoring of progress, skill level, or performance such as suggesting options for monitoring tools/means and metrics for success, including steps in the direction of behavior change.	Encourage patient to utilize activity log, fitness tracker, or pedometer to reinforce success and self-awareness.
Natural consequences	Information about health consequences	Provide information about health consequences of performing a behavior.	Provide information that physical activity can largely prevent or ameliorate the symptoms of musculoskeletal conditions by adopting a healthy lifestyle that includes regular PA. The more physically active a person is, the less likely they are to suffer from conditions including low back pain and osteoarthritis.
	Information about emotional consequences	Provide information about emotional consequences of performing a behavior.	Provide information about the positive benefits of physical activity to: Reduce feelings of depression and stress; Enhance your mood and overall emotional well-being; Increase your energy level; Improve sleep.
Comparison of behavior	Demonstration of the behavior	Provide an observable sample of the performance of the behavior, directly in person or indirectly via video, etc, for the patient to aspire to or imitate.	Demonstrate to the patient what the physical activity behavior will look like either in-person or via audiovisual means (eg, YouTube video).
Associations	Prompts/cues	Introduce or define environmental or social stimulus with the purpose of prompting or cuing the behavior.	The patient agrees to put running shoes in front of the back door as a reminder to go for a walk.
Repetition and substitution	Habit formation	Prompt rehearsal and repetition of the behavior in the same context repeatedly so that the context elicits the behavior	Ask the patient about what habits they engage in before or after the planned PA. Prompt the patient to stack the new habit onto a previously existing habit.
	Graded tasks[a]	Set optimal initial challenge, making tasks increasingly difficult but achievable until behavior is performed.	Ask the patient what a reasonable long-term PA goal is, and then ask about a reasonable first step toward that goal. Gradually progress PA toward goal to provide structure and minimize future failure.
Identity	Framing/reframing	Suggest the deliberate adoption of a perspective or new perspective on behavior in order to change cognitions or emotions about performing the behavior.	Ask the patient if they might think of the PA discussed as a step toward their goals rather than as increasing activity.
Self-belief	Focus on past successes	Prompt the patient to think about previous successes at behavioral changes to build confidence for change.	Ask the patient "What have you learned from previous attempts to change?"

Abbreviation: BCT, behavior change technique.
[a]*Indicate BCTs that have been supported across systematic reviews and meta-analyses examining BCTs and PA promotion.*

TABLE 2 Example Person-Centered, Autonomy Supporting Brief Intervention to Improve Physical Activity in Routine Clinical Practice[8]

Step	Example
Ask permission to discuss a behavior.	"I noticed you indicated that you are not regularly physically active on your intake forms. Would it be okay if we discussed this behavior today?"
Ask about history with the behavior.	"Can you tell me about a time in your life when you were regularly physically active? What was different in your life then?"
Ask about the benefits of the behavior.	"What benefits do you see to being regularly physically active? If you were regularly physically active now, how would your life be different?"
Ask about the barriers to the behavior.	"What is getting in the way of being regularly physically active? How can you problem-solve to reduce these barriers?"
Identify environmental and social supports.	"What resources do you have that would help you to be regularly physically active? Are there individuals in your daily life who would support your efforts to be regularly physically active?"
Assess importance of change.	"How important do you believe it is for you to become more physically active?" (0-10 scale)
Assess confidence to change.	"How confident are you today that you could become more physically active? (0-10 scale)
Ask if patient is ready to take a first step.	"What would a first step toward being more regularly physically active be?"
Create a SMART goal.	Example goal: I will ask my spouse to walk with me after dinner for 30 min on Monday and Wednesday evening next week.
Inquire about confidence in achieving goal.	"How confident are you that you will accomplish this goal?" (0-10 scale)
Express appreciation for the patient's willingness to make positive changes.	"I'm thankful that we were able to have this conversation today. I appreciate your creation of a plan to become more physically active and I am confident that you will be successful."
Arrange for follow-up/accountability.	"Next visit I look forward to hearing about your initial success with your plan to get more physically active."

TABLE 3 Comparison of self-report physical activity screening tools

Tool	Description	Target Age Group	Measurement Properties Assessed
Physical Activity and Sedentary Behavior Questionnaire (PASB-Q)	A 7-item questionnaire measuring MVPA in the last week, frequency of muscle strengthening exercises per week, perceived aerobic fitness, and sedentary behaviors	Adults and older adults	Reliability, construct validity
Rapid Assessment of Physical Activity (RAPA)	A 9-item questionnaire with the response options of yes or no to questions covering the range of levels of PA from sedentary to regular vigorous PA, as well as strength training and flexibility	Older adults	Reliability, criterion validity
Physical activity vital sign (PAVS)	2 questions: • "How many days during the past week have you performed physical activity where your heart beats faster and your breathing is harder than normal for 30 minutes or more?" • "How many days in a typical week do you perform activity such as this?"	Adults	Construct validity, concurrent validity, criterion validity
Single question (Milton et al)[11]	"In the past week/past month, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your breathing rate? This may include sport, exercise, and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that may be part of your job."	Adults	Reliability, responsiveness, criterion validity

Abbreviations: MVPA, moderate-to-vigorous physical activity; PA, physical activity.

and feedback mechanisms for quality improvement initiatives. Incorporating PA promotion into existing audit and feedback mechanisms may be a feasible and sustainable opportunity for clinical managers to consider.

SUMMARY

Physical activity is projected to decrease in the general population by an additional 20% by 2050. Promoting PA in routine clinical practice is urgently needed to maximize clinicians' impact on the health of society. It is paramount that clinicians implement PA promotion into routine practice. We shared suggestions to enhance clinicians' knowledge, skills, and confidence to promote PA, and opportunities for organizations to reinforce

this behavior in care pathways. It is time for clinicians to walk the walk in addition to talking the talk when it comes to promoting PA in clinical practice.

Key Points

1. Physical activity (PA) is associated with significant health benefits for those with musculoskeletal disorders.
2. PA promotion is effective to improve patients' PA.
3. Clinicians infrequently promote PA in routine clinical practice.
4. Building clinicians' capacity can occur through enhancing knowledge, skills, and confidence.
5. Building organizations' capacity can occur through incorporating baseline PA screening and audit and feedback mechanisms into workflows. ◉

STUDY DETAILS

AUTHOR CONTRIBUTIONS: Dr Rethorn contributed to the manuscript design and the first draft of the manuscript. All authors contributed to writing the manuscript, project management, and approval of the manuscript for publication.

DATA SHARING: There are no data available from this manuscript.

PATIENT AND PUBLIC INVOLVEMENT: Patients were not directly involved in this manuscript.

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APPENDIX 1

SELECTED GLOBAL PHYSICAL ACTIVITY PROMOTION PRACTICES BY PHYSICAL THERAPISTS

Author (year)	Country	PA Promotion Practices
Abaraogu et al (2016)[1]	Nigeria	56% regularly assess patients' PA levels
Aweto et al (2013)[2]	Nigeria	36% regularly promote PA
Barrett et al (2013)[3]	UK	34% regularly assess patients' PA levels
Freene et al (2017)[4]	Australia	55% regularly promote PA
Kunstler et al. (2018)[5]	Australia	43% regularly promote PA
Lowe et al (2017)[6]	UK	65% regularly assess patients' PA levels
Rea et al (2004)[7]	United States	54% regularly promote PA
Rethorn et al (2021)[8]	United States	13% regularly assess patients' PA levels 42% regularly promote PA
Shirley et al (2010)[9]	Australia	54% regularly promote PA
Tuna et al (2020)[10]	Turkey	16% regularly promote PA

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APPENDIX 2

EVIDENCE-BASED RESOURCES TO FACILITATE BEHAVIOR CHANGE

Books

- Rollnick S, Miller WR, Butler CC. *Motivational Interviewing in Health Care, Helping Patients Change Behavior*. Guilford Press; 2007.
- Moore M, Tschannen-Moran B. *Coaching Psychology Manual*. Lippincott Williams & Wilkins; 2015.
- Prochaska JO, Prochaska JM. *Changing to Thrive, Using the Stages of Change to Overcome the Top Threats to Your Health and Happiness*. Simon and Schuster; 2016.
- Ryan RM, Deci EL. *Self-Determination Theory, Basic Psychological Needs in Motivation, Development, and Wellness*. Guilford Publications; 2017.

Online resources

- Physioplus course - Integrating physical activity into clinical practice and the community
- Embracing Health Coaching in Clinical Practice webinar
- Physiotherapy Alberta Health Coaching Toolkit
- BMJ Learning – Motivational interviewing in brief consultations
- National Board for Health & Wellness Coaching
- Society for Behavioral Medicine

Training courses

- Motivational Interviewing Network of Trainers
- Wellcoaches School of Coaching
- Vanderbilt University Health Coaching Certificate Program
- Duke University Integrative Health Coach Program
- Mayo Clinic Wellness Coach Program
- Georgetown University Certificate in Health & Wellness Coaching

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Low Back Pain in Low- and Middle-Income Countries, Part 1: The Problem

Low back pain (LBP) is a common disabling and costly health condition. It has been the leading cause of "years lived with disability" globally for the past 3 decades. The disability due to LBP has increased up to 57% and is predicted to further rise in the coming decades.[5] Data related to LBP are predominantly published from high-income countries, while no high-quality population-level data are available from low- and middle-income countries (LMICs).[16]

LMICs constitute low-income and upper/lower middle-income countries classified by the World Bank as countries with a per capita gross national income of less than $12 535. LMICs are home to 85% of the world's population. Currently, 62% of the world's population living in poverty live in the middle-income countries alone. The proportion of the people living in poverty in LMICs is projected to grow as a result of the ongoing COVID-19 pandemic, conflicts and violence, and climate change–related crises. Health systems in LMICs are often overwhelmed by communicable and noncommunicable diseases, of which LBP is not considered a priority.

In this first paper, we summarize the extent of the problem: the prevalence, disability, and costs of LBP in LMICs.

SYNOPSIS: Low back pain (LBP) is the leading cause of disability in the low- and middle-income countries (LMICs), imposing substantial burden on individuals and health systems. The societal burden of LBP in LMICs challenges the United Nations' Sustainable Development Goals of eliminating poverty and improving health and well-being by pushing the people with the lowest socioeconomic position on the planet to greater poverty and more disability. This *LBP in LMICs Series* aims to (1) summarize the current state of LBP management in LMICs, (2) propose what best care for LBP in LMICs may look like, and (3) provide policy recommendations and a call to action. In this first paper, we summarize the extent of the problem: the prevalence, disability, and costs of LBP in LMICs. *J Orthop Sports Phys Ther 2022;52(5):233-235. doi:10.2519/jospt.2022.11145*

KEY WORDS: *chronic pain, developing countries, low back pain, musculoskeletal disorders, musculoskeletal pain, pain management*

Prevalence in LMICs

High-quality prevalence data on LBP are lacking for many LMICs.[6] The most recent Global Burden of Disease study had no high-quality primary prevalence data for LMICs—it predominantly consisted of modeled (estimated) data.[16] Only 9 of 488 (2%) country-level prevalence reports were from South Asia, although it is home to almost one quarter of the world's population.[16] South Asia is also home to the highest number of people with LBP (96.3 million) among all regions of the world.[18]

Systematic reviews of available prevalence studies have identified high LBP prevalence rates in LMICs. One-year prevalence and point prevalence of LBP in adults in Africa are 57% and 39%, respectively.[11] The prevalence of nonspecific LBP in Latin America ranged from 9% to 81%, with 1-year prevalence up to 67%.[4,12] Although LBP is commonly considered a condition of adults, an increasing number of studies have reported LBP in children and adolescents in LMICs,[12,14] with up to 58% adolescents reporting LBP in Africa.[11] Lifetime LBP prevalence in the LMICs can be as high as 93%, with greater prevalence in working populations.[12,14]

A majority of published studies face limitations, such as (1) inconsistent use of LBP definition; (2) survey of 1 specific occupation group (eg, nurses) or in 1 geographical location; and (3) use of clinical samples rather than community samples, producing nonreliable and nonrepresentative data.[11,14] The overarching reason for these limitations relates to a lack

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of funding for resources to conduct high-quality population-level studies.[11] There is a need for high-quality research to estimate prevalence and identify risk factors for LBP using accepted LBP definitions, reliable and valid questionnaires, and population-based representative samples. One way to achieve this efficiently is by incorporating LBP-related questions within the existing national health surveys.[7,8]

Disability

In 2017, in South Asia alone, 10.8 million years were lived with disability, the highest of the 21 world regions.[18] In addition, Southern Latin America, another LMIC region, had the highest age-standardized years lived with disability rate (1404 per 100 000 persons) in the same year.[18] *The Lancet* series on LBP emphasized that the overall LBP-related disability is rising globally[1,5] and that these increases are most pronounced in the LMICs.[9] The reasons for increasing disability include the rapid increase in population aging in LMICs, concomitant increase in coexisting noncommunicable diseases, and increasing use of expensive and potentially harmful procedures for LBP that might lead to iatrogenic pain and disability (eg, surgeries causing chronic postsurgical pain).[13,15] Further, LBP disability is known to be associated with lower socioeconomic positioning, psychological distress, and physically demanding occupations, all increasing an individual's risk of LBP disability in LMICs.[1,5]

Costs

Direct and indirect costs of LBP at the individual, societal, and health system levels are currently unknown in LMICs[5] other than Brazil.[2] LBP-related costs in Brazil from 2012 to 2016 were equivalent to US $460 million, with estimated societal costs of US $2.2 billion.[2] Extensive use of costly, ineffective, and potentially harmful procedures and interventions is common in LMICs; this causes personal harm and financial strains on society.[3] For example, 100% of patients visiting an orthopaedic clinic in India received imaging for their LBP[3] despite the recommendations against routine imaging, while more than 880 000 diagnostic images were ordered in Brazil in 4 years from 2012 to 2016.[2] Between 1995 and 2014, the total number of spinal surgeries and associated costs in Brazil increased by 260% and 540%, respectively,[17] and are further rising in 2021.[10] Alarmingly, 46% to 90% of clinicians in India and Brazil recommend bed rest for LBP, also against current treatment recommendations.[5] This causes productivity losses and financial burden in the working population who is the most susceptible to LBP.

The societal burden of LBP challenges the United Nations' Sustainable Development Goals of eliminating poverty and improving health and well-being by pushing the people already living in low socioeconomic conditions to greater poverty and more disability. Resources are more limited in LMICs than in high-income countries, and these should be utilized carefully for effective health system spending and strategic research.

Why This Series?

Physical therapists are at the forefront of treating LBP and can be leaders in providing effective, inexpensive, and safe care. As a leading physical therapy journal, the *Journal of Orthopaedic & Sports Physical Therapy* can reach patients, clinicians, researchers, and policy makers in LMICs and promote positive clinical and policy reforms to support the best possible evidence-based LBP care.

This LBP in LMICs Series aims to

(1) summarize the current state of LBP management in LMICs,
(2) propose what best care for LBP in LMICs may look like, and
(3) provide policy recommendations and a call to action.

Alongside this series, the authors aim to develop a "Consortium for Low Back Pain in the Low- and Middle-Income Countries"—a leadership group that will aim to develop research agenda and identify appropriate models of care for delivering high-quality LBP care in the LMICs in the first instance and as an urgent priority. If you are a person with a lived experience of LBP or a clinician, researcher, policy maker, or other stakeholder associated with LBP in LMICs and would like to be involved in this series and beyond, connect with the lead author (saurab.sharma@unsw.edu.au) directly. The consortium members will collaborate to help achieve the aforementioned aims of the consortium. They will also have opportunities to either lead or collaborate on research that addresses high-priority LBP research questions in the LMICs. Consider using the hashtag #BackPainLMICs on social media to join the conversation and spread the word to facilitate this agenda.

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