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Development of an Item Bank for a Health-Related Quality of Life Measure in Spondyloarthritis

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ABSTRACT. ***Objective.*** Health-related quality of life (HRQOL) is an important aspect in the management of chronic diseases such as spondyloarthritis (SpA). A promising approach to reduce respondent burden when measuring HRQOL is the use of shorter patient-reported outcome measures (PROMs) delivered using computerized adaptive tests (CATs). However, the lack of an item bank that covers the entire continuum of the HRQOL domain impedes the development of CATs to measure HRQOL among patients with SpA. We aimed to develop an item bank for an HRQOL measure among patients with SpA based on the items from existing validated PROMs.

Methods. This study is guided by the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) and Patient Reported Outcomes Measurement Information System (PROMIS) standards. Relevant articles were retrieved from PubMed, Embase, and PsycINFO (Ovid) databases. Items from existing PROMs were binned and winnowed according to the facets of HRQOL in the World Health Organization (WHO) quality of life framework.

Results. We identified 147 relevant articles, from which written permission was obtained for including 31 PROMs into the item bank. PROMs contained 1039 items, which underwent binning and winnowing. This resulted in 968 items covering 23 domains of HRQOL in the WHO framework, with the number of items within each domain ranging from 1 to 453.

Conclusion. We created an item bank to measure HRQOL among patients with SpA using items from validated PROMs. This set can provide the foundation for the development of CATs to measure HRQOL among patients with SpA.

Key Indexing Terms: health-related quality of life, patient-reported outcome measures, spondyloarthropathies, systematic review

Spondyloarthritis (SpA) refers to a clinically heterogeneous group of diseases including ankylosing spondylitis (AS), nonradiographic axial spondyloarthritis (nr-axSpA), psoriatic arthritis (PsA), inflammatory bowel disease–associated SpA, and undifferentiated SpA (USpA).[1] SpA causes significant pain, fatigue, and mobility impairment,[2-4] all of which may bring about significantly reduced health-related quality of life (HRQOL).[5,6] The World Health Organization (WHO) defined quality of life (QOL) as "individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment."[7] Numerous instruments have been developed to measure HRQOL among patients with SpA.[8] However, most of the instruments have been developed using classical test theory (CTT) and include a common item set regardless of the

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respondent's HRQOL level.[8] Therefore, instruments developed using CTT may result in significant respondent burden and low precision.[9]

A novel approach to overcome the limitations of CTT may be to use item response theory (IRT) to create new patient-reported outcome measures (PROMs) for measuring HRQOL in SpA using computerized adaptive tests (CATs). CATs enable brief assessment by selecting questions from an item bank that provide the maximum amount of information based on previous responses,[10] thus minimizing respondent burden.[11,12] In order to achieve higher precision, it is recommended to include items that cover the entire continuum of the domain intended to be measured.[13] Therefore, the first step to develop a CAT is to create an item bank consisting of questions measuring the domain. A possible way to create an item bank is by using questions from existing instruments, as seen in other studies[14,15] and in the field of rheumatoid arthritis.[16,17]

However, to date, there are no item banks available for the measurement of HRQOL among patients with SpA. As numerous PROMs have been developed and validated for use in the measurement of HRQOL in SpA,[8] an item bank consisting of the most representative items may improve the relevance and precision of measurement.[18] The candidate items can serve as the basis for future research for development of CATs to measure HRQOL in SpA. Therefore, this study aims to develop an item bank for HRQOL measure based on the items from existing validated PROMs. The findings from this study may allow researchers to develop CATs to measure HRQOL more precisely among patients with SpA.

METHODS

This systematic review was guided by the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement.[19] Standards published by the Patient Reported Outcomes Measurement Information System (PROMIS) committee were adapted for the development of the item bank.[20] Ethics approval was not required for this study.

Search strategy. We used the same search strategy and results as described in our previous systematic review.[8] Briefly, the PubMed, Embase, and PsycINFO (Ovid) databases were searched for any articles published from inception until June 30, 2017. A search strategy with 3 components (disease terms, construct of interest, and measurement properties) was used (Supplementary Tables S1-S3, available from the authors upon request). The search records were downloaded into Endnote X7 (Clarivate Analytics), and duplicate articles were removed. An updated search was performed in PubMed for the period of 2017 to 2022.

Article selection. All titles and abstracts were screened independently by 2 reviewers (KP and JQL). A third reviewer (YHK) was consulted when disagreement arose between the 2 reviewers. For articles that were potentially relevant, the full text of these articles was independently reviewed by the same 2 reviewers. Articles were included if they were full-text original publications in English that validated PROMs containing items relevant to facets of HRQOL as defined by WHO[7] among patients with SpA. Articles were excluded if the PROMs were completed by proxy, or if they were unpublished articles, conference abstracts, expert opinions, or narrative reviews. Animal studies, case studies, and non-English studies were also excluded.

Data extraction. The following data were extracted from the articles by 2 reviewers: (1) study population characteristics, including sample size and age; (2) disease characteristics of the study population, including disease type and disease duration; and (3) PROM characteristics, including name of PROM, number of items, and response options.

Identification of existing PROMs for inclusion. For the assessment of PROMs for inclusion, reviewers obtained information regarding the PROM through internet searches. Copies of the shortlisted PROMs were retrieved either from sources available to the public (ie, official websites or research publications), or by requesting copies from the developers or study investigators of these PROMs. Permission was obtained from the study investigators for inclusion of the PROM into the item bank. Where possible, permission from the PROM developers was sought when the study investigators were not in a position to provide consent due to claims of intellectual property. After the initial contact, 2 follow-up reminder emails were sent to study investigators who did not respond. We did not exclude PROMs based on study design or sample size.

The final list of PROMs for which permission was obtained was evaluated. Item characteristics extracted consisted of (1) context: instructions for answering the item; (2) response options: response choices from which the respondent is asked to select; (3) recall period: duration of time that the respondent was to consider in answering the question; and (4) instrument of origin.

Item classification (binning). Item classification, or binning, refers to a systematic process for grouping items according to meaning and specific latent construct. The number of items that would adequately represent a bin was not predetermined, as the purpose of this process was to identify sufficient items that encompass the meaning of the bin and to eliminate unnecessary redundancy in the pool of items.[13]

Two independent reviewers (KP and JQL) were involved in the item classification (binning) process. Items that covered 2 different domains were categorized in the 2 respective domains. For example, the item, "In the past week, to what degree has fatigue interfered with your ability to work" would be binned into both "energy and fatigue" as well as "working capacity" domains. A 2-stage process was carried out for binning. First-order binning was completed at the level of the domains, guided by the 25 facets of HRQOL in the WHOQOL framework (eg, overall HRQOL and general health, pain and discomfort, energy and fatigue).[21] Second-order binning was completed at the level of the subdomains, where the items were further categorized based on their qualitative characteristics. A third reviewer (JKP) was consulted in case of disagreement during the item classification (binning) process. Generic and disease-specific PROMs were not treated differently during the binning process. The WHOQOL framework was chosen because it was developed in 15 international field centers simultaneously, making it potentially applicable cross-culturally.[21]

Item selection (winnowing). The process of winnowing aims to narrow the large pool of items down to a representative set of items, by identifying item characteristics that would either include or exclude them from the item bank based on the definition of the domains.[13] Two reviewers (JKP and KP) independently assessed each of the bins, and the following criteria were then used to eliminate items: (1) content of the item was inconsistent with the definition of HRQOL; (2) item was semantically redundant; (3) item's wording was confusing or ambiguous; and (4) item was open ended, which increases the difficulty of implementation. The criteria for item selection were adapted from a similar study.[22]

After the 2 reviewers had completed the item selection independently, a third reviewer (YHK) was consulted to identify the items that best represented each domain, as well as the items for removal.

RESULTS

Identification of existing PROMs for inclusion. The detailed search results and characteristics of the articles from the original search have been reported elsewhere.[8] After the update search, we identified a total of 147 relevant articles to be included in the systematic review after title/abstract screening, full-text review, and hand-searching of relevant articles (Figure). The studies were

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mostly conducted among patients with AS (n = 78), followed by PsA (n = 58; Table 1). Review of the included articles identified 80 unique PROMs measuring QOL in SpA (Supplementary Table S4, available from the authors upon request).

After obtaining written permission from study investigators and/or PROM developers, 31 PROMs were included in the item bank, as presented in Table 2. The other PROMs were excluded due to a lack of consent (Supplementary Table S5, available from the authors upon request). A total of 1039 items were collated from the included PROMs.

Item evaluation. At the binning stage, an interim item bank containing 1039 items was created. At the winnowing stage, 71 items were removed (57 were found to be inconsistent with the definition of QOL, 3 were found to be semantically redundant with previous items, 6 had ambiguous wording and 5 items were open ended). This resulted in 968 items covering 23 domains, with the number of items within each domain ranging from 1 to 453 (Table 3). The "activities of daily living" domain had the highest number of items (453 items), followed by "mobility" (159 items), "pain and discomfort" (95 items), "participation in and opportunities for recreation/leisure activities" (84 items), and "negative feelings" (64 items). There was only 1 item identified each for "home environment" and "financial resources" domains. There was no item identified for "physical safety and security" and "spirituality/religion/personal beliefs" domains. Binned and winnowed items that were granted approval by the study investigators or PROM developers to be openly listed in the item bank are presented in Supplementary Table S6 (available from the authors upon request).

DISCUSSION

This systematic review summarizes the process of developing an item bank for measuring HRQOL in SpA. To the best of our knowledge, this is the first systematic review to collate the items from various PROMs measuring HRQOL in SpA into an item bank. Increasing emphasis placed on patient-centered care[23,24] reflects increasing reliance on PROMs including QOL.[25,26] Despite the potential benefits of PROMs, their use is frequently dismissed in clinical settings, which may be partially attributed to the impracticality of administering paper-based questionnaires in a time-pressured environment.[27-29] Administration using a CAT algorithm may serve as a quicker and potentially more relevant and accurate method of assessing patient-reported outcomes.[10] This study identified 968 items covering 23 domains of HRQOL based on the WHOQOL framework. In our study, the "activities of daily living" had the highest number of items, followed by "mobility," "pain and discomfort," "participation in and opportunities for recreation/leisure activities," and "negative feelings." This

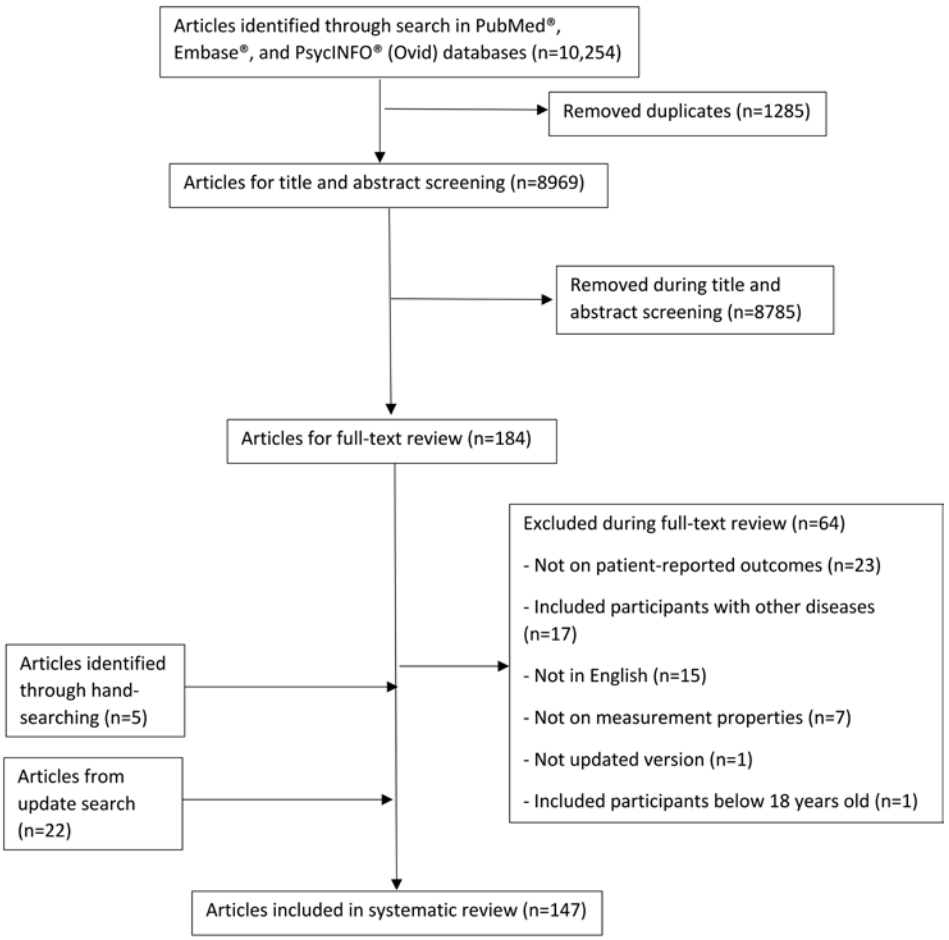

Figure. Flow chart of the systematic literature review. Adapted and republished with permission from Png et al.[8]

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Table 1. Characteristics of articles included (N = 147).

	No. of Articles (%)
Disease type[a]	
SpA in general	7 (4.8)
AxSpA	12 (8.2)
Nonradiographic axSpA	2 (1.4)
Ankylosing spondylitis	78 (53.1)
Psoriatic arthritis	58 (39.5)
IBD-SpA	1 (0.7)
Undifferentiated SpA	3 (2.0)
Mean disease duration[b], yrs	
0 to ≤ 10	42 (28.6)
> 10 to ≤ 20	63 (42.9)
> 20	10 (6.8)
Sample size	
< 30	5 (3.4)
30-49	9 (6.1)
50-99	39 (26.5)
≥ 100	92(62.6)
Mean age[b], yrs	
≤ 40	29 (19.7)
> 40 to ≤ 50	67 (45.6)
> 50 to ≤ 60	33 (22.4)

[a] Some articles evaluated > 1 disease type, thus the sum is > 147. [b] Some articles either did not report the disease duration or presented values in the form of median (range). These articles were not included in the reporting of mean disease duration. AxSpA: axial spondyloarthritis; IBD-SpA: inflammatory bowel disease–related spondyloarthritis; SpA: spondyloarthritis.

is similar to findings from our previous review on the top-ranked QOL domains of relevance for patients with SpA.[30]

However, it should be noted that there is only 1 item for each of the "home environment" and "financial resources" domains. We also did not identify any items for WHOQOL "physical safety and security" and "spirituality/religion/personal beliefs" domains. Input from qualitative studies with patients and expert panels from various countries may be useful to determine whether the above-mentioned domains are relevant to HRQOL among patients with SpA. The item bank to measure HRQOL in SpA from our current study is dynamic—new items for new domains could potentially be generated from qualitative studies, and items from existing PROMs may be included into the item bank once permission is granted.

Moving forward, the item bank should be reviewed and revised before being calibrated using IRT. The items that underwent binning and winnowing originated from different PROMs, and were validated in different countries, languages, and sociocultural contexts. Recognizing the differences among the items, the item revision process would be prudent to facilitate administration of the items as a coherent test. The item bank from our study is open to inclusion of new domains, and inclusion of better items to represent new domains as our understanding of HRQOL in SpA improves.

This study has several strengths. Three databases, as well as sensitive search filters, were used to capture as many potentially relevant articles as possible. As the original search strategy ended on June 30, 2017, we performed an update search in January 2022, and

Table 2. List of patient-reported outcome measures (PROMs) included in the item bank.

PROM	Generic or Specific to SpA
ASAS EF	Disease-specific
ASAS HI	Disease-specific
Body chart	Disease-specific
DASH	Generic
DFI	Disease-specific
EASi-QoL	Disease-specific
EDAQ	Generic
FACIT-F	Generic
FAIR	Generic
FLARE	Generic
HAQ-S	Disease-specific
ILBPDI	Generic
IPAQ	Generic
Jenkins Sleep Scale	Generic
LFIS-RA	Generic
MAF	Generic
MDHAQ	Generic
MFI	Generic
mSQUASH	Disease-specific
Multidimensional PROM[a]	Disease-specific
PsAID	Disease-specific
QuAD	Generic
Qualisex	Generic
RLDQ	Disease-specific
SASPA	Disease-specific
SPS-6	Generic
s-SRPQ	Disease-specific
ULS-8	Generic
VLA	Generic
WPAI:SpA	Disease-specific
5T-PRO	Generic

[a] Certain questions were excluded as irrelevant to QOL. 5T-PROs: Patient-Reported Outcomes Thermometer–5-item scale; ASAS EF: Assessment of Spondyloarthritis international Society Environmental Factors; ASAS HI: Assessment of Spondyloarthritis international Society Health Index; DASH: Disabilities of Arm, Shoulder, and Hand questionnaire; DFI: Dougados Functional Index; EASi-QoL: Evaluation of Ankylosing Spondylitis Quality of Life; EDAQ: Evaluation of Daily Activity Questionnaire; FACIT-F: Functional Assessment of Chronic Illness Therapy–Fatigue; FAIR: Fear Assessment in Inflammatory Rheumatic Diseases; FLARE: Flare Assessment in Rheumatoid Arthritis; HAQ-S: Health Assessment Questionnaire for the Spondyloarthropathies; ILBPDI: Istanbul Low Back Pain Disability Index; IPAQ: International Physical Activity Questionnaire; LFIS-RA: Leeds Foot Impact Scale for Rheumatoid Arthritis; MAF: Multidimensional Assessment of Fatigue; MDHAQ: Multidimensional Health Assessment Questionnaire; MFI: Multidimensional Fatigue Inventory; mSQUASH: modified Short Questionnaire to Assess Health-Enhancing Physical Activity; PsAID: Psoriatic Arthritis Impact of Disease; QOL: quality of life; QuAD: Questionnaire for Arthritis Dialogue; RLDQ: Revised Leeds Disability Questionnaire; SASPA: Stockerau Activity Score for Psoriatic Arthritis; SpA: spondyloarthritis; SPS-6: 6-item Standford Presenteeism Scale; s-SRPQ: Short Form of the Social Role Participation Questionnaire in Patients with Ankylosing Spondylitis; ULS-8: 8-item short form UCLA Loneliness scale; VLA: Valued Life Activity; WPAI:SpA: Work Productivity and Activity Impairment questionnaire – Ankylosing Spondylitis.

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Table 3. Summary of domains and number of items.[a]

Domains	No. of Items	Most Representative Item
Overall QOL and general health	13	How would you describe your general health today?
Physical		
Pain and discomfort	95	How much spine pain have you had over the past week?
Energy and fatigue	44	I have energy.
Sleep and rest	28	I sleep badly at night.
Psychological		
Positive feelings	5	I feel like doing all sorts of nice things.
Thinking, learning, memory, and concentration	8	I find it hard to concentrate.
Self-esteem	10	During the past week, how much of the time have you felt embarrassed or self-conscious because of your AS?
Body image and appearance	3	Circle the number that best describes the skin problems, including itching you felt due to your psoriatic arthritis during the last week.
Negative feelings	64	Sometimes my condition makes me feel like giving up.
Level of independence		
Mobility	159	I am not able to walk outdoors on flat ground.
Activities of daily living	453	During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder, or hand problem?
Dependence on medication or treatments	8	You increased your doses of pain killers or antiinflammatory medication over several consecutive days.
Working capacity	39	In the past week, did you have any difficulty doing your work in your usual way?
Social relationships		
Personal relationships	15	During the past week, how much did your AS interfere with family life or friendships?
Social support	10	My friends understand me.
Sexual activity	20	I have lost interest in sex.
Environment		
Physical safety and security	0	Not applicable
Home environment	1	I modify my home and work environments.
Financial resources	1	I have experienced financial changes because of my rheumatic disease.
Health and social care: availability and quality	8	I have difficulties getting worsening of my disease acknowledged by a healthcare professional.
Opportunities for acquiring new information and skills	4	How much physical difficulty do you have attending school or continuing education?
Participation in and opportunities for recreation/leisure	84	In the past week, to what degree has fatigue interfered with your ability to engage in leisure and recreational activities?
Physical environment: pollution/noise/traffic/climate	3	I think that my disease was triggered by something in the environment, like pollution.
Transport	28	I have difficulty operating the pedals in my car.
Spirituality/religion/personal beliefs		
Spirituality/religion/personal beliefs	0	Not applicable

[a] Sum of number of items is more than 968 as some items were grouped into > 1 domain. AS: ankylosing spondylitis; QOL: quality of life.

included additional PROMs obtained from the updated search. In addition, the rigor of this study was enhanced by following the PRISMA statement[19] and PROMIS standards.[20]

There are some limitations to our study. First, we included only articles published in the English language. However, there were only 15 foreign-language articles excluded during the full-text review. Second, the item bank does not include items from PROMs for which we did not receive consent for inclusion or were unable to contact the study investigators and/or PROM developers. However, our item bank has captured most of the facets of HRQOL in the WHOQOL framework, and the excluded PROMs did not capture any unique domains of HRQOL. Additionally, while we have adopted the WHOQOL framework in this study, there are other frameworks and classification systems for HRQOL in the literature. A related concept may be health and functioning, such as that of the WHO International Classification of Functioning, Disability, and Health (ICF).[31] The ICF framework has been used in several studies as the foundation to explore HRQOL.[32-34] Future studies can explore describing the biopsychosocial health content of the PROMs using the ICF framework.[35]

In conclusion, this study has identified and collated the items from 31 unique PROMs measuring HRQOL in SpA into an item bank through a systematic review. Researchers will be able to select appropriate items from the item bank for the creation of new PROMs. Future research may consider revising and

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reviewing the items through cognitive interviews, calibrating the items through IRT, and developing a CAT to measure HRQOL in SpA more precisely.

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