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BRIEF REPORT

A Novel Qualitative Study Assessing Patient-Reported Outcome Measures Among People Living with Psoriatic Arthritis or Ankylosing Spondylitis

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ABSTRACT

Introduction: Patient-reported outcome measures (PROMs) are used to capture patient perspectives in disease assessment. The objective of this study was to capture feedback about commonly used PROMs for spondyloarthritis (SpA) through semi-structured group discussions with individuals diagnosed with psoriatic arthritis (PsA) or ankylosing spondylitis (AS). The goal was to identify PROM content that most resonated with patient experiences and is therefore suitable for implementation in SpA clinical practice.
Methods: Semi-structured tasks and probes were designed to elicit qualitative patient feedback on several general health and disease-specific PROMs. During a series of in-person and telephone meetings, participants with PsA or AS were asked to identify content that resonated with them and to identify items that may not have captured their personal experiences living with their disease. Both individualized and small group review and concept elicitation were captured after participant review of PROMs.
Results: Both PsA and AS participants identified concepts that reflected their experiences living with a chronic disease, including fatigue, isolation, depression, inter-personal relationships, and sexual intimacy. Constructs incorporated into existing PROMs, such as pain, physical function, ability to perform activities of daily living, and stiffness, were also identified as important to participants. There were a few qualitative differences in participant perceptions about what they would like to see addressed by PROMs. For example, AS participants said that they would like to see PROMs elicit feedback about their experiences with pelvic and chest pain (e.g., as a result of chest inflammation/tenderness and chest expansion). PsA participants felt that PROMs should include measures about the embarrassment and shame that they experience as well as the impact of PsA on their daily lives.
Conclusion: Results of these qualitative assessments suggest that PROMs should be incorporated more frequently in outpatient settings to help improve the quality of decision-making conversations between patients and their healthcare providers. Participants indicated that constructs such as isolation, depression, fatigue,

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and relationships with others were critical to inform healthcare professionals about the patient experience of living with their disease.

Keywords: Ankylosing spondylitis; Patient experience; Patient-reported outcome measures (PROMs); Psoriatic arthritis; Qualitative research; Spondyloarthritis

Key Summary Points

Qualitative feedback was captured from participants living with psoriatic arthritis (PsA) and ankylosing spondylitis (AS) regarding patient-reported outcome measures (PROMs) typically utilized in these disease states

Concepts identified by both PsA and AS participants that best reflected their experiences included fatigue, isolation, depression, inter-personal relationships, and sexual intimacy. Additionally, elements incorporated into existing PROMs, namely pain, physical function, ability to perform activities of daily living, and stiffness, were also identified as important to participants. A few qualitative differences were noted based on disease state

Based on participants' feedback, it was felt that PROMs should be more deeply embedded in routine clinical care, thereby facilitating greater shared decision-making with healthcare providers. Isolation, depression, fatigue, and relationships with others were identified as critical concepts to include to better understand participants' experiences living with PsA and AS

DIGITAL FEATURES

This article is published with digital features, including a summary slide, to facilitate understanding of the article. To view digital features for this article go to https://doi.org/10.6084/m9.figshare.13692541.

INTRODUCTION

Incorporating patient perspectives into outcomes research is important to understand patient experiences of living with disease [1]. The steps involved in the design and development of patient-reported outcome measures (PROMs) can be an exceptionally thorough, detailed, multi-phase process involving item generation, content review, statistical analyses, and validation [2, 3], yet patient insights into the content and applicability of these measures are not always captured during the instrument development process.

In an extensive review of 189 studies describing the development of 193 PROMs, one-quarter of those studies had no patient involvement [4]. When patients were involved, the most common forms of involvement were item development (58.5%), comprehension related (50.8%), and patient feedback as to which outcome might be important to measure (10.9%) [4]. Similarly, another study found that patient participation was only reported as part of the development process for 42% of PROMs and that the most common form of patient involvement was in the domain/item generation stage [5].

PROMs used in spondyloarthritis (SpA) include the HAQ-DI/HAQ-S (Health Assessment Questionnaire Disability Index/Health Assessment Questionnaire for the Spondyloarthropathies) [6–8], BASDAI (Bath Ankylosing Spondylitis Disease Activity Index) [9], ASQoL (Ankylosing Spondylitis Quality of Life Instrument) [10], PROMIS-29 (Patient-Reported Outcome Measurement Information System-29) [11], PsAID 9/12 (Psoriatic Arthritis Impact of Disease Questionnaire for 9 or 12 domains of health) [12, 13], SF-36 (36-Item Short-Form Health Survey) [14, 15], and RAPID3 (Routine Assessment of Patient Index Data 3) [16]. Some of these instruments are general health measures (HAQ-DI, PROMIS-29, RAPID3, SF-36), while others are disease-specific (PsAID,

ASQoL, BASDAI). Utilization of these measures in clinical research has been well described in the literature, although content validation with disease-specific populations is generally lacking, with the exception of the PsAID and ASQoL.

The objective of this study was to capture feedback on commonly used PROMs in SpA from individuals living with psoriatic arthritis (PsA) or ankylosing spondylitis (AS). Through this exercise, we aimed to identify PROM content that resonated with patient experiences and was therefore suitable for implementation in SpA clinical practice. This type of qualitative feedback has not been reported previously in the published literature. As such, these findings can fill an important gap to inform the design of future research efforts focused on the use of PROMs to deliver more patient-centered care for individuals with PsA and AS.

METHODS

Patient Selection

Consistent with accepted sample size targets for qualitative research [17], the goal of this study was to recruit 12 individuals with PsA and 12 individuals with AS to participate in Patient Engagement Research Council (PERC) activities. The PERC represents a diverse group of disease-aware participants living with chronic health conditions who can provide their insights and feedback around a specific, structured series of activities.

Study participants were recruited using social media and other online advertising, outreach to patient advocacy organizations, and by referral from healthcare providers. Eligible participants self-reported that they had a diagnosis of PsA or AS and were under the care of a rheumatologist; all agreed to participate in the PERC.

A self-reported diagnosis of PsA was based on a participant responding "Yes" to the question, "Have you been diagnosed with psoriatic arthritis? Psoriatic arthritis includes problems with the skin (e.g., itchy red patches or silvery scales) as well as inflammation of the joints (joint pain, redness, and swelling). Other symptoms can include fatigue, swollen fingers and toes, or issues with the fingernails or toenails." A self-reported diagnosis of AS was based on a participant responding "Yes" to the question, "Have you been diagnosed with ankylosing spondylitis? Ankylosing spondylitis typically involves chronic inflammation of the spine, pelvis, and other joints (with pain, redness, and swelling). This results in back pain, morning stiffness, and fatigue. Additionally, other symptoms can include pain and inflammation in heels and soles of feet. Apart from joints, inflammation of the eyes, skin, or bowels may also occur."

Subjective sampling was used, and participants were selected based on characteristics including gender, age, race/ethnicity, condition epidemiology, and clinical characteristics to ensure diversity. For example, participants with PsA were asked if they had joint symptoms in their hands, feet, knees, or ankles; inflammation in a few joints that would be painful, swollen, hot, or red; inflammation in fingers or toes; pain or swelling in the heels or bottom of the feet; patchy, scaly, raised areas of red and inflamed skin; or pits and ridges in fingernails or toenails.

Participants reported taking prescription non-steroidal anti-inflammatory drugs (NSAIDs; e.g., celecoxib, meloxicam, naproxen, or ibuprofen), a disease-modifying antirheumatic drug (e.g., methotrexate, sulfasalazine, or leflunomide), a biologic drug (e.g., etanercept, adalimumab, infliximab, golimumab, certolizumab pegol, secukinumab, or ustekinumab), an enzyme inhibitor (e.g., apremilast [PsA only]), and/or a steroid (e.g., prednisolone) to help treat their PsA or AS. Individuals who reported taking no medication or only over-the-counter NSAIDs were not eligible to participate.

Once participants were screened and qualified, they were invited to participate in a variety of engagement activities, including review of PROMs, over a 2-year contracted time period.

Compliance with Ethics Guidelines

Patients were informed that participation in these meetings was voluntary, that responses would be recorded, that no treatments would be

provided, and that they could withdraw at any time. Participants signed a consent and release form that communicated confidentiality and Health Insurance Portability and Accountability Act (HIPAA)-compliant practices. All data were de-identified; thus, no ethics board review was required. The purpose of this study was to collect participants' personal perspectives and qualitative insights. The study was also conducted in accordance with the Helsinki Declaration of 1964 and its later amendments.

Research Engagement Tasks

Participants engaged in face-to-face and virtual meetings in a group setting to review and provide feedback on commonly used PROMs in SpA to better understand the value of current tools and identify gaps. A series of tasks, logistics, and time allocations of each engagement with participants are described in Table 1.

As displayed in Table 1, all participants reviewed the general health PROMs, PROMIS-29 and SF-36. The PsA participants also reviewed the HAQ-DI, RAPID3, and PsAID questionnaires, while the AS participants reviewed the ASQoL, BASDAI and HAQ-S. The length of time allocated to PROM review varied from 60 to 120 min, depending on whether the review and discussion occurred during in-person meetings or by teleconference.

The specific probes and tasks presented around the PROM review are outlined in Table 2. Participants were instructed to review the PROM, identify content that resonated with them, and to identify items that may not have captured their personal experiences living with their disease.

In addition to PROM review, participants engaged in activities and discussions that included, but were not limited to: open-ended discussions around diagnosis (e.g., time to receive an accurate diagnosis, ways in which diagnosis impacts daily life), use of information resources to learn about the disease and its treatment, types of resources or tools that would be helpful to people living with and navigating their diagnosis, and ways to engage better with participants.

All patient engagements were audio-recorded and transcribed. Transcripts were reviewed by a senior qualitative researcher (MLP) to identify key themes that corresponded to the goals and objectives identified for each engagement activity.

RESULTS

Patient Characteristics

Twenty-four individuals participated in the study: 12 with PsA and 12 with AS. Most patients were white and $\geq$ 35 years of age (Table 3). One-third of participants in each group reported experiencing symptoms for $\geq$ 10 years before they received a diagnosis of PsA or AS, respectively.

PsA

PsA participants reviewed the HAQ-DI, PROMIS-29, PsAID-9/12, RAPID3, and SF-36. Participants provided detailed reactions and insights following their review of the PROMs, such as a desire to see their healthcare providers use these types of measures in practice for baseline assessment, longitudinal monitoring, and discussion. Others reported that their healthcare providers had administered PROMs but that they fell into a "black hole" with little to no follow-up. For example, some participants expressed that it would have been helpful to have discussions with their healthcare providers on their responses to the PROMs and tracking PROM responses over time as a measure of response to treatment. PsA participants also expressed interest in being able to track their PROM responses for "trends over time" regarding their disease, flares, or changes in their overall health. The two measures that PsA participants identified as being most complete were the PsAID-12 and PROMIS-29.

Overall, participants viewed these measures favorably regarding their attempt to elicit patient assessment about living with their disease. Though participants were not asked to self-administer or complete the measures, they

Table 1 PERC participants PROM review by method and time allocations

Review type	Psoriatic arthritis PERC		Ankylosing spondylitis PERC	
	In person	Teleconferences	In person	Teleconferences
Participants	12	5 and 7 per call date	12	6 and 5 per call date
PROM reviewed	HAQ-DI	PsAID-9	ASQoL	BASDAI
	PROMIS-29	PsAID-12	PROMIS-29	HAQ-S
	RAPID3		SF-36	PROMIS-29
	SF-36			
Introduction to PROM presentation	20–30 min led by SDC	Participants asked to review PROM prior to teleconference	20–30 min led by SDC	Participants asked to review PROM prior to teleconference
Independent and group PROM review/ discussions*	Led by MLP	Call facilitated by SDC and JA	Led by MLP	Call facilitated by SDC and JA
PROM review/ discussions	90 min including independent review followed by small group discussions	45–50-min discussion with a 30-min independent pre-read of the PROM prior to teleconference	60 min including independent review followed by small group discussions	45–50-min discussion with a 30-min independent pre-read of the PROM prior to teleconference
Total time allocated	120 min	60 min	90 min	60 min

The 12 PsA and 12 AS PERC participants were asked to participate in follow-up teleconferences for program updates and to discuss additional PROMs. Each disease-specific PERC was divided into two groups so that the number of participants on each teleconference was limited to maximize feedback and discussions. All 12 PsA PERC members were able to participate, as were 11 of 12 AS PERC members (one AS PERC member was not available to participate)

ASQoL Ankylosing Spondylitis Quality of Life, *BASDAI* Bath Ankylosing Spondylitis Disease Activity Index, *HAQ-DI* Health Assessment Questionnaire-Disability Index, *HAQ-S* Health Assessment Questionnaire for the Spondyloarthopathies, *PERC* Patient Engagement Research Councils, *PROM* patient-reported outcome measure, *PROMIS-29* Patient-Reported Outcomes Measurement Information System-29, *PsAID-9/PsAID-12* Psoriatic Arthritis Impact of Disease Questionnaire 9/12 domains, *RAPID3* Routine Assessment of Patient Index Data 3, *SF-36* 36-Item Short-Form Health Survey

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did not perceive them to be a burden and felt that they could be an important part of an office visit.

Theme: Mental Health, Relationships, and Employment

The consensus among PsA participants was that mental status questions were critical and that if PROMs were not used, healthcare providers may not ask (or ask enough) about mental health. Participants mentioned topics such as isolation,

Table 2 PROM review questions

Psoriatic arthritis	Ankylosing spondylitis
Please have your group consider what PROM questions resonated or reflected your experiences living with PsA. What items "missed the mark"?	Please have your group consider what PROM questions resonated or reflected your experiences living with AS
What have the authors overlooked or forgotten to measure as it relates to PsA? Or in other words, what might be a limitation to using these scales with people living with PsA?	What might be a limitation to using these scales with people living with AS?
Do these 4 PROMs meet your group's expectations as to what a patient-centric research study should include, either now or in the future?	Which one or two of these PROMs would you expect (or recommend) be included in an AS research study?
If you could design the ideal patient-reported outcome tool, what would it look like or include/ask about? What aspects of living with PsA would you want reflected (or asked about) in the tool? If this "idea" tool provided you with a score, say, overall a measure of improvement in a person's health because of treatment—or the PROM data showed that people were doing well would the data help you decide which treatment you might select for your PsA?	Do these 3 PROMs meet your group's expectations as to what a patient-centric research study should include, either now or in the future?
	If you could design the ideal patient-reported outcome tool, what would it look like or include/ask about? What aspects of living with AS would you want reflected (or asked about) in the tool? If this "ideal" tool provided you with a score, say, overall a measure of improvement in a person's health because of treatment—or the PROM data showed that people were doing well would the data help you decide which treatment you might select for your AS?

AS ankylosing spondylitis, *PROM* patient reported outcome measure, *PsA* psoriatic arthritis

loneliness, and feelings of hopefulness about their treatment options as content that was critical to capture in PROMs. PsA participants also felt that PROMs should elicit information about pain and ability to function because "pain is always present" and therefore an important aspect of understanding the patient experience. Some participants expressed concerns about the accuracy and value of pain measurement in existing PROMs.

Another aspect of participant feedback pertained to intimate relationships and the decision to have children. A few PsA participants felt that the PROMs should incorporate questions pertaining to how their diagnosis has impacted relationships as well as their ability to engage in and maintain a committed relationship.

Some PsA participants expressed that PROMs should contain questions about employment, related to their ability to work, their ability to keep a job, or if they felt precarious about their ability to maintain employment (e.g., because of extended absences due to their disease, inability to predict the potential effect of disease flares on work schedules, or worsening health).

Theme: Depression, Isolation, and Fear

PsA participants felt that the PsAID-9/12 captured their experiences and concerns living with their disease. Of note, participants identified instrument content pertaining to depression, isolation, and fear that they felt was critical for others to be able to understand their daily experiences. One patient also identified how their disease impacted sexual intimacy and indicated that it would be helpful if this topic was incorporated into a measure.

> "Every question [PsAID] hits the spot…Depression. Sometimes I do feel depressed and it's usually leading a week before my treatment." *Female participant*
> "Because both the social participation and the depression are vitally important for

Table 3 PERC participant demographics

	PsA PERC (N = 12)	AS PERC (N = 12)
Gender		
Female	10	6
Male	2	6
Age range		
25–34 years	3	3
35–44 years	2	5
45–54 years	4	3
55 and over	3	1
Race/ethnicity		
White/Caucasian	7	7
Black/African-American	1	2
Hispanic/Latino	2	0
Asian	2	1
Other	0	2
Years before diagnosis (patient reported)		
Less than 1 year	3	7
2–10 years	5	1
10 or more years	4	4

AS ankylosing spondylitis, *PERC* Patient Engagement Research Council, *PsA* psoriatic arthritis

me…social participation and depression go hand in hand. A lot of it comes back to…fatigue. Because when I'm over-fatigued, then my social participation drops, and when my social participation drops, then my level of depression goes up. And those things are kind of important to me when speaking with my doctor." *Male participant*

"For me it's the embarrassment and shame, is a huge one, and I scaled that really high…the embarrassment and shame part is something that personally affects me on a daily basis…if I know it's going to be a hot day and I know that I'm either going to be very conspicuous in hiding my skin or I'm going to be in a very public place where I'm going to be kind of limping because I've had really flare in my hips I will choose to be reclusive…and affects my depression and my social participation." *Female participant*

"I loved both of them [PsAID-9 and PsAID-12]. The thing that really struck me was the question about fear. I guess since I'm 57…I often think of my future and I have a lot of fear about aging with this disease." *Male participant*

"I don't think enough people talk about how that [PsA] affects their sex lives and how that being affected could really affect someone—like I said marriage or depression level or confidence or so on…" *Female participant*

Participants expressed that the PsAID-12 was more complete than the PsAID-9 because of the additional questions related to depression, social participation, and embarrassment.

Theme: Fatigue

Participants perceived the PsAID content to reflect their experiences managing ever-present, sometimes debilitating fatigue, as well as sleep challenges, which can make it difficult to function on a daily basis.

"It [PsAID-9 and PsAID-12] touched on everything and it touched on the things the doctor usually doesn't ask and when I go in there I forget. It was really nice to have all that different stuff on there. The sleep problems. The function. Leisure activities. It makes you feel like it's all important." *Female participant*

"The fatigue is what kills me because I can work through pain, I can take something to help dull the pain, but there's nothing I can take to get my energy back…" *Male participant*

"You can get rid of pain or you can get it where you can bear it or you can function, but that fatigue is just—to me, what I always say is it's like walking through

quicksand with an elephant on my back." *Female participant*

Overall, PsA participants reported that the PsAID was relevant for capturing the emotional impact of PsA, which could inform treatment-related decisions if scores worsen over time. Participants also expressed that the PsAID could be used to inform healthcare providers about experiences that may otherwise not be prioritized during relatively short clinical encounters.

PsA participants liked that the PROMIS-29 includes items pertaining to fatigue, which they felt captured their experience of living with their disease.

Theme: Depth of Feedback

PsA participants indicated that the PsAID-9/12 and PROMIS-29 resonated with their experiences.

"If you need brevity, the PsAID-12 and 9 are great…then [comparing to the PROMIS-29] also how much the tiredness prevented you from accomplishing things, so just a little more detailed, and a little more insight with the PROMIS which is good." *Male participant*

"Addressed the whole person" PsA. [*no additional patient characteristics due to handwritten notes*]

"This survey [PROMIS-29] is much more all-encompassing" PsA. [*no additional patient characteristics due to handwritten notes*]

"This [PROMIS-29], to me, is perfect! Pointed questions, time frames, and pertinent information. I would fill this out feeling like my condition was being well understood, and with the feeling that I could accurately answer the questions to give a 'true' impression of my PsA." [*no additional patient characteristics due to handwritten notes*].

AS Patient Feedback

AS participants reviewed the ASQoL, BASDAI, HAQ-S, PROMIS-29, and SF-36 and were asked to consider which PROM best represented or resonated with their experience living with AS. They were also asked what might be missing from these measures in terms of being able to explain or quantify their experiences living with AS.

Overall, AS participants reported that aspects of each instrument captured the complexities of living with AS. Participants focused on the HAQ-S and the BASDAI as measures that most resonated or captured their experiences living with their disease, including stiffness, completing physical actions and movements, and fatigue.

Theme: Activities of Daily Living

Participants said that they liked that the HAQ-S content focused on movements and actions that they completed on a daily basis (e.g., carrying groceries) and felt that the instrument would provide a fairly comprehensive picture of what they were able (and unable) to do because of their AS.

"I do appreciate that they ask about living life things, like carrying grocery bags." *Female participant*

"I really like that the HAQ is more objective and that it focuses on actions or movements that one might do on a daily basis." *Gender not identifiable from audio*

"I really liked the grocery bag question and the sitting question. I just thought that I'd be able to give a more valid answer to those questions." *Female participant*

The one aspect of the HAQ-S that a few participants struggled with was wanting to elaborate on (and therefore potentially communicate to healthcare providers) the length of time spent in pain. A few participants also wanted to understand the numeric indices of the HAQ-S in relation to what these meant to their disease, their pain, and their ability to complete tasks.

"I marked myself as a 70 but what does that mean? [Referring to HAQ-S measure of stiffness "0 = No Stiffness and 100 = Very severe stiffness"]… the second question, 'Are you able to sit for long periods of

time?' Whenever I'm asked that question, I often wonder what exactly is a long period of time? Because it doesn't ask to clarify is it 30 min? Is it an hour? Is it an entire day? So, one person may have the worst amount of time in 30 min but—and answer with much difficulty. But then another person may sit the entire day and answer the same question, so it doesn't really, exactly, kind of rate how much sitting hurts." *Male participant*

Theme: Fatigue

AS participants reported that fatigue content from the PROMs captured their experiences living with the disease and that fatigue had a significant impact on their daily lives. Participants indicated that they felt healthcare providers did not elicit this information, which in turn may have led to underestimating the significant impact fatigue had on their ability not only to complete activities of daily living but also to engage in activities that they enjoyed. In general, AS participants reported that fatigue was under-emphasized and was not something that healthcare providers wanted to "touch" or "solve."

"My provider used it [BASDAI] to assess me. And I find it to be a really representative tool for my condition." *Male participant*

"The [BASDAI] form overall looks very inviting and not as intimidating as other forms." *Male participant*

"I was really happy to see that the fatigue was listed. That's one that it seems that none of the doctors want to touch. You know, everyone seems to be focused on their area—rheumatology, orthopedic, etc. And you try to talk to them about fatigue, and it's like, you know, it's taboo. No one wants to touch it or try to solve it." *Male participant*

"Fatigue and tiredness is something that I struggle with on a day-to-day basis. And in speaking with other rheumatologists in the past, it's something that can be under-emphasized probably. So, I love that it's called out as one of the first questions there." *Male participant*

"I think it's essential that we look at fatigue and that it's evaluated. I do wonder how to give context to fatigue. Particularly in communication between the patient and the healthcare provider because when I'm saying that my fatigue is severe, I'm saying that like I can't get anything done. Like, nothing at all. But, like—how could we provide the texture to that in the conversation? I guess that's my thing. Because, like, fatigue, it's not just a physical and mental, emotional aspects of it, but then there's like a psych out factor, too, where you don't want to waste energy you do have. So, like I don't know like—it's just hard to say, like I might be terrified to go grocery shopping because I feel like crap, but I know I could feel crappier. But then, if I feel a little better, do I want to risk it? But, I still have to go grocery shopping." *Female participant*

Similar to feedback collected from PsA participants, AS participants also indicated that they wished that their physician would use PROMs (or PROM-like questions) in clinical practice to track patient-reported experiences over time. The longitudinal aspect of disease monitoring was especially important to participants.

DISCUSSION

Participants identified the PsAID-9/12 and the PROMIS-29 as reflective of their disease impact from PsA. As the focus of this work was on content that most resonated with participants, it was not feasible to focus learnings by each of the seven measures presented to participants to consider. Participants had mixed experiences with PROMs in their disease management. Some had previously answered PRO-type questions throughout living with disease, whereas others said that they had not been asked these types of questions by their healthcare providers and would have liked to provide their feedback. A few participants expressed frustration with answering health inventory questions about their disease progression as they felt their responses fell into a "black hole" and they did

not receive feedback on any improvement (or worsening) over time based on their responses.

From each of the patient engagement activities, it was clear that some constructs resonated with both PsA and AS participants. For example, both patient groups identified content pertaining to pain, depression, isolation, fatigue, and relationships with others as most relevant. Participants appreciated being asked to review this content, and some said that they would like to address this type of information with their healthcare providers in the future.

Limitations

While participants were recruited and selected based on a number of considerations, including representation of both men and women, ensuring a range of years since diagnosis, and age and ethnic/racial diversity, their diagnoses were self-reported, and limited information was collected about the potentially diverse disease manifestations of PsA and AS. In addition, the participant population may have been limited if individuals excluded themselves based on their current health or an inability to travel to/from the in-person meetings. Furthermore, the individuals who agreed to participate in this study were likely to be relatively more health-engaged or actively aware of their diseases than the much broader PsA or AS patient community, limiting the generalizability of these results to broader patient populations.

Other limitations include the small sample size ($n = 24$) and the time constraint to discuss each PROM within 45 and 120 min. Meetings included PROM didactic presentations and review of multiple PROMs in both individual and group discussions, in which participants were asked to consider the instrument in its entirety rather than conducting extensive reviews or discussions of each item/statement. The number of people involved in each engagement and the amount of time allocated between PROM may have also impacted the ability to collect patient insights.

Capturing the patient voice through qualitative research engagements such as this lends depth and insight into understanding patient experiences and the kinds of support that they may need to be able to track their disease and potentially enhance understanding and engagement in future clinical encounters.

As expected, there was overlap in patient experiences between PsA and AS for fatigue and difficulty with activities of daily living. Participants reported that healthcare providers often did not fully understand how fatigue impacted their decision to complete activities of daily living, such as self-care and grocery shopping, as well as their inter-personal relationships.

CONCLUSIONS

Of the various PROMs that were reviewed and discussed in these patient engagement activities, the four that resonated the most were the PsAID-9/12, PROMIS-29, HAQ-S, and BASDAI. Participants identified content that was meaningful or relevant to their experiences living with either PsA or AS and reported some level of encouragement or, in some instances, a sense of self-validation that items or statements existed that reflected their experiences living with their disease.

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Data Availability. The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

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