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Treatment Satisfaction and Decision-making from the Patient Perspective in Axial Spondyloarthritis: Real-World Data from a Descriptive Cross-sectional Survey Study from the ArthritisPower Registry

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Objective. Aims were to *1*) to characterize patient decision-making with treatment for axial spondyloarthritis (axSpA) and *2*) to explore relationships among decision-making, treatment satisfaction, and biologic disease modifying antirheumatic drugs (bDMARDs).

Methods. ArthritisPower participants with physician-diagnosed axSpA were invited to complete an online survey about their treatment and their most recent physician visit. Analysis compared treatment decision by satisfaction and bDMARD status.

Results. Among the 274 participants, 87.2% were female, and the mean age was 50 years. Of participants, 79.5% had researched treatment before their most recent physician visit, and 56.9% discussed treatment change at their most recent physician visit. Of treatment-change discussions, 69.2% of them were related to escalation, compared with deescalation (27.6%) and/or switching (39.1%). Among those participants who discussed a change, 73.7% agreed to it because they felt that their disease was not being controlled (54.9%) or felt that it could be better controlled on new treatment (20.3%). Top symptoms prompting change were back/buttock pain (63.3%), other joint pain (55.1%), and fatigue (54.1%). Among bDMARD-treated participants (n = 128), important factors for treatment decisions were prevention of long-term axSpA consequences (92.9%) and doctor's advice (87.5%). Among 43.4% of participants reporting treatment dissatisfaction, 37% did *not* discuss treatment change. Current bDMARD use was more common in satisfied (61.9%) than dissatisfied participants (26.9%).

Conclusion. In this cross-sectional study of a predominantly female axSpA population, patients frequently researched treatment options and discussed escalation with their providers. Under two-thirds of participants who were dissatisfied with treatment discussed changes at their most recent visit. Current bDMARD use was associated with higher satisfaction, and bDMARD users considered prevention of long-term consequences and doctor's advice to be very important for decision-making.

INTRODUCTION

Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that affects 0.9% to 1.4% of adults in the United States (1–3). Many patients with axSpA unnecessarily experience symptoms and long-term consequences of axSpA because they lack optimal treatment (4–7). As treatment options expand, opportunities to improve disease management are increasing. However, the process of selecting, accessing, and evaluating treatments is complicated. Understanding the treatment decision-making process, from the patient perspective, may facilitate optimization of treatments for individuals with axSpA.

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SIGNIFICANCE & INNOVATIONS

- Understanding patient treatment decision-making processes may facilitate improvements in patient experiences and outcomes.
- In this study of patient decision-making in axial spondyloarthritis, most patients researched treatment changes prior to their most recent provider visit and discussed treatment escalation at their visit.
- Treatment dissatisfaction was reported by nearly one-half of participants, and less than two-thirds of dissatisfied participants discussed a treatment change at their most recent visit.
- Current biologic disease modifying antirheumatic drug (bDMARD) use was associated with higher patient satisfaction, and bDMARD users considered prevention of long-term consequences and doctor's advice to be very important for decision-making.

There are several barriers to treatment in axSpA, including a lack of knowledge about axSpA diagnosis and treatments. AxSpA can be difficult to recognize, and diagnostic delays are common. In a recent survey of ankylosing spondylitis (AS) patient members of the CreakyJoints online community and members of the associated ArthritisPower registry, Ogdie et al found that more than 60% of patients received an AS diagnosis 2 or more years after they first sought medical attention for axSpA-related symptoms (8). Even after diagnosis, many axSpA patients lack rheumatologist specialty care, and immunomodulatory treatments for rheumatic conditions are infrequently prescribed by non-rheumatology providers (9).

Access to appropriate medications and information may also limit treatment. Inadequate or variable insurance coverage may prevent patients from receiving an intended treatment (10–12). Furthermore, patients are frequently treated with medications that fail to directly address the underlying autoimmune condition (13,14). Recent evidence has shown that roughly a quarter of commercially insured axSpA patients and up to three-quarters of publicly insured axSpA patients rely on opioids for pain management (15). Moreover, the numerous treatment options may cause confusion among axSpA patients, and providers may not be optimally equipped to communicate the risks and benefits of the various medications with their patients because provider training and resources for implementing shared decision-making are limited (16,17).

The goal of this research was to better understand how patients make decisions about their treatments. Specifically, we aimed to characterize axSpA patients' treatment discussions and decisions at their most recent provider visit. We also aimed to explore the relationships among treatment decision-making, treatment satisfaction, and biologic disease modifying antirheumatic drug (bDMARD) use, from the patient perspective.

MATERIALS AND METHODS

Study design and population. This was an ancillary study to the ArthritisPower research registry (Advarra Institutional Review Board [IRB] protocol #00026788). ArthritisPower is a collaboration between the nonprofit Global Healthy Living Foundation and rheumatology researchers at the University of Alabama at Birmingham. Launched in 2015, ArthritisPower comprises members with a self-reported rheumatic and musculoskeletal disease diagnosis who have provided consent to participate in research studies and provide data via the ArthritisPower application using a smartphone or web-based equivalent (18); all studies receive approval from the registry's patient governing board (19).

Members of the ArthritisPower registry who were residents of the United States or US territories, were 19 years of age or older (21 years of age or older for Puerto Rico residents), had a self-reported physician diagnosis of AS or axSpA (as indicated by survey screening questions), and had access to a computer or smartphone to complete online surveys were eligible to participate in this study. During the period from November 2019 to March 2020, members were sent unique survey links via an email invitation, which read, "Understanding AS: What Is Your Experience with Ankylosing Spondylitis (AS)/Axial Spondyloarthritis (axSpA)?" specifying that the goal of the study was to understand patients' perspectives of AS/axSpA symptoms and quality of life, as well as their treatment decision-making process. Up to two email reminders were sent to nonresponders. After agreeing to participate in this ancillary study, participants completed the survey screening questions and were then directed to the ArthritisPower application, where they responded to five electronic patient-reported outcome (ePRO) assessments, followed by an 81-item online survey developed in partnership with patient research partners. The survey collected data on current disease activity via the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), which is scored on a 0-10 scale with scores of 4 or more indicating suboptimal control of disease (20). In addition, the survey included disease-agnostic instruments developed by the National Institutes of Health (NIH) for the Patient-Reported Outcomes Measurement Information System (PROMIS):

PROMIS Pain Interference–Computerized Adaptive Testing version (CAT), PROMIS Physical Function–CAT, PROMIS Sleep Disturbance–CAT, and two one-item questions adapted from the PROMIS Global Health measure, namely, physical health and depression (21). PROMIS short forms are considered reliable measures of disease activity in AS (22). Information about the participants' symptom history, family history, medications, disease management strategies, and most recent treatment discussions and decisions with their provider were also captured. Those participants who reported ever being treated with a bDMARD were also asked questions about their experience with such treatment. The survey was programmed using Health Insurance Portability and Accountability Act (HIPAA)-compliant SurveyMonkey software and took participants 20 to 35 minutes to complete. The study was reviewed and deemed exempt by the Advarra IRB (protocol #00039559).

Statistical analysis. Descriptive summary statistics of participant demographics were conducted for the overall cohort and by treatment subgroup based on whether the participant was currently on a bDMARD or not, as well as on the level of satisfaction with current treatment. Categorical variables were analyzed by frequency counts and percentages. Continuous variables were analyzed by mean (SD), minimum, and maximum. χ^2 and ANOVA tests were used to determine significant differences in demographic characteristics. Demographic characteristics, treatment change discussion, and decision-making were compared according to whether or not the participant was on a bDMARD and by level of current treatment satisfaction. χ^2 tests were used to determine significant differences in treatment satisfaction by treatment (bDMARD use vs. not), and significance was determined at an alpha of 0.05. Data were analyzed as observed with no imputation for missing data. All analyses were performed using SAS version 9.4 (SAS Institute).

RESULTS

Invitations to participate were emailed to 2,727 eligible members of ArthritisPower. Emails were opened by 48% (1,321 of 2,727) of those eligible, and the registration link was clicked by 29% of those who saw it (387 of 1,321). A total of 353 members completed the screener, of whom 274 met the inclusion criteria and completed the ePRO assessments and survey. Ten percent (274 of 2,727) of those eligible for the study in the ArthritisPower registry participated (Figure 1). Comparing the known variables (age, gender, race) among those who participated from the registry with those who did not, we found that the mean age of survey completers was 3 years younger than those with axSpA in the wider registry (P < 0.001).

Of the 274 participants, the mean age was 49.9 (SD 11.1) years, 239 (87.2%) were female, and 234 (85.4%) were white (Table 1). The majority of participants (225 [82.1%]) had been
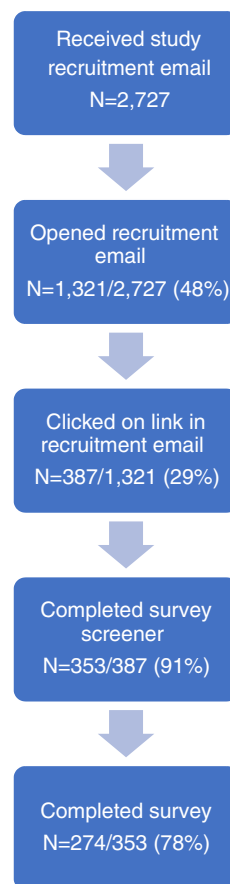
Figure 1. Participant flow diagram.

diagnosed with axSpA by a rheumatologist. On average, participants experienced a gap of 10 or more years from when they reported first noticing axSpA symptoms (mean [SD] age 29.7 [13.2] years) and receiving an initial axSpA diagnosis by a physician (mean [SD] age 40.4 [12.1] years). Lower treatment satisfaction was significantly associated with having a college or higher degree, having a higher body mass index, having current peripheral arthritis, and not currently being on a bDMARD (P < 0.01) (Table 1).

Among other rheumatic or musculoskeletal disease diagnoses participants reported ever having received from a physician, among the most common were osteoarthritis (128 [46.7%]), degenerative disk disease (123 [44.9%]), and spinal stenosis (95 [34.7%]) (see Supplemental Table 1 for full list of conditions). Sixteen percent of participants (n = 44) reported that at least one parent had been diagnosed with axSpA, and 24 (8.8%) reported that a sibling had.

Forty-seven percent of participants (n = 128) were on a bDMARD at the time of study, and an additional 53 (19.3%) participants had been on a bDMARD in the past (Table 1), with adalimumab being the most common in both cases (Supplemental Table 2). Participants currently on a bDMARD were younger

Table 1. Demographic and clinical characteristics by axSpA treatment satisfaction and whether or not on a bDMARD (N = 274)

	All Patients (N = 274)	Treatment Satisfaction					Biologic Status		
		Very Satisfied (n = 34)	Somewhat Satisfied (n = 121)	Somewhat or Very Dissatisfied (n = 119)	P Value*	Adjusted P Value**	Patients on bDMARD (n = 128)	Patients Not on bDMARD (n = 146)	P Value*
Age, years	49.9 ± 11.1	49.1 ± 12.6	49.3 ± 11.5	50.9 ± 10.2	0.491	1.473	46.9 ± 10.3	52.6 ± 11.1	<0.001
Female	239 (87.2)	29 (85.3)	97 (80.2)	113 (95.0)	0.003	0.009	106 (82.8)	133 (91.1)	0.040
White	234 (85.4)	33 (97.1)	104 (86.0)	97 (81.5)	0.075	0.225	115 (89.8)	119 (81.5)	0.051
College degree or higher	149 (54.4)	8 (23.5)	64 (52.9)	77 (64.7)	<0.001	<0.001	73 (57.0)	52 (35.6)	<0.001
Employed	134 (48.9)	21 (61.8)	60 (49.6)	53 (44.5)	0.204	0.612	71 (55.5)	63 (43.2)	0.042
Age at onset, years	29.7 ± 13.2	30.2 ± 13.3	27.7 ± 12.2	31.6 ± 13.9	0.071	0.213	26.9 ± 12.2	32.2 ± 13.5	<0.001
Age at diagnosis[a], years	40.4 ± 12.1	39.6 ± 12.4	38.5 ± 12.3	42.5 ± 11.6	0.033	0.099	37.9 ± 12.1	42.6 ± 11.8	0.001
First degree relative with axSpA	61 (22.3)	6 (17.7)	30 (24.8)	25 (21.0)	0.614	1.842	28 (21.9)	33 (22.6)	0.885
Body mass index[b]	31.77 ± 8.6	29.4 ± 6.8	30.6 ± 8.2	33.6 ± 9.2	0.008	0.024	30.9 ± 7.8	32.5 ± 9.2	0.119
Current medications									
bDMARD	128 (46.7)	26 (76.5)	70 (57.9)	32 (26.9)	<0.001	<0.001	128 (100)	-	-
csDMARD	31 (11.3)	5 (14.7)	16 (13.2)	10 (8.4)	0.400	1.199	17 (13.3)	14 (9.6)	0.336
Steroid	45 (16.4)	3 (8.8)	19 (15.7)	23 (19.3)	0.332	0.996	23 (18.0)	22 (15.1)	0.518
Prescription NSAID	121 (44.2)	14 (41.2)	58 (47.9)	49 (41.2)	0.535	1.605	59 (46.1)	62 (42.5)	0.546
Other prescription medication[c]	137 (50.0)	13 (38.2)	61 (50.4)	63 (52.9)	0.316	0.948	70 (54.7)	67 (45.9)	0.146
Current manifestations									
Inflammatory arthritis	186 (67.9)	16 (47.1)	77 (63.6)	93 (78.2)	0.001	0.004	84 (65.6)	102 (69.9)	0.454
Back/buttock pain improves with NSAIDs	128 (46.7)	19 (55.9)	56 (46.3)	53 (44.5)	0.501	1.503	52 (40.6)	76 (52.1)	0.059
Heel enthesitis	80 (29.2)	9 (26.5)	32 (26.5)	39 (32.8)	0.522	1.566	36 (28.1)	44 (30.1)	0.715
Elevated CRP	78 (28.5)	12 (35.3)	30 (24.8)	36 (30.3)	0.414	1.242	40 (31.3)	38 (26.0)	0.339
Psoriasis skin rash[a]	38 (13.9)	6 (17.7)	12 (9.9)	20 (16.8)	0.241	0.723	21 (16.4)	17 (11.6)	0.255
Uveitis/iritis	32 (11.7)	4 (11.8)	12 (9.9)	16 (13.5)	0.696	2.088	11 (8.6)	21 (14.4)	0.137
IBD[a]	26 (9.5)	3 (8.8)	10 (8.3)	13 (10.9)	0.773	2.319	12 (9.4)	14 (9.6)	0.952
HLA-B27+ (self-reported)	130 (47.5)	18 (52.9)	68 (56.2)	44 (37.0)	0.009	0.028	69 (53.9)	61 (41.8)	0.045
Patient-reported outcomes									
BASDAI[d], 0-10	6.8 (1.9)	5.4 (1.7)	6.5 (1.9)	7.5 (1.6)	<0.001	<0.001	6.4 (1.8)	7.1 (1.9)	0.002
Pain interference[e]	66.1 (6.1)	62.3 (5.5)	65.0 (6.8)	68.3 (4.6)	<0.001	<0.001	65.3 (5.7)	66.8 (6.4)	0.056
Physical function[e]	36.0 (6.4)	40.1 (5.9)	36.8 (6.7)	34.0 (5.6)	<0.001	<0.001	36.7 (5.6)	35.3 (7.0)	0.078
Sleep disturbance[e]	61.2 (8.7)	56.9 (8.6)	60.1 (8.4)	63.4 (8.4)	<0.001	<0.001	59.8 (8.5)	62.4 (8.7)	0.015
Depression[f]	2.5 (0.93)	3.0 (0.92)	2.5 (0.90)	2.3 (0.90)	<0.001	<0.001	2.6 (0.9)	2.3 (0.9)	0.001
Self-rated health[f]	2.2 (0.87)	2.6 (0.81)	2.2 (0.88)	2.1 (0.85)	0.002	0.007	2.1 (0.8)	2.3 (0.9)	0.173

* Statistical significance among groups of participants who were very satisfied, somewhat satisfied, or somewhat or very dissatisfied with their current axSpA treatment (or between groups of participants who were on a bDMARD or were not on a bDMARD), P < 0.05; t tests were performed for continuous variables and χ² tests for categorical variables; P values are nominal in nature and should be interpreted in an exploratory manner.
** Bonferroni adjustment: P value was multiplied by the number of pairs.
[a] Diagnosed by a physician, as reported by participant.
[b] kg/m²; n = 272 out of 274 because weight was an optional response.
[c] Other prescription medications included prescription muscle relaxers, nerve pain medications or antidepressants, and opioids.
[d] BASDAI is scored on a 0-10 scale with scores of 4 or more indicating suboptimal control of disease.
[e] t score, PROMIS measure on 0-100 t score with mean of 50 for general US population; every 10 points = 1 SD; scores signify more (higher score) or less (lower score) of the symptom measured; 7-day look-back period.
[f] Single-item measures from PROMIS Global: score ranged from 1 (poor) to 5 (excellent) for self-rated health and 1 (always) to 5 (never) for self-rated depression; 7-day look-back period.
Abbreviations: axSpA, axial spondyloarthritis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; bDMARD, biologic disease modifying antirheumatic drug; CRP, C-reactive protein; csDMARD, conventional synthetic disease modifying antirheumatic drug; HLA-B27, human leukocyte antigen B27; IBD, inflammatory bowel disease; NSAID, non-steroidal anti-inflammatory drug; PROMIS, Patient-Reported Outcomes Measurement Information System.
Data are n (%) or mean ± SD.

(mean [SD] age of 46.9 [10.3] years vs. 52.6 [11.1] years, $P < 0.001$), were less frequently female (106 [82.8%] vs. 133 [91.1%], $P = 0.040$), were more frequently white (115 [89.8%] vs. 119 [81.5%], $P = 0.051$), were more frequently college educated (73 [57.0%] vs. 52 [35.6%], $P < 0.001$), were more frequently employed (71 [55.5%] vs. 63 [43.2%], $P = 0.042$), and had better disease control compared with those not on a bDMARD (Table 1). Participants' mean (SD) BASDAI scores were 6.8 (1.9), with mean score of 6.4 (1.8) for participants on bDMARD versus 7.1 (1.9) for participants not on a bDMARD, a difference that was significant at $P = 0.002$ (Table 1). The most common current axSpA symptom manifestations reported by participants were inflammatory arthritis other than spine (84 [65.6%] for participants on bDMARD vs. 102 [69.9%] for those not on bDMARD, $P = 0.454$) and back or buttock pain that improves with non-steroidal anti-inflammatory drugs (52 [40.6%] for participants on bDMARD vs. 76 [52.1%] for those not on bDMARD, $P = 0.059$) (Table 1). Forty-eight percent (n = 130) of participants reported that they had had a human leukocyte antigen B27 (HLA-B27) positive blood test (69 [53.9%] for participants on bDMARD vs. 61 [41.8%] for those not on bDMARD, $P = 0.045$), whereas 29% (n = 79) said that they had never had the test, and nearly one-quarter (23.7% [n = 65]) were unsure.

Treatment discussion. Among all participants, 56.9% (n = 156) discussed a treatment change at their most recent physician visit, 79.5% (n = 124) of whom researched the treatment change on their own and 46.2% (n = 72) of whom reported having raised the issue with their clinician themselves. Most treatment changes discussed were related to escalating treatment (initiating new medication or increasing dose, 108 [69.2%]) compared with deescalating (stopping a medication or reducing dose, 43 [27.6%]) and/or switching medications (61 [39.1%]) (Table 2). A higher proportion of participants on a bDMARD than those not on a bDMARD discussed switching medications (52.0% vs. 26.6%, $P = 0.001$) (Supplemental Table 3).

Overall, the remaining 43% of participants (n = 118) reported that a treatment change was not discussed at their last visit, and the most frequent reason given for the absence of discussion was "Other" (47 [39.8%]), with write-in explanations including change in or lack of (treatment) access, testing/lack of updated test results, and doctor not listening to participant's concerns. Many participants whose treatment change was not discussed at the last visit felt thatit was because either they (36 [30.5%]) or their physician (42 [35.6%]) were happy with the current treatment. bDMARD-treated participants more frequently reported their own (23 [45.1%]) and their physician's satisfaction (26 [51.0%]) with current treatment as the reason a treatment change was not discussed compared with non-bDMARD participants (13 [19.4%] and 16 [23.9%], respectively, with differences significant at $P = 0.003$ and $P = 0.002$, respectively) (Supplemental Table 3).

Treatment decisions. The majority of participants (85.3% [n = 133]) who discussed a treatment change agreed to it (Table 3). Ninety-eight participants (73.7% of those agreeing to a

Table 2. Treatment discussions by level of treatment satisfaction

	All Participants (N = 274)	Very Satisfied (n = 34)	Somewhat Satisfied (n = 121)	Somewhat or Very Dissatisfied (n = 119)	P Value	Adjusted P Value
Treatment change discussed, n (%)	156 (56.9)	10 (29.4)	71 (58.7)	75 (63.0)	0.002	0.006
Initiated discussion about treatment change, n (%)	72 (46.2)	4 (40.0)	26 (36.6)	42(56.0)	0.059	0.177
Researched treatment change before visit, n (%)	124 (79.5)	7 (70.0)	57 (80.3)	60 (80.0)	0.744	2.232
Type of treatment change discussed[a]						
Escalating (initiating or increasing dose), n (%)	108 (69.2)	8 (80.0)	51 (71.8)	49 (65.3)	0.521	1.563
Deescalating (stopping or reducing dose), n (%)	43 (27.6)	2 (20.0)	19 (26.8)	22 (29.3)	0.808	2.424
Switching medications, n (%)	61 (39.1)	3 (30.0)	26 (36.6)	32 (42.7)	0.628	1.884
Other[b], n (%)	18 (11.5)	1 (10.0)	9 (12.7)	8(10.7)	0.919	2.757
Treatment change not discussed, n (%)	118 (43.1)	24 (70.6)	50 (41.3)	44(37.0)	0.002	0.006
Reasons treatment change was not discussed[a]						
Other[c], n (%)	47 (39.8)	4 (16.7)	16 (32.0)	27 (61.4)	<0.001	0.002
My provider is happy with my treatment, n (%)	42 (35.6)	13 (54.2)	19 (38.0)	10 (22.7)	0.032	0.096
I am happy with my treatment, n (%)	36 (30.5)	19 (79.2)	17 (34.0)	0 (0.0)	<0.001	<0.001
I do not discuss treatment options with my provider, n (%)	18 (15.3)	0 (0.0)	6 (12.0)	12 (27.3)	0.008	0.024

[a] Participants could select more than one reason; the top four most frequently selected reasons are shown.
[b] The label "Other" includes free text responses from participants such as exercise, physical therapy, surgery, waiting on results, insurance, pregnancy, etc.
[c] Other reasons that treatment change was not discussed include free text responses from participants such as doctor does not listen to my concerns, change in or lack of access, changing is not an option/not needed, tests or lack of results, don't know.
Statistical significance among groups of participants by level of treatment satisfaction, $P < 0.05$; t tests were performed for continuous variables and χ^2 tests for categorical variables; P values are nominal in nature and should be interpreted in an exploratory manner. Bonferroni adjustment: P value was multiplied by the number of pairs. Fisher's exact test was used to determine statistical significance.

Table 3. Treatment decisions by level of treatment satisfaction

	All Participants (N = 274)	Very Satisfied (n = 34)	Somewhat Satisfied (n = 121)	Somewhat or Very Dissatisfied (n = 119)	P Value	Adjusted P Value
Agreed to treatment change, n (%)	133 (85.3)	7 (70.0)	62 (87.3)	64 (85.3)	0.351	1.053
Agreed to treatment change by end of visit, n (%)	87 (65.4)	6 (85.7)	43 (69.4)	38 (59.4)	0.255	0.765
Reasons for agreeing to treatment change[a]						
My disease was not being controlled, n (%)	73 (54.9)	1 (14.3)	30 (48.4)	42 (65.6)	0.013	0.039
Other (ie, benefits of medication not worth cost, insurance coverage, disease inactive), n (%)	32 (24.1)	2 (28.6)	15 (24.2)	15 (23.4)	0.955	2.865
Side effects with previous treatment, n (%)	28 (21.1)	1 (14.3)	11 (17.7)	16 (25.0)	0.548	1.644
My disease was controlled but I thought it could be better controlled on a new treatment, n (%)	27 (20.3)	3 (42.9)	19 (30.7)	5 (7.8)	0.002	0.006
Benefits not worth the risk of side effects, n (%)	16 (12.0)	1 (14.3)	10 (16.1)	5 (7.8)	0.351	1.053
Type of treatment change(s) made[a]						
Escalating (initiating or increasing dose), n (%)	79 (59.4)	5 (71.4)	39 (62.9)	35 (54.7)	0.516	1.548
Deescalating (stopping/reducing dose), n (%)	41 (30.8)	1 (14.3)	18 (29.0)	22 (34.4)	0.504	1.512
Switching medications, n (%)	40 (30.1)	0 (0.0)	20 (32.3)	20 (31.3)	0.203	0.609
Other, n (%)	22 (16.5)	2 (28.6)	7 (11.3)	13 (20.3)	0.268	0.804
Did not agree to treatment change, n (%)	23 (14.7)	3 (30.0)	9 (12.7)	11 (14.7)	0.351	1.053
Reasons for not agreeing to treatment change[a]						
Did not think there were medication options better than current treatment, n (%)	14 (60.9)	3 (100.0)	8 (88.9)	3 (27.3)	0.006	0.018
Concerned about potential side effects with new treatment, n (%)	13 (56.5)	1 (33.3)	6 (66.7)	6 (54.6)	0.591	1.773
Happy with current treatment, n (%)	12 (52.2)	3 (100.0)	8 (88.9)	1 (9.1)	<0.001	0.001
Concerned about an increase in symptoms with new treatment, n (%)	10 (43.5)	0 (0.0)	3 (33.3)	7 (63.6)	0.105	0.315
Did not want to take treatments that require injections or infusions, n (%)	9 (39.1)	1 (33.3)	4 (44.4)	4 (36.4)	0.912	2.736

[a] Participants could select more than one reason; the top five most frequently selected reasons are shown.
Statistical significance among groups of participants by level of treatment satisfaction, $P < 0.05$; t tests were performed for continuous variables and χ^2 tests for categorical variables; P values are nominal in nature and should be interpreted in an exploratory manner. Bonferroni adjustment: P value was multiplied by the number of pairs. Fisher's exact test was used to determine statistical significance.

change) reported that they made a treatment change, because their disease was not controlled by their previous treatment (54.9% [n = 73/133]) or because they thought it could be better controlled by a change in treatment (20.3% [n = 27/133]). The top symptoms driving treatment changes overall were pain in back or buttock (63.3% [n = 62/98]), pain in other joints (55.1% [n = 54/98]), and fatigue (54.1% [n = 53/98]) (Figure 2). Most participants (98 [62.8%]) made a decision about their treatment change by the end of the clinic visit, whereas 24 (15.4%) needed less than a week, and 34 (21.8%) needed a week or more to decide. Among all participants who made a treatment change (n = 133), 79 (59.4%) reported treatment escalation, 41 (30.8%) reported deescalation, and 40 (30.1%) reported a switch. Deescalations were less frequent (14 [21.2%] vs. 27 [40.3%], $P = 0.017$), and switches were more common (25 [37.9%] vs. 15 [22.4%], $P = 0.051$) among those on a bDMARD compared with those who were not (Supplemental Table 3). Among the 128 participants currently on bDMARD therapy, the factors considered most important when making treatment decisions were preventing other long-term consequences of untreated axSpA (118 [92.2%]), preventing damage from axSpA (114 [89.1%]), advice from their doctor (112 [87.5%]), and how

good or bad the disease was making them feel at the time of a treatment change decision (84 [65.6%]) (Figure 3). Among the 14.7% (n = 23) of participants declining the treatment change that was offered, the top reasons were participants not believing that there were more efficacious options than their current treatment (60.9% [n = 14]) and worries about potential side effects of a new treatment (56.5% [n = 13]) (Table 3). Participants did not specify what they meant by "Other" for their treatment discussion, but they did for other treatment decisions they made. Participants reported deciding on additional approaches to disease management such as swimming, physical therapy, acupuncture, or surgery, or they specified the reason for a lack of a decision (ie, awaiting further testing, insurance coverage, or approval/availability of new medication).

Treatment satisfaction. Among all participants, 34 (12.4%) were very satisfied with their current axSpA treatment, 121 (44.2%) were somewhat satisfied, and 119 (43.4%) were somewhat or very dissatisfied (Table 1). BASDAI and ePRO symptom scores were significantly better among participants who were very satisfied with treatment compared with the scores of those who were somewhat satisfied or dissatisfied (Table 1). Most bDMARD-
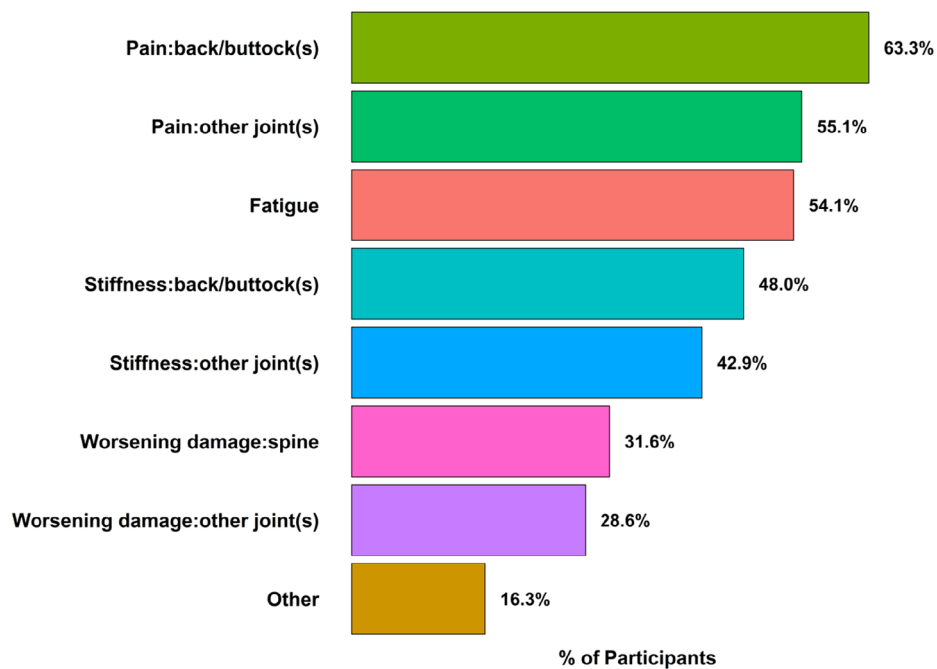
Figure 2. Top symptoms[‡] prompting axSpA treatment change among those who made a change at most recent visit (n = 98[†]). [†]Participants who made a treatment change and a reason they reported for it was that their disease was not being controlled by the treatment that they were previously on or that their disease was being controlled but they thought it could be better controlled by a change in treatment. [‡] Participants could select more than one symptom.
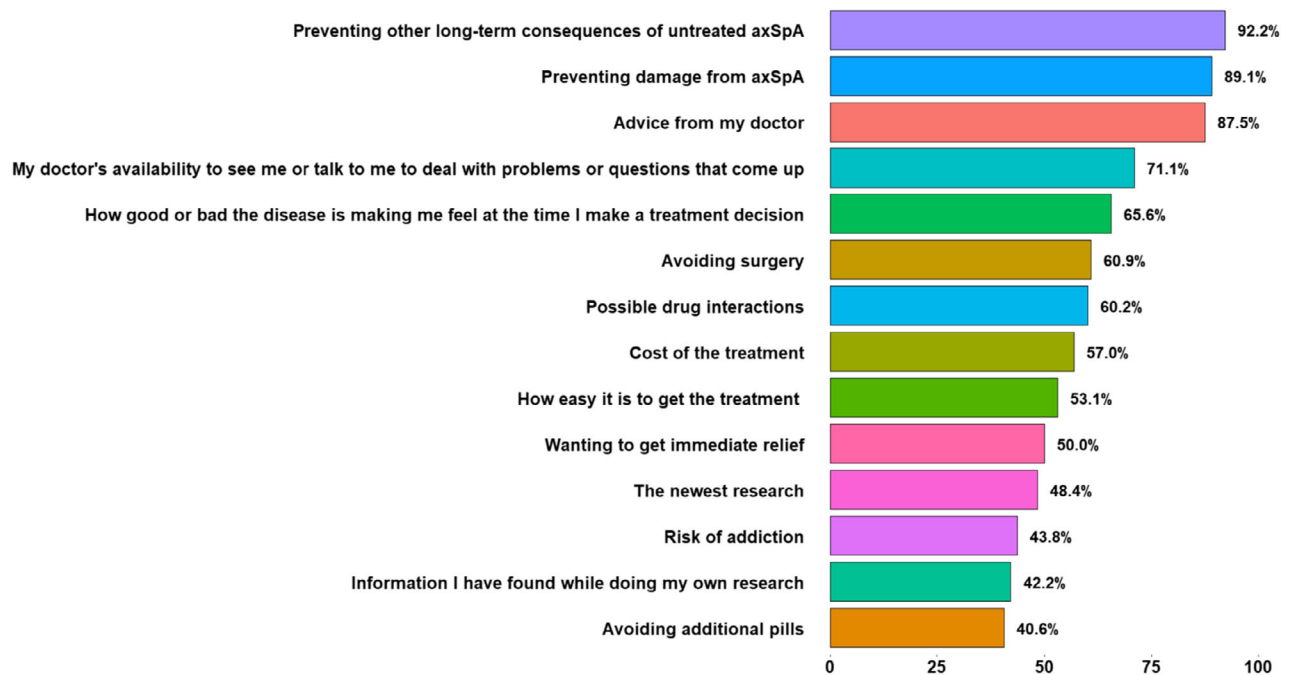

Figure 3. Factors considered very important to axSpA patients on a bDMARD when making decisions about their treatment (N = 128[‡]) (full list of factors in Supplemental Table 4). [‡] Participants could select more than one reason. Responses selected by <40% of participants: Intuition or gut response when I ask myself if this is the right thing to do (35.2%), How easy the treatment is to use or do (such as taking a pill versus doing yoga) (32.0%), Concern that the treatment will only work for a short time and I should save the treatment option for a later date when I feel worse (26.6%), How often I have to take the treatment (daily versus weekly versus monthly) (23.4%), How often I will need to get imaging tests (X ray, ultrasound) on this medication (21.1%), How often I will need to get lab tests on this medication (19.5%), Avoiding needles or injections (14.1%), Whether people will judge me for my pain management strategy (8.6%), Personal recommendations from family or friends (6.3%), Whether the treatment is a natural remedy (4.7%), Advertisements (0.8%).

treated participants reported being somewhat satisfied (54.7% [n = 70/128]) or very satisfied (20.3% [n = 26/128]) with their current axSpA treatment (Table 1), and 68 (53.1%) were satisfied with how well it controls axSpA-related pain. Moreover, participants who were overall very satisfied with treatment were more often on a bDMARD (26 [76.5%]) than not on a bDMARD (8 [23.5%]) (Table 1). Among all participants, a greater proportion who were somewhat or very dissatisfied with their axSpA treatment discussed a change at their last visit (75 [63.0%]) compared with those who were somewhat satisfied (71 [58.7%]) or very satisfied (10 [29.4%]) (P = 0.002; P_{adj} = 0.006). Among patients who expressed high satisfaction with their current treatment, the majority (24 [70.6%]) did not discuss a treatment change (Table 2). Regardless of the level of treatment satisfaction, most participants (85.3% [n = 133]) agreed to the treatment change when one was discussed (Table 3). Most patients agreeing to a treatment change made their decision before the end of their provider visit (87 [65.4%]), whereas 46 (34.6%) needed additional time after their visit to make a decision.

DISCUSSION

In this real-world study of axSpA treatment decision-making from the patients' perspective, about three-fifths of participants discussed a treatment change at their last provider visit, and the vast majority agreed to the change. Treatment escalation was the predominant change discussed and decided on, most often because participants felt their axSpA was not adequately controlled. Current bDMARD use was associated with higher patient satisfaction with treatment, and bDMARD users prioritized the prevention of long-term consequences and physician advise in their decision-making processes.

Overall, these data indicate that patients want better control of their axSpA symptoms. Although reasons for suboptimal disease control were not comprehensively assessed in this study, the fact that the majority of treatment changes were escalations suggests that undertreatment was frequently perceived to contribute to suboptimal disease control. The most common reason for declining a change in treatment was patient belief that there were no better treatment options, and nearly one-half of patients on bDMARDs were dissatisfied with their treatment. This may reflect inadequate effectiveness with currently available treatments (ie, failure to suppress active axSpA inflammation). Furthermore, patients may experience symptoms from noninflammatory processes that do not respond to axSpA treatments.

These findings support and extend prior studies examining axSpA patient treatment concerns and preferences, particularly regarding tumor necrosis factor inhibitor (TNFi) therapy. Patients tend to be hopeful, but they have mixed feelings about bDMARDs, including a sense of anxiety and hopelessness (23). In an analysis of AS patient discussions on social media, patients voiced uncertainty about starting or continuing bDMARD therapy, and the

uncertainty manifested chiefly in their numerous questions about it, especially their worries about its long-term effectiveness (24). The cross-sectional study presented here asked only about immediate symptoms or symptoms at the time a decision was made rather than longer-term symptoms, but it was notable that prevention of long-term consequences/damage was more important to bDMARD participants, compared with participants not on bDMARDs, than were current symptoms (ie, "how good or bad the disease is making me feel at the time of a treatment decision").

Patients increasingly supplement information from physicians with online resources about health and treatment options (26). Given the fact that many participants in this study did their own research about treatments before their visit and raised the topic of treatment change themselves, patient education and support that reinforces the information that is received from clinicians should be made available online where patients can accurately self-educate and discover additional resources for learning about treatments. Shared decision-making, which makes use of tools such as information and decision aids for patients, presents a useful paradigm for engaging patients in treatment decisions (27). Therefore, a follow-up study that examines the factors affecting axSpA patient treatment decision-making with their physician—such as trust and open communication—and that identifies modifiable barriers or facilitators to optimizing axSpA treatment is merited. Ultimately, patients expect greater control of their disease activity and symptoms from axSpA treatment. Therefore, more options, including supplemental therapies, need to be considered with patients.

Strengths of this study include the fact that no other studies, to date, have quantified real-world axSpA patient decision-making processes from discussion to decision with a provider, according to patients' level of satisfaction with current treatment. This study adds important insight into the perspective and experience of patients and their decision-making about axSpA treatment, especially women living with axSpA and other comorbidities experiencing high disease activity.

These findings should be interpreted in the context of the limitations characteristic of patient surveys. Patient perspectives may be subject to patients' bias and experience. Participants in the study are part of an online registry and patient community and may be more likely to take part regularly in research studies and thus may have had greater interest in managing their disease, giving rise to the potential for selection bias. In the social media study reporting axSpA patient attitudes about TNFi treatment, patients had expressed a lack of trust in physicians and a need for psychological and social support, namely, an understanding from others in their social circle of what it is like to live in a body affected by the disease (24). In our study, participants largely expressed trust in their physician and considered the physician's guidance to be important in their treatment change decision. This may be due to a potential halo effect engendered by the online CreakyJoints (CreakyJoints.org) patient community, of which many of the study

participants are also members, whose website and social media platforms offer axSpA information and social support. Our study included 46% participants with a college-level education, a higher proportion than the 36% of college-educated adults in the overall US population (28), and this may have affected how patients reported the relative frequency of factors in their treatment decision-making. A greater proportion of women than is typically observed with axSpA participated in this study. Although axSpA is considered a male-dominant disease (3), the predominance of women in this study may be explained by the fact that women are typically more active online for such topics (25). The study relied on patients' self-report of diagnosis of axSpA, which may have under- or overrepresented symptoms, and provider confirmation of diagnosis was not obtained. However, about half of participants in this study were currently using bDMARD therapies, two-thirds had used them in the past, and most reported receiving their axSpA diagnosis from a rheumatologist, which contributes to the validity of the diagnoses.

Participants in this study were different than axSpA patients in other studies in important ways. There was a higher percentage of females and a lower percentage of participants reporting HLA-B27 positivity, but this may have been due to participants' lack of awareness about blood tests they had been given: one-quarter of participants in this study did not know whether they had been tested for HLA-B27. BASDAI and other ePRO scores were higher than in other registries (29) and similarly high (ie, BASDAI 6.4-6.5) to those seen in clinical drug trial populations (30,31), suggesting high axSpA activity with or without a high burden of symptoms unrelated to axSpA. Moreover, it is possible that axSpA patients displeased with their health and seeking help may have been more likely to participate. Although we acknowledge that this patient population is not representative of the general axSpA population, there is merit in researching this understudied segment of the population.

In conclusion, this predominantly female axSpA population frequently researched treatment options prior to their visit, discussed treatment changes at their most recent appointment, and agreed to change treatment because they desired better disease control. However, a substantial percentage of patients dissatisfied with their treatment did not discuss a treatment change at their most recent visit, suggesting a need to improve patient–provider communication and shared decision-making. Concerns of preventing long-term damage and doctor's advice highly influenced patient treatment decisions. The large proportion of the population who were dissatisfied with their axSpA treatment indicates an expectation of better treatment options.

ACKNOWLEDGMENTS

AUTHOR CONTRIBUTIONS

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