

Patient Empowerment Among Adults With Arthritis: The Case for Emotional Support

Kathleen L. Carluzzo¹ , Erin M. Knight¹ , Karen E. Schifferdecker² , Rebecca L. Butcher¹ ,
Guy S. Eakin³, Julie A. Eller³, and Jasvinder A. Singh⁴ 

ABSTRACT. *Objective.* This study aimed to identify differences in patient empowerment based on biopsychosocial patient-reported measures, the magnitude of those differences, and which measures best explain differences in patient empowerment.

Methods. This was a cross-sectional observational study of 6918 adults with arthritis in the US. Data were collected from March 2019 to March 2020 through the Arthritis Foundation Live Yes! INSIGHTS program. Patient empowerment, measured by the Health Care Empowerment Questionnaire, included 2 scales: Patient Information Seeking and Healthcare Interaction Results. Patient-reported outcomes were measured using the Patient Reported Outcomes Measurement Information System (PROMIS)-29 and PROMIS emotional support scale. ANOVA assessed differences between groups, and Spearman rank correlation assessed correlations between variables. Hierarchical regression analysis determined the contributions of sociodemographic characteristics, arthritis type, and patient-reported health measures in explaining patient empowerment ($\alpha = 0.05$).

Results. Empowerment was lower among those who were male, older, less educated, or who had lower income, osteoarthritis, less emotional support, or better physical function, although the effect was small-to-negligible for most of these variables in the final regression models. Empowerment did not differ by race/ethnicity in unadjusted or adjusted analysis. In final regression models, emotional support contributed the most to explaining patient empowerment.

Conclusion. Emotional support is important for patient empowerment. This suggests that programs that seek to improve patient empowerment should target and measure effects on emotional support.

Key Indexing Terms: osteoarthritis, patient empowerment, patient-centered outcomes research, perceived social support, rheumatoid arthritis

Arthritis is a common health issue throughout the world, affecting 23% of US adults or > 54 million people.¹ Arthritis causes severe pain and physical limitation, and is the leading cause of disability in the US.² Not surprisingly, people with arthritis engage more frequently with the healthcare system. Patients with rheumatoid arthritis (RA) are almost twice as likely as matched controls to visit a physician.³ Virtually all patients with osteoarthritis (OA; 92%) see a physician at least annually.⁴

Given the prevalence, disease burden, and frequency of healthcare visits for individuals with arthritis, strategies to enhance patient empowerment are increasingly used to help individuals manage arthritis and other chronic diseases.⁵ Patient empowerment is a multidimensional construct that involves both the ability of individuals to obtain information related to their care and aspects of the patient–provider interaction that support and facilitate this ability.^{6,7} A mounting body of

This work was supported through a contract with the Arthritis Foundation.

¹K.L. Carluzzo, MS, Senior Research Associate, E.M. Knight, PhD, Senior Research Associate, R.L. Butcher MS, MPH, Senior Research Scientist and Associate Director, Center for Program Design and Evaluation, Geisel School of Medicine, Dartmouth College, Hanover, New Hampshire;

²K.E. Schifferdecker, PhD, MPH, Director of Center for Program Design and Evaluation and Associate Professor, Geisel School of Medicine, Dartmouth College, Hanover, New Hampshire; ³G.S. Eakin, Senior Vice President of Scientific Strategy, J.A. Eller, Director, Patient Centered Strategies, Arthritis Foundation, Atlanta, Georgia; ⁴J.A. Singh, MBBS, MPH, Physician, Medicine Service, Birmingham VA Medical Center, and Professor of Medicine and Epidemiology at the Schools of Medicine and Public Health at University of Alabama at Birmingham, Birmingham, Alabama, USA.

JAS has received consultant fees from Crealta/Horizon, Medisys, Fidia, PK Med, Two Labs Inc., Adept Field Solutions, Clinical Care Options,

Clearview Healthcare Partners, Putnam Associates, Focus Forward, Navigant Consulting, Spherix, MediQ, Jupiter Life Science, UBM LLC, Trio Health, Medscape, WebMD, and Practice Point Communications; and the National Institutes of Health and the American College of Rheumatology. JAS has received institutional research support from Zimmer Biomet Holdings. JAS owns stock options in TPT Global Tech, Vaxart Pharmaceuticals, Atyu Biopharma, Adaptimmune Therapeutics, GeoVax Labs, Pieris Pharmaceuticals, Enzolytics, Seres Therapeutics, Tonix Pharmaceuticals, and Charlotte's Web Holdings. JAS is a member of the executive committee of Outcome Measures in Rheumatology Trials (OMERACT), an organization that receives arms-length funding from 12 companies. The remaining authors declare no conflicts of interest relevant to this article.

Address correspondence to K. Carluzzo, Williamson Building #537, One Medical Center Drive, Lebanon, NH 03756, USA.
Email: kathleen.l.carluzzo@dartmouth.edu.

Accepted for publication January 14, 2022.

evidence indicates that empowered patients are better able to participate in managing their health in partnership with health-care providers (HCPs).^{8,9} However, the measurement and assessment of empowerment has varied across different populations and has not been sufficiently tested among individuals with arthritis.^{10,11,12,13,14} Evidence suggests a range of biopsychosocial factors influence patient empowerment and related concepts, including gender, age, emotional support, and physical and mental health.^{10–16} However, evidence of the relative impact of a comprehensive set of factors affecting patient empowerment among those with arthritis is lacking.

In March 2019, the Arthritis Foundation launched the Live Yes! INSIGHTS program (INSIGHTS) to longitudinally track the burden of disease and empowerment among adults living with arthritis. This effort uses validated patient-reported outcome measures (PROMs) in 3 areas: physical health, social and emotional health, and experience of care (specifically patient empowerment).¹⁷ The purpose is to collect data to inform the Arthritis Foundation's volunteer network, patient-centered advocacy, and research agendas, and to connect patients to educational and supportive resources. PROMs and demographic measures were selected for INSIGHTS using a longitudinal mixed methods process with extensive input from patients, providers, and advocates for people with arthritis, and included interviews with key stakeholders, a critical literature review, focus groups, and a structured consensus-building process.¹⁷ As a result of this process, INSIGHTS includes the Healthcare Empowerment Questionnaire (HCEQ)¹⁸ to measure patient empowerment, the Patient Reported Outcomes Measurement Information System (PROMIS)-29 Profile v2.1^{19,20} and PROMIS Emotional Support Short Form v2.0²¹ scales to measure physical and emotional health, and demographic measures. Over 15,000 adults living with arthritis participated in INSIGHTS in the first 18 months.

Given the importance of empowerment for individuals living with arthritis, the purpose of this study was to understand experiences of empowerment among US adults with arthritis, and key factors associated with empowerment. We focused on 2 questions related to patient empowerment: (1) What is the relationship between key study variables (sociodemographics, arthritis type, physical and mental health, and emotional support) and patient empowerment; and (2) Which characteristics contribute most to explaining differences in patient empowerment outcomes?

METHODS

Study design, setting, and participants. This was a cross-sectional observational study of adults with arthritis in the US who participated in INSIGHTS.²² Through INSIGHTS, adults with arthritis are invited to complete PROMs through an online survey in a nonclinical setting. Participants are recruited actively through the Arthritis Foundation's volunteer-driven community engagement network, through social media and email campaigns, and passively through its website. INSIGHTS participants are aged ≥ 18 years, are English speaking, provide informed consent to participate, and are not incentivized. This study was reviewed by the Institutional Review Boards of Advarra (Pro00032161) and Dartmouth College (#00031180) and deemed exempt from further review by both.

To gauge the extent of engagement in the Arthritis Foundation, participants in the first 6 months of the study were asked about their involvement for the past year. Involvement was categorized as none in the past year, passive (visited or created a profile on the website, or signed up to receive emails), or active (participated in groups, events, or online communities; volunteered; or participated as an advocate, an event speaker, or in a research study).

Due to the possible effects of the coronavirus disease 2019 (COVID-19) pandemic, we restricted analysis to surveys completed between March 19, 2019 (INSIGHTS launch), and March 15, 2020 (inception of widespread pandemic-related shutdowns in the US). Sociodemographic data were collected at baseline, so we analyzed baseline surveys of respondents and excluded follow-up surveys.

Measures. The primary outcome, patient empowerment, was measured by 2 of the 3 scales of the HCEQ¹⁸ (Supplementary Table 1, available with the online version of this article). Involvement in Decisions (6 items), which we refer to as Patient Information Seeking, involves the ability to ask questions and obtain explanations and advice. Involvement in Interactions (8 items), which we refer to as Healthcare Interaction Results, measures patients' experiences with being able to talk to providers to get their questions answered, have their choices respected, and get the help and information needed. The third HCEQ scale, Degree of Control, was excluded in the measure-selection process that preceded this study.¹⁵ The authors felt that renaming the HCEQ scales improved interpretability and understanding of the concepts being measured, and obtained permission from the HCEQ's authors.¹⁸ Prior analysis by Knight et al²³ using INSIGHTS data found that the shortened 14-item version of the HCEQ used in INSIGHTS performed well among adults with arthritis and replicated findings from the original HCEQ validation study by Gagnon et al.¹⁸

The questionnaire instructs respondents to answer HCEQ items based on the health services they received for their arthritis during the last 6 months, in keeping with the original measure. Each item is assessed on a 4-point scale, first based on the respondent's feelings ("Did you feel that..."), and then on importance ("How important is it that..."). We calculated scale scores by summing the cross-product of feeling and importance ratings for items within each scale. Scores range from 3 to 48 for Patient Information Seeking, where a higher score means more information seeking, and from 4 to 64 for Healthcare Involvement Results, where a higher score means more involvement. Population norms have not yet been established for the HCEQ, so we used a 10% difference in scores to indicate meaningful difference (4.6 points for Patient Information Seeking and 6.1 points for Healthcare Interaction Results).²⁴

In addition to the HCEQ, the INSIGHTS questionnaire includes sociodemographic information, type and duration of arthritic condition(s), the PROMIS-29 Profile v2.1,^{19,20} PROMIS Emotional Support Short Form v2.0,²¹ and the PROMIS pain intensity scale (0–10 points), which collectively assess a range of patient-reported biopsychosocial measures.²⁵ None of the continuous variables were grouped; the 2 lowest levels of education, less than high school ($n = 55$) and high school/General Education Development (GED; $n = 700$) were combined for analysis.

PROMIS emotional support (4 items) assesses the extent to which individuals feel they have someone to talk to, to confide in, and who appreciates them.²¹ The PROMIS-29 (seven 4-item short forms) measures the following: ability to participate in social roles and activities, anxiety, depression, fatigue, pain interference (extent to which pain interferes with activities of daily living), physical function (ability to perform physical activities with ease), and sleep disturbance (quality, problems, and difficulty with sleep). These measures have been extensively validated.^{26,27,28,29,30,31} PROMIS items utilize a 7-day recall period. All items within a short form must be complete for a score to be calculated. Raw summed scores for PROMIS short form measures were converted to t -score metrics, for which a mean of 50 represents the average score for the US general population and ± 10 is 1 SD.^{32,33} Higher PROMIS scores indicate more of the construct being

measured (eg, higher anxiety scores indicate more anxiety; higher physical function scores indicate greater functioning).³² Internal consistency was assessed with this sample for each scale using Cronbach α .

Statistical analysis. Most of the tests we used are robust to minor assumption violations, and with few exceptions, our data met the required assumptions for inferential statistics. For statistical tests that are sensitive to assumption violations, we used equivalent nonparametric tests. Descriptive statistics were used to summarize respondents' sociodemographics, health characteristics, and patient-reported outcomes (PROs). We tested for differences in outcomes among sociodemographic groups using ANOVA. Spearman rank correlations, using pairwise deletion of missing data, assessed the relationship between patient empowerment and key quantitative variables.

We used hierarchical regression analysis with robust standard errors to understand the importance of sociodemographic characteristics, mental and physical health, and emotional support in explaining empowerment outcomes. We prioritized selecting moderately correlated variables and developed theory-based models to show the unique contribution of factors on outcomes and allow comparisons between models. Informed by the preliminary analyses, existing literature, and our aims and hypotheses about variables of importance, we selected physical function, depression, and emotional support. Additional analysis and consideration were given to other measures in the PROMIS-29 but were excluded from the final models due to low correlation with the outcomes or high correlation with the measures selected for inclusion in the model (violating the multicollinearity assumption). As in prior studies,^{32,33,34} we checked for interactions between key variables (eg, depression and emotional support), but they did not contribute significantly to the model, so interaction terms were not included. After adjusting for sociodemographics and then arthritis type, PROMIS measures were included in order of perceived primacy in relation to the participant's health condition (physical function, then depression, then emotional support) to demonstrate the extent to which each measure explains variance in the outcome over and above what is explained by the variables already in the models.

Cohen f , a measure of effect size for multiple regression, quantified the magnitude of model variables on the outcomes.³⁴ We interpreted effect sizes as indicated by Cohen: small $f^2 \geq 0.02$, medium $f^2 \geq 0.15$, and large $f^2 \geq 0.35$.³⁵ Subgroups with ≤ 12 cases were excluded from analyses. Analyses were performed using Stata/SE version 15.1 (StataCorp.).

RESULTS

Study participant demographics. A total of 12,560 individuals completed surveys during the study time frame (Figure 1). Of these, 30% were ineligible for this study because they had not seen a doctor in the past 6 months (required for completing the HCEQ) or did not report having doctor-diagnosed OA or inflammatory arthritis (RA, psoriatic arthritis, ankylosing spondylitis, gout, and juvenile arthritis persistent to adulthood). Another 15% of respondents were excluded because they did not provide sufficient data (key demographics or HCEQ scales). The remaining 6,918 participants were confirmed eligible and included in the study. Demographics are described in Table 1. Respondents were primarily White (86.5%), female (88.6%), urban-dwelling (87.8%), and held at least a 4-year college degree (53.4%; Table 1). Respondents represented 50 states, the District of Columbia, and Puerto Rico.

Nearly one-third of the study sample ($n = 2001$) completed the survey in the first 6 months and indicated their involvement level in the Arthritis Foundation. Of those, 505 (25%) indicated no involvement in the past year, 922 (46%) reported passive engagement (visited the website, received emails), and 574 (29%) reported being actively engaged (volunteered, advocated, led groups).

PROs and health characteristics. Roughly one-third of respondents each had OA, inflammatory arthritis, or both types of arthritis. The study population mean was within 1 SD of the general population t -score mean for each of the following PROMIS measures: ability to participate in social roles and activities, anxiety, depression, emotional support, fatigue, and sleep disturbance (Table 2).^{32,33} In contrast, the study population mean was > 1 SD below the general population mean on physical function, and > 1 SD above the mean on pain interference.^{32,33} Respondents' HCEQ scores covered the full range of possible

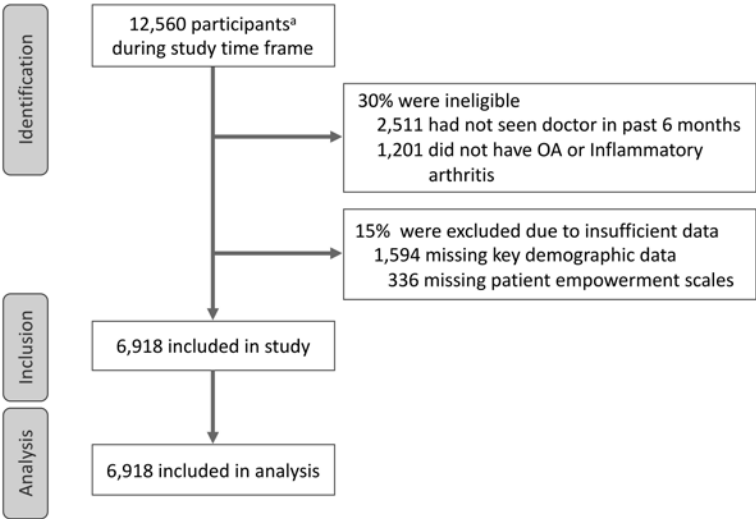


Figure 1. STROBE participant flow diagram. ^a Participants were identified through the Arthritis Foundation's Live Yes! INSIGHTS program, from March 19, 2019 through March 15, 2020. OA: osteoarthritis; STROBE: STrengthening the Reporting of OBservational studies in Epidemiology.

Table 1. Participant characteristics and demographic differences in patient empowerment measures (N = 6918).

	n (%)	Patient Empowerment			
		Patient Information Seeking ^a		Healthcare Interaction Results ^a	
		(range 3–48)		(range 4–64)	
		Mean (SD)	F	Mean (SD)	F
Gender			9.09** ^b		9.70** ^b
Men/male	781 (11.3)	30.4 (11.3)		38.0 (14.6)	
Women/female	6128 (88.6)	31.6 (11.1)		39.7 (14.6)	
Nonbinary/Another gender	9 (0.1)	30.2 (13.6)		38.2 (15.6)	
Race/ethnicity			1.67 ^b		0.71 ^b
White ^c	5985 (86.5)	31.5 (11.1)		39.6 (14.6)	
Black or African American ^c	383 (5.5)	32.5 (10.5)		39.3 (14.6)	
Hispanic or Latino	316 (4.6)	30.7 (10.8)		38.7 (14.0)	
> 1 Race ^c	111 (1.6)	33.1 (11.9)		39.7 (15.0)	
Asian ^c	70 (1.0)	30.4 (11.9)		38.9 (15.5)	
American Indian, Alaska Native ^c	33 (0.5)	30.5 (11.7)		35.6 (15.2)	
Middle Eastern or North African ^c	12 (0.2)	30.3 (13.7)		36.4 (16.5)	
Native Hawaiian/Pacific Islander ^c	8 (0.1)	26.0 (11.4)		30.9 (8.7)	
Education level			32.20**		36.65**
≤ High school diploma/GED	755 (10.9)	29.2 (11.4)		36.5 (14.9)	
Some college	2467 (35.7)	30.6 (10.9)		38.0 (14.4)	
4-year college degree	1914 (27.7)	31.8 (11.1)		40.4 (14.6)	
Graduate degree	1782 (25.8)	33.3 (10.9)		41.8 (14.3)	
Household income			17.33**		34.76**
< \$15,000	445 (6.4)	30.1 (11.2)		35.2 (14.6)	
\$15,000–\$24,999	675 (9.8)	29.7 (11.2)		36.8 (14.5)	
\$25,000–\$49,999	1496 (21.6)	30.2 (10.9)		37.4 (14.1)	
\$50,000–\$74,999	1437 (20.8)	31.9 (11.1)		40.0 (14.5)	
\$75,000–\$99,000	1108 (16.0)	31.8 (10.9)		40.4 (14.2)	
≥ \$100,000	1757 (25.4)	33.1 (11.2)		42.4 (14.6)	
Geographic area ^d			0.50		8.30**
Urban	5820 (87.8)	31.6 (11.1)		39.7 (14.6)	
Rural	811 (12.2)	31.3 (11.1)		38.2 (14.5)	
Missing, n	287				
Arthritis type			20.16**		30.89**
OA	2458 (35.5)	30.5 (11.1)		36.9 (14.1)	
IA ^e	1947 (28.1)	32.6 (11.3)		42.3 (15.0)	
OA and IA ^e	2513 (36.3)	31.6 (10.8)		39.7 (14.4)	

^a A difference of 10% is considered meaningful: 4.6 points for Patient Information-Seeking and 6.1 points for Healthcare Interaction Results (higher scores indicate more of each domain being measured). ^b F statistic and its P value were assessed and reported for groups of n > 12. ^c Non-Hispanic. ^d Geographic areas based on 2010 rural-urban commuting areas (available at: www.ers.usda.gov). ^e IA includes rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, gout, and juvenile arthritis persistent to adulthood. ** P < 0.01. GED: General Education Development; IA: inflammatory arthritis; OA: osteoarthritis.

scores for both Patient Information Seeking (3–48 points) and Healthcare Interaction Results (4–64 points). Cronbach α for HCEQ and PROMIS scales were within the acceptable range, > 0.80 (Table 2), indicating scale reliability with this population.

Differences in empowerment between groups. We noted significant sociodemographic differences for empowerment as measured by the HCEQ (Table 1). Women, people with more education or higher incomes, and people with inflammatory arthritis (vs OA) reported higher levels of Patient Information Seeking and Healthcare Interaction Results. Ratings of Healthcare Interaction Results were higher among urban compared to rural residents, but there was no difference in Patient Information Seeking by geography. Differences were statistically significant, but typically small—less than our chosen 10% threshold to indicate meaningful difference. Only education (high school education or

less vs graduate degree) was meaningfully different for Patient Information Seeking, and only income (< US \$15,000 vs ≥ \$100,000) was meaningfully different for Healthcare Interaction Results. There was no difference in either of the 2 patient empowerment outcomes by race/ethnicity (P > 0.05). Although some groups (namely gender and race) were unequal in size, the analyses were adequately powered and passed the Levene test for homogeneity of variance, indicating no concern of unequal variance despite the relatively smaller group size.

Given the importance of patient empowerment in this study, we checked for differences between those who did not see a doctor in the past 6 months and those who did. A Mann-Whitney U test showed no significant difference ($z = 1.10$, P = 0.28) between emotional support of those who did not see a doctor compared to those who did (both median 49).

Table 2. Descriptive statistics, Cronbach α , and correlation with Health Care Empowerment Questionnaire (HCEQ).

Measure	Mean (SD)	Cronbach α^a	Spearman Rank Correlation Patient Information Seeking	Healthcare Interaction Results
HCEQ scales				
Patient Information Seeking	31.5 (11.1)	0.94	–	0.66**
Healthcare Interaction Results	39.5 (14.6)	0.94	0.66**	–
Health characteristics				
Age, yrs	60.7 (13.0)	N/A	–0.08**	–0.08**
No. of arthritic conditions	2.7 (1.7)	N/A	0.01	–0.04**
Years since diagnosis	17.3 (13.4)	N/A	–0.02	0.01
PROMIS measures (<i>t</i> -scores)				
Ability to participate in social roles and activities	46.2 (8.2)	0.95	–0.08**	–0.25**
Anxiety	56.0 (9.4)	0.91	–0.12**	–0.26**
Depression	55.1 (9.3)	0.92	–0.16**	–0.30**
Emotional support	48.9 (9.2)	0.95	0.25**	0.36**
Fatigue	59.4 (9.5)	0.95	–0.06**	–0.18**
Pain interference	62.9 (7.7)	0.96	–0.07**	–0.25**
Physical function	35.4 (6.3)	0.90	–0.09**	–0.23**
Sleep disturbance	54.7 (8.3)	0.86	–0.06**	–0.19**

^a Cronbach α is a measure of scale reliability for which values > 0.80 are considered acceptable. ** $P < 0.01$. PROMIS: Patient Reported Outcome Measurement Information System.

Factors associated with empowerment. Final models for both patient empowerment outcomes are presented in Table 3. Full hierarchical results are shown in Supplementary Tables 2 and 3 (available with the online version of this article).

Explaining Patient Information Seeking. In checking the assumption of linearity, we identified a curvilinear relationship between Patient Information Seeking and age, in which information-seeking increases with age until 43 years and then

Table 3. Final regression models for variables explaining Patient Information Seeking and Healthcare Interaction Results among adults with arthritis ($n = 6810$).

	Patient Information Seeking				Healthcare Interaction Results			
	<i>b</i>	SE <i>b</i>	β	f^2	<i>b</i>	SE <i>b</i>	β	f^2
Gender (female)	1.54**	0.42	0.04	< 0.01	2.86**	0.50	0.06	0.01
Age	0.33**	0.07	0.38	< 0.01	–0.06**	0.01	–0.05	< 0.01
Age ²	< 0.01**	< 0.01	–0.44	0.01	–	–	–	–
Income, household	0.11	0.09	0.01	< 0.01	0.24*	0.12	0.03	< 0.01
Education level	1.02**	0.14	0.09	0.01	0.90**	0.18	0.06	< 0.01
Arthritis type				0.01				0.02
OA	–	–	–	–	–	–	–	–
IA ^a	1.59**	0.36	0.06		4.04**	0.44	0.12	
OA and IA ^a	1.31**	0.30	0.06		3.65**	0.37	0.12	
Physical function ^b	–0.02	0.02	–0.01	< 0.01	–0.23**	0.03	–0.10	0.01
Depression ^b	–0.08**	0.02	–0.07	0.00	–0.23**	0.02	–0.15	0.02
Emotional support ^b	0.26**	0.02	0.21	0.04	0.44**	0.02	0.28	0.08
Constant	11.45**	2.65			34.25**	2.34		
Model statistics				0.01				0.25
<i>R</i> ²		0.09				0.20		
<i>F</i>		66.90**				202.23**		
Change in <i>R</i> ²		0.04				0.06		
<i>F</i> for change in <i>R</i> ²		261.78**				505.90**		

^a IA includes rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, gout, and juvenile arthritis persistent to adulthood. ^b Patient Reported Information System (PROMIS) measure. * $P < 0.05$. ** $P < 0.01$. *b* is the unstandardized coefficient, SE *b* is the standard error of the unstandardized coefficient, β is the standardized coefficient. f^2 is Cohen f^2 for which ≥ 0.02 is small, ≥ 0.15 is medium, and ≥ 0.35 is large effect size for multiple regression. IA: inflammatory arthritis; OA: osteoarthritis.

decreases. We addressed this by including a quadratic term for age in the model. Four sociodemographic variables (gender, age, education, and income) were included in Model 1, and we subsequently added arthritis type (Model 2), then physical function (Model 3), then depression (Model 4), and finally emotional support (Model 5). Altogether, the final model (Model 5) explained 9.0% of the variance in Patient Information Seeking (Table 3). The estimates for sociodemographic factors (gender, age, education) and depression retained their magnitude, significance, and direction with information-seeking, while income and physical function were no longer significant in the final model. Greater emotional support was linked to higher levels of information-seeking and the full hierarchical regression results show that emotional support was the most important factor in explaining Patient Information Seeking (β 0.21), although the effect size was small (f^2 0.04).

Explaining Healthcare Interaction Results. The same model variables were selected and included in the same order for Healthcare Interaction Results as with Patient Information Seeking. Altogether, the final model (Model 5) explained 20.2% of the variance in Healthcare Interaction Results (Table 3). The estimates for sociodemographic factors, physical function, and depression retained their magnitude, significance, and direction with Healthcare Interaction Results in the final model. Similar to Patient Information Seeking, greater emotional support was linked to greater Healthcare Interaction Results. The full hierarchical regression results show that emotional support was the most important factor in explaining Healthcare Interaction Results (β 0.28), although the effect size was small (f^2 0.08). Arthritis type and depression each also had small effects on Healthcare Interaction Results (f^2 0.02 for each).

Additional considerations. To test our selection of depression over anxiety in the models, we conducted a sensitivity analysis. We compared the results of preliminary and final models with anxiety vs depression added in Model 4 and retained in Model 5 for both outcomes. The results were very similar, with anxiety contributing slightly less to the models than depression. Covariates in the models performed similarly with anxiety as with depression (data not shown).

DISCUSSION

In our cross-sectional sample of 6918 US adults with arthritis, Healthcare Interaction Results—the notion that patients discuss questions with providers, that choices are respected, and that they get the help and information needed—was influenced by many factors. Relevant factors included emotional and physical health, gender, age, arthritis type, and education. We saw similar but weaker trends for Patient Information Seeking, which is the ability to ask questions and obtain explanations and advice. These findings are consistent with studies of related constructs.^{10,11,12,13,14}

Although there is abundant evidence indicating disparities in health outcomes and experiences of care across racial/ethnic groups among adults with arthritis,^{1,36,37} our study found no measurable differences of patient empowerment across racial/ethnic groups. This suggests that empowerment, as measured by

the HCEQ, is equally valued and experienced regardless of race/ethnicity, at least in these adults with arthritis. A recent study of the related skill of self-management found that its prevalence also does not differ by race/ethnicity.¹⁶

After controlling for sociodemographic differences, emotional support contributed the most to explaining both patient empowerment outcomes, compared to arthritis type and physical and mental health indicators. Emotional support is an important factor in a broad range of health outcomes both for the general population^{38,39,40} and those with arthritis specifically.⁴¹ Family, friends, and caregivers play a critical role in providing emotional support to patients with chronic illness, but there is also an opportunity for clinical providers, community-based programs, and advocacy organizations to provide emotional support. Baumhauer and Bozic advocate for an expanded role of specialists in addressing the social and emotional needs of patients,⁴² and provide evidence that empowerment is linked to improved outcomes.⁴³ Arthritis treatment guidelines increasingly acknowledge attention to patient preferences and goal-setting as part of evidence-based care.⁴⁴ For example, the recent OA care guidelines specifically recommend “physical, psychosocial, or mind-body” interventions, the sequence or combination of which may depend greatly on understanding patient goals and preferences.⁴⁵ Patient empowerment indicates how willing or able patients may be to identify and share their goals and preferences. As such, measurements of or attention to patient empowerment and emotional support could inform which patients need more support to feel empowered and share their goals and preferences. Equally as important, community- and peer-based supports such as those offered through the Arthritis Foundation’s network of local volunteers and online communities could be leveraged to enhance emotional support for patients along with other skills in information-seeking to prepare for visits with providers and address areas of concern or needs most relevant to them.

Although our study provides important insights into patient empowerment, it has several limitations. First, there is potential selection bias as we did not randomly select participants. The study sample is not representative of the general population of people with arthritis. (eg, high proportion of White and/or female participants).¹ Types of selection bias implicated include undercoverage, nonresponse bias, and voluntary response bias. Prior research indicates lower internet use among people with low education, low income, and Hispanic and Black individuals.⁴⁶ This study collected data through a web-based survey, which may have contributed to undercoverage of individuals in these groups. Male, Black, and Hispanic respondents are less likely to respond to surveys than female and White individuals.^{47,48} This study would have benefited from oversampling groups that tend to participate at lower rates. There may have been voluntary response bias related to affiliation with or perceptions of the Arthritis Foundation. However, although respondents typically had some level of engagement or familiarity with the Arthritis Foundation, it was largely passive involvement (visiting the website, receiving emails). Second, we asked participants to self-report their arthritis diagnoses. While confirmation with clinical data is preferable, the metaanalysis by Peeters et al

of 16 studies found that accuracy of self-reported arthritis type (specifically OA and RA) was acceptable for large-scale studies in which rheumatologist examination is not feasible.⁴⁹ Third, the recall period for the experience of care measure (HCEQ) was 6 months, whereas the recall period for PROMIS measures was 7 days. It may have been ideal to have the same recall period on all measures used, but we have confidence in both the process used to select optimal measures for the INSIGHTS study¹⁷ and the design and validation of the respective measures.^{18,26–31} Both recall periods are appropriate, given the constructs measured and their frequency of fluctuation. In terms of the models, the low R^2 of both regression models indicates that > 90% of the variance in Patient Information Seeking and nearly 80% of the variance in Healthcare Interaction Results are explained by factors not included in our models. Future studies should explore other factors contributing to patient empowerment, such as experiences related to the specific healthcare visit being assessed, frequency of visits, and type of providers seen. Finally, norms have not yet been established for the HCEQ, so it is unclear what scores might correspond to low vs high patient empowerment. As such, we were unable to examine characteristics of participants who may fall under these categories. Future studies should establish norms and benchmarks to improve the interpretation of HCEQ results. Despite its limitations, our present study benefited from a large sample that adequately powered the analyses, allowed for subgroup analysis by arthritis type, reduced the chance of type II errors, and allowed us to detect small differences in outcomes.

The results of this study improve understanding of what does and does not influence patient empowerment, enabling HCPs, advocacy groups, peers, and caregivers to better support people with arthritis. The role that emotional support plays in explaining patient empowerment provides a basis for further examination of the effect of supportive community resources on health outcomes for people with arthritis. Further studies are needed to understand whether interventions on empowerment directly lead to improved outcomes among patients.

ACKNOWLEDGMENT

We thank Lynn Foster-Johnson, PhD, for her consultation on components of the statistical analysis; the Arthritis Foundation's Live Yes! INSIGHTS Academic Advisory Board for consultation on groupings by arthritis type; and the leaders, staff, and volunteers of the Arthritis Foundation who were responsible for envisioning INSIGHTS, recruiting participants, and collecting data, making this study possible.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

- Barbour KE, Helmick CG, Boring M, Brady TJ. Vital signs: prevalence of doctor-diagnosed arthritis and arthritis-attributable activity limitation - United States, 2013-2015. *Morb Mortal Wkly Rep* 2017;66:246-53.
- Centers for Disease Control and Prevention (CDC). Prevalence and most common causes of disability among adults—United States, 2005. *MMWR Morb Mortal Wkly Rep* 2009;58:421-6.
- Hanly JG, Thompson K, Skedgel C. A longitudinal study of ambulatory physician encounters, emergency room visits, and hospitalizations by patients with rheumatoid arthritis: a 13-year population health study. *J Rheumatol* 2017;44:1421-8.
- Cisternas MG, Yelin E, Katz JN, Solomon DH, Wright EA, Losina E. Ambulatory visit utilization in a national, population-based sample of adults with osteoarthritis. *Arthritis Rheum* 2009; 61:1694-703.
- Cerezo PG, Juvé-Udina ME, Delgado-Hito P. Concepts and measures of patient empowerment: a comprehensive review. *Rev da Esc Enferm da USP* 2016;50:667-74.
- Angelmar R, Bermann B. Patient empowerment and efficient health outcomes. In: *Financing sustainable healthcare in Europe, new approaches for new outcomes, conclusions from a collaborative investigation into contentious areas of healthcare*. Luxembourg: Ministry of Health; 2007.
- Rappaport J. Terms of empowerment/exemplars of prevention: toward a theory for community psychology. *Am J Community Psychol* 1987;15:121-48.
- Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care: effects on patient outcomes. *Ann Intern Med* 1985;102:520-8.
- Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. *Iran Red Crescent Med J* 2014;16:e12454.
- Kjeken I, Dagfinrud H, Mowinckel P, Uhlig T, Kvien TK, Finset A. Rheumatology care: involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis Rheum* 2006;55:394-401.
- Baltaci D, Eroz R, Ankarali H, Erdem O, Celer A, Korkut Y. Association between patients' sociodemographic characteristics and their satisfaction with primary health care services in Turkey. *Kuwait Med J* 2013;45:291-9.
- Brekke M, Hjortdahl P, Kvien TK. Involvement and satisfaction: a Norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic noninflammatory musculoskeletal pain. *Arthritis Rheum* 2001; 45:8-15.
- Neame R, Hammond A, Deighton C. Need for information and for involvement in decision making among patients with rheumatoid arthritis: a questionnaire survey. *Arthritis Care Res* 2005;53:249-55.
- Ackermans L, Hageman MG, Bos AH, Haverkamp D, Scholtes VAB, Poolman RW. Feedback to patients about patient-reported outcomes does not improve empowerment or satisfaction. *Clin Orthop Relat Res* 2018;476:716-22.
- Cooper LA, Roter DL. Patient-provider communication: the effect of race and ethnicity on process and outcomes of healthcare. In: Smedley BD, Stith AY, Nelson AR, editors. *Unequal treatment: confronting racial and ethnic disparities in health care*. Washington, DC: National Academies Press; 2003:552-93.
- Johnson AJ, Sibille KT, Cardoso J, et al. Patterns and correlates of self-management strategies for osteoarthritis related pain among older non-Hispanic Black and non-Hispanic white adults. *Arthritis Care Res* 2021;73:1648-58.
- Schifferdecker KE, Butcher RL, Knight E, et al. Stakeholder development of an online program to track arthritis-related patient-reported outcomes longitudinally: Live Yes! INSIGHTS. *ACR Open Rheumatol* 2020;2:750-9.
- Gagnon M, Hébert R, Dubé M, Dubois MF. Development and validation of an instrument measuring individual empowerment in relation to personal health care: the Health Care Empowerment Questionnaire (HCEQ). *Am J Health Promot* 2006;20:429-35.
- Cella D, Weinfurt K, Revicki D, et al. PROMIS-29 Profile v2.1. PROMIS Health Organization and PROMIS Cooperative

- Group; 2005. [Internet. Accessed February 4, 2022.] Available from: https://www.healthmeasures.net/index.php?option=com_instruments&view=measure&id=849&Itemid=992
20. Hays RD, Spritzer KL, Schalet BD, Cella D. PROMIS®-29 v2.0 profile physical and mental health summary scores. *Qual Life Res* 2018;27:1885-91.
21. Patient-Reported Outcomes Measurement Information System. Emotional support: a brief guide to the PROMIS Emotional Support instruments. [Internet. Accessed February 4, 2022.] Available from: https://www.healthmeasures.net/images/promis/manuals/PROMIS_Emotional_Support_Scoring_Manual.pdf
22. Arthritis Foundation. Live Yes! INSIGHTS Program [Internet. Accessed February 4, 2022.] Available from: <https://www.arthritis.org/liveyes/insights>
23. Knight E, Carluzzo K, Schifferdecker KE, Creek E, Butcher R, Eakin G. Psychometric characteristics of the Health Care Empowerment Questionnaire in a sample of patients with arthritis and rheumatic conditions. *Heal Expect* 2021;24:537-47.
24. Ringash J, O'Sullivan B, Bezjak A, Redelmeier DA. Interpreting clinically significant changes in patient-reported outcomes. *Cancer* 2007;110:196-202.
25. Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. *Clin Rehabil* 2017;31:995-1004.
26. Rose M, Bjorner JB, Gandek B, Bruce B, Fries JF, Ware JE. The PROMIS Physical Function item bank was calibrated to a standardized metric and shown to improve measurement efficiency. *J Clin Epidemiol* 2014;67:516-26.
27. Amtmann D, Cook KF, Jensen MP, et al. Development of a PROMIS item bank to measure pain interference. *Pain* 2010;150:173-82.
28. Lai JS, Cella D, Choi S, et al. How item banks and their application can influence measurement practice in rehabilitation medicine: a PROMIS Fatigue item bank example. *Arch Phys Med Rehabil* 2011;92:S20-7.
29. Pilkonis PA, Choi SW, Reise SP, Stover AM, Riley WT, Cella D; PROMIS Cooperative Group. Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment* 2011;18:263-83.
30. Hahn EA, DeWalt DA, Bode RK, et al; PROMIS Cooperative Group. New English and Spanish social health measures will facilitate evaluating health determinants. *Health Psychol* 2014;33:490-9.
31. Buysse DJ, Yu L, Moul DE, et al. Development and validation of patient-reported outcome measures for sleep disturbance and sleep-related impairments. *Sleep* 2010;33:781-92.
32. Health Measures. PROMIS t-score metric interpretation. [Internet. Accessed February 4, 2022.] Available from: <https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis>
33. Cella D, Riley W, Stone A, et al; PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol* 2010;63:1179-94.
34. Selya AS, Rose JS, Dierker LC, Hedeker D, Mermelstein RJ. A practical guide to calculating Cohen's $f(2)$, a measure of local effect size, from PROC MIXED. *Front Psychol* 2012;3:111.
35. Cohen J. Multiple regression and correlation analysis. In: *Statistical power analysis for the behavioral sciences* 2nd ed. Hillsdale, NJ: Lawrence Erlbaum Associates; 1988; 410-4.
36. Barton JL, Trupin L, Schillinger D, et al. Racial and ethnic disparities in disease activity and function among persons with rheumatoid arthritis from university-affiliated clinics. *Arthritis Care Res* 2011;63:1238-46.
37. Yip K, Navarro-Millán I. Racial, ethnic, and healthcare disparities in rheumatoid arthritis. *Curr Opin Rheumatol* 2021;33:117-21.
38. Reblin M, Uchino BN. Social and emotional support and its implication for health. *Curr Opin Psychiatry* 2008;21:201-5.
39. Kovács P, Pánczél G, Balatoni T, et al. Social support decreases depressogenic effect of low-dose interferon alpha treatment in melanoma patients. *J Psychosom Res* 2015;78:579-84.
40. Worrall H, Schweizer R, Marks E, Yuan L, Lloyd C, Ramjan R. The effectiveness of support groups: a literature review. *Ment Heal Soc Incl* 2018;22:85-93.
41. Dures E, Almeida C, Caesley J, et al. Patient preferences for psychological support in inflammatory arthritis: a multicentre survey. *Ann Rheum Dis* 2016;75:142-7.
42. Baumhauer JF, Bozic KJ. Value-based healthcare: patient-reported outcomes in clinical decision making. *Clin Orthop Relat Res* 2016;474:1375-8.
43. Andrawis J, Akhavan S, Chan V, Lehil M, Pong D, Bozic KJ. Higher preoperative patient activation associated with better patient-reported outcomes after total joint arthroplasty. *Clin Orthop Relat Res* 2015;473:2688-97.
44. Skelly A, Chou R, Dettori J, et al. Noninvasive nonpharmacological treatment for chronic pain: a systematic review. Rockville: Agency for Healthcare Research and Quality; 2018; AHRQ Publication No. 18-EHC013-EF (Comparative Effectiveness Review, no. 209).
45. Kolasinski SL, Neogi T, Hochberg MC, et al. 2019 American College of Rheumatology/Arthritis Foundation guideline for the management of osteoarthritis of the hand, hip, and knee. *Arthritis Care Res* 2020;72:149-62.
46. Hsia J, Zhao G, Town M. Estimating undercoverage bias of internet users. *Prev Chronic Dis* 2020;17:E104.
47. Porter SR, Whitcomb ME. Non-response in student surveys: the role of demographics, engagement and personality. *Res High Educ* 2005;46:127-52.
48. Voigt LF, Koepsell TD, Daling JR. Characteristics of telephone survey respondents according to willingness to participate. *Am J Epidemiol* 2003;157:66-73.
49. Peeters GME, Alshurafa M, Schaap L, de Vet HCW. Diagnostic accuracy of self-reported arthritis in the general adult population is acceptable. *J Clin Epidemiol* 2015;68:452-9.