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CLINICAL CASE SERIES

Aspects of Patient Experience Associated With Improved Scoliosis Research Society-22 Revised (SRS-22R) and European Quality of Life Five-Dimension Five-Level (EQ-5D-5L) Scores in Patients With Adolescent Idiopathic Scoliosis Managed With Observation or Bracing

Yi Ling Chua, MD, Alyssa Jia Ning Toh, BSc, Xavier Yeow Boon Tan, DBSc, Daryl Chen Yi Pan, DBSc, Nicole Kim Luan Lee, PhD, and Kevin Boon Leong Lim, FRCS(Eng), FRCSEd(Orth), MBA

Study Design. Prospective cohort study.

Objective. The purpose of this study was to evaluate the relationship between patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) in adolescent idiopathic scoliosis (AIS) managed nonsurgically with bracing or observation.

Summary of Background Data. PREMs and PROMs are increasingly used to assess the effectiveness of patient-centered health care provision. To date, no study has attempted to study the relationship between PREMs and PROMs in AIS.

Methods. All patients who visited our one-stop, tertiary center for AIS between 2020 and 2021, were asked to complete pairs of PREMs and PROMs questionnaires. PREMs were evaluated using our institution's outpatient experience survey adapted from Hospital Consumer Assessment of Healthcare Providers and Systems survey. PROMs were determined via the Scoliosis Research Society-22 revised (SRS-22r) and European Quality of Life Five-Dimension Five-Level (EQ-5D-5L) forms.

Results. In total, we included 730 patients who completed pairs of PREMs and PROMs questionnaires. 451 patients were treated by observation and 279 were braced. In the observation group, there was no association between patient experience and SRS-22r or EQ-5D-5L scores. In the brace group, improved SRS-22r were associated with higher PREM scores. In particular, having confidence and trust in treating physicians ($r = 0.34$), reporting that their worries and concerns were addressed during treatment ($r = 0.34$) and being taught self-care ($r = 0.33$, $P < 0.0001$ for all) were most highly correlated with better SRS-22r scores.

Conclusions. In patients with AIS treated with bracing, improved patient experience was positively correlated with better patient reported outcomes, especially if patients' concerns were addressed during treatment and they received supportive care and education on self-care. In contrast, patient experience did not correlate with PROMs in children and adolescents with AIS who were under observation.

Key Words: adolescent idiopathic scoliosis, patient-reported experience measures, patient-reported outcome measures, bracing

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Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) are increasingly used in the clinical setting to measure the effectiveness of health care provided. The patient experience is defined by the Beryl Institute as "the sum of all interactions, shaped by an organisation's culture, that influence patients' perceptions across the continuum of care."[1] PREMs assess the perspectives of patients on the health care they received and can be influenced by physicians' bedside manners, respectful and courteous treatment, clean surroundings and appropriate privacy.[1] Meanwhile, PROMs evaluate health-related quality of life as reported by patients and is used as a surrogate for the effectiveness of care delivered. When evaluated together, PREMs and PROMs

help us to understand the needs of patients and serve as a foundation for improvement of health care processes and services.

Adolescent idiopathic scoliosis (AIS) is a condition that can result in significant back deformity and changes in appearances of affected teenagers, with subsequent impact on their health-related quality of life throughout adolescence. AIS can be managed either surgically or nonsurgically with observation or bracing depending on the severity of one's deformity. In the present study, we seek to answer the question—if there is any association between patients' experiences as evaluated through PREMs and their reported outcomes for those with AIS who were managed nonsurgically. We hypothesize that certain aspects of care, such as higher level of trust and confidence in the treating team, will be associated with improved patient-reported outcomes.

To the best of our knowledge, there is no study in the current literature evaluating the relationship between PREMs at outpatient visits and Scoliosis Research Society-22 Revised (SRS-22r) and European Quality of Life Five-Dimension Five-Level Version (EQ-5D-5L) scores in the pediatric population with AIS managed nonsurgically with bracing and observation. Therefore, the aim of our study was to study the relationship between PREMs and PROMs in this subgroup of patients with AIS, with the objective of identifying specific visit, health care provider and environmental factors that may be associated with improved outcome scores.

Despite the increasing emphasis on patient-centered care, there has also not been any clear established link between patient satisfaction and clinical outcomes or effectiveness of care. Some authors have attempted to investigate the relationship between PREMs and PROMs in surgical patients. Black et al[2] analyzed data from 4089 hip replacements, 4501 knee replacements, and 1793 groin hernia repairs and reported weak positive associations between patients' experiences as evaluated by questionnaires based on the National Inpatient Surveys by the Picker Institute and disease-specific PROMs for hip and knee replacements, as well as EQ-5D-5L scores.[3]

Hence, through our present study, we aim to determine whether there is any association between PREMs and PROMs in a unique population of pediatric patients with AIS, so as to better focus discussions between patients and providers during their care and improve modifiable environmental factors.

MATERIALS AND METHODS

This study was carried out at a tertiary, one-stop facility for children and adolescents with AIS. Patients who visited our institution between 2020 and 2021 were invited to complete a set of questionnaires assessing PREMs and PROMs.

PREMs were evaluated using our institution's outpatient experience feedback form (Supplemental file, Supplemental Digital Content 1, http://links.lww.com/BRS/B992) adapted from the Hospital Consumer Assessment of Healthcare Providers and Systems survey.[4,5] The PREMs form comprised of 23 questions, assessing seven domains of patient-centered care, adapted from Santana et al[6] (Supplemental file, Supplemental Digital Content 1, http://links.lww.com/BRS/B992 and Table 1).

PROMs comprised of the SRS-22r and EQ-5D-5L questionnaires, which evaluated health-related quality of life pertaining to pain, function, self-image, mood, and

TABLE 1. Domains of Patient-Centered Care and Patient-Reported Experience Measures (PREMs)	
Patient-centered care domains	**Patient-reported experience measures (PREMs)**
Listening to patients	How often did doctors/doctor's assistants/nurses listen carefully to you? If you had worries or concerns during your treatment, how often did the doctor/nurse discuss them with you?
Respecting preferences, needs, and values	How often did doctor's assistant/nurses/counter staff treat you with courtesy and respect? How often do you think that staff worked well and in an age-appropriate manner with you? How often did you have enough privacy?
Providing supportive care	How often did you have confidence and trust in the doctors/nurses treating you?
Engaging patients in care plans	How often were you given enough input or say in your care?
Integration and coordination of care	How often were the different staff members consistent with each other in providing you information about your care? How often was there good communication between the different staff members treating you? How often was the doctor/nurse fully aware of your important medical information?
Education and providing information	How often did doctors/doctor's assistant/nurses/counter staff explain things in a way you could understand? Were you taught all you needed to know about how to care for yourself at home? Did you get information about what symptoms or health problems to look out for after you left the hospital?
Physical comfort	How often did areas around you appear clean?
*Patient-centered care domains adapted from Santana et al.[6]	

mental health. The EQ-5D-5L mean index score is calculated using a specific formula from the descriptive EQ-5D-5L system, which assigns 1 to 5 points depending on the responder's answer—1 point or level 1 indicating no problem in a particular domain and 5 points representing extreme difficulty.[7,8] EQ-5D-5L mean index values range from 0 (worst state possible) to 1 (full health).[7,8] The EQ-Visual Analog Scale score was rated on a scale of 0 to 100 points, with 0 points indicating the worst possible health status and 100 points indicating the best possible health status.

PREMs and PROMs questionnaires were distributed to patients via quick response codes at the end of their clinic visit. They were allowed to complete it on their personal mobile devices with guidance from clinic staff when necessary.

Inclusion and Exclusion Criteria

All patients with AIS aged 8 to 21 years of age, regardless of Risser grade, who visited our institution for follow-up and were treated with brace or under observation were included in the study. Patients without completed PREMs and PROMs and those awaiting surgery were excluded.

Statistical Analyses

Statistical analyses were performed using SPSS software (IBM SPSS Statistics for Windows, Version 19.0. Armonk, NY). Comparisons between groups were made using unpaired Student t tests for parametric data and Mann-Whitney U tests for nonparametric data. Fisher exact test was used to analyze dichotomous data. Multivariate regression analysis with Pearson correlation coefficient (r) was used to examine associations between PREMs and PROMs. Final effect scores ranged between –1 (negative linear correlation) and +1 (positive linear correlation). The values of $0.1 < |r| < 0.3$, $0.3 < |r| < 0.5$, and $|r| > 0.5$ detected weak, medium, and strong correlations, respectively. Significance was assessed through χ^2 test, with $P < 0.05$ considered statistically significant.

RESULTS

A total of 730 patients filled up pairs of PREM and PROM questionnaires. Total 451 patients were managed with observation and 279 patients underwent bracing. The patient demographics of the 2 cohorts are summarized in Table 2.

Age, ethnicity, and BMI were similar between the groups. There were more females than males in both the observation (66% *vs.* 34%) and brace groups (87% *vs.* 13%; $P < 0.001$). The brace cohort had a larger mean Cobb angle than the observation group ($33.7° \pm 11.61$ *vs.* $21.6° \pm 14.17$, $P < 0.001$).

The differences in mean scores of various domains of SRS-22r between observation and brace groups are represented in Figure 1. Compared with the observation group, the brace cohort had statistically significantly lower total SRS-22r scores and poorer function, self-image, and mental

TABLE 2. Patient Demographics of Observation and Brace Groups

	Observation (n = 451)	Bracing (n = 279)	*P*
Age, y			
Mean	14.6 ± 1.96*	14.6 ± 1.72	0.13
Median	14.6	14.2	—
Sex			
Males	155 (34)†	36 (13)	< 0.001
Females	296 (66)	243 (87)	—
Ethnicity			
Chinese	393 (87)	235 (84)	0.23
Malay	30 (7)	17 (6)	—
Indian	10 (2)	6 (2)	—
Others	18 (4)	21 (8)	—
Body mass index (BMI), kg/m2	18.4 ± 3.33	18.6 ± 3.07	0.61

*Data expressed mean ± SD.
†Data expressed as number (percentage).

health. Both groups had similar pain levels and satisfaction with management.

The EQ-5D-5L scores in each domain of the two cohorts are summarized in Table 3. The observation group had more favorable EQ-5D-5L mean index scores (0.90 ± 0.17 *vs.* 0.88 ± 0.19, $P = 0.037$) and EQ-Visual Analog Scale scores (86.50 ± 18.40 *vs.* 83.15 ± 19.03, $P = 0.001$). The brace group reported greater difficulty in their usual activities than the observation group (1.09 ± 0.30 *vs.* 1.05 ± 0.23, $P = 0.029$). Scores were similar between the two cohorts in the rest of the categories pertaining to mobility, self-care, pain, and discomfort, as well as anxiety and depression.

The PREMs scores of the observation and brace cohorts are summarized in Figure 2. Compared with the brace group, patients under observation reported more favorable total PREMs score (3.80 ± 0.32 *vs.* 3.74 ± 0.36, $P = 0.017$) and better experience in the PREM domains of being (1) listened to ($P = 0.003$), (2) provided with supportive care ($P = 0.032$), and (3) education and information provision ($P = 0.045$). Both groups had similar PREMs scores in (1) having their preferences, needs and values respected, (2) being engaged in their care plans, (3) integration and coordination of care, and (4) physical comfort.

Observation Group

In the observation group, no significant correlation was found between PREMs and SRS-22r or EQ-5D-5L scores.

Brace Group

Table 4 summarizes the significant results of the correlation analysis between PREMs and SRS-22r (PROMs). In the brace group, an intermediate positive correlation was
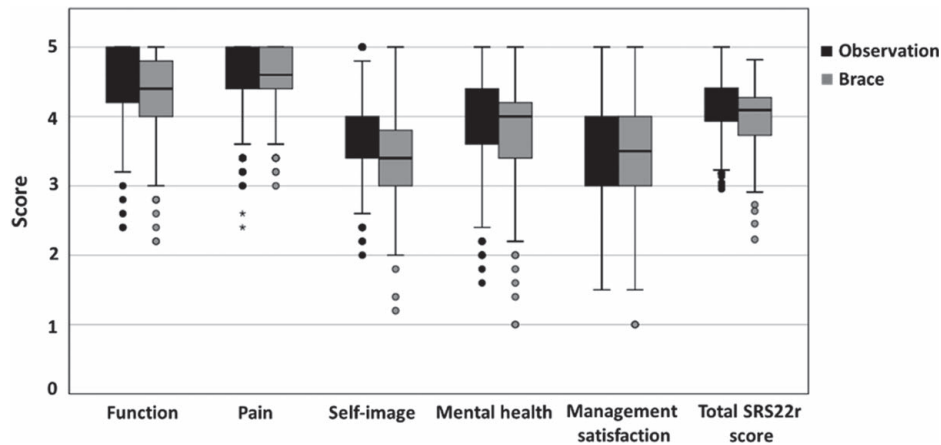
SRS-22r Domains	Observation (n = 451)	Bracing (n = 279)	P-Value	Difference in Scores Between Groups	Minimum Detectable Measurement Difference (MDMD)[9]
Function	4.53 ± 0.50	4.35 ± 0.58	< 0.001	0.18	0.24
Pain	4.61 ± 0.48	4.57 ± 0.46	0.131	0.04	0.30
Self-image	3.66 ± 0.51	3.39 ± 0.58	< 0.001	0.27	0.30
Mental Health	3.96 ± 0.69	3.78 ± 0.73	0.003	0.18	0.27
Management satisfaction	3.64 ± 0.73	3.54 ± 0.77	0.173	-	-
Total score	4.14 ± 0.38	3.98 ± 0.43	< 0.001	-	-

Data expressed as mean ± standard deviation.*Significant P-value.

Figure 1. Comparison between observation and brace groups in domains of SRS-22R. Data expressed as mean ± SD. *Significant *P*-value. SRS-22R indicates Scoliosis Research Society-22 Revised.

observed between total SRS-22r scores and patient-reported level of confidence and trust in doctors ($r = 0.31$) and nurses ($r = 0.34$, $P < 0.0001$ for both). Increased satisfaction with management in SRS-22r was positively correlated with having confidence and trust in the treating doctors ($r = 0.32$, $P < 0.0001$).

Higher total SRS-22r scores were weak to moderately positively correlated with being treated with courtesy and respect by the doctor's assistant ($r = 0.30$), having worries and concerns addressed during treatment ($r = 0.34$), communication in an age-appropriate manner ($r = 0.30$), and being taught how to care for oneself at home ($r = 0.33$, $P < 0.0001$ for all).

TABLE 3. Comparison Between Observation and Brace Groups in EQ-5D-5L Domains			
EQ-5D-5L domains	Observation (n = 451)	Bracing (n = 279)	*P*
Mobility	1.05 ± 0.25	1.05 ± 0.23	0.40
Self-care	1.01 ± 011	1.02 ± 0.17	0.62
Usual activities	1.05 ± 0.23	1.09 ± 0.30	0.029*
Pain and discomfort	1.27 ± 0.45	1.33 ± 0.47	0.076
Anxiety and depression	1.18 ± 0.40	1.21 ± 0.43	0.37
EQ-5D-5L Mean Index score	0.90 ± 0.17	0.88 ± 0.19	0.037*
EQ-VAS (Visual Analog Scale) score	86.50 ± 18.40	83.15 ± 19.03	0.001*

Data expressed as mean ± SD.
*Significant P-value.
EQ-5D-5L indicates European Quality of Life 5-Dimension 5-Level.
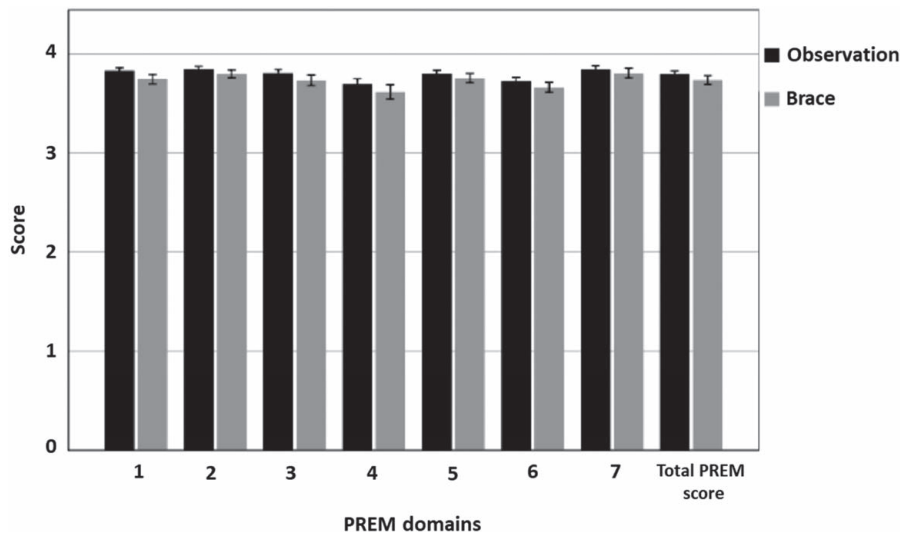
PREMs Domains	Observation (n = 451)	Bracing (n = 279)	P-Value
1. Listening to patients	3.83 ± 0.33	3.75 ± 0.40	0.003*
2. Respecting preferences, needs and values	3.85 ± 0.29	3.80 ± 0.35	0.061
3. Providing supportive care	3.81 ± 0.41	3.73 ± 0.46	0.032*
4. Engaging in care plans	3.70 ± 0.59	3.62 ± 0.62	0.085
5. Integration and coordination of care	3.80 ± 0.38	3.76 ± 0.39	0.109
6. Education and providing information	3.73 ± 0.40	3.66 ± 0.43	0.045*
7. Physical comfort	3.84 ± 0.40	3.81 ± 0.42	0.223
Total score	3.80 ± 0.32	3.74 ± 0.36	0.017*

*Data expressed as mean ± standard deviation. *Significant P-value.*

Figure 2. Comparison between observation and brace groups in PREMs domains. Data expressed as mean ± SD. *Significant *P*-value. PREM indicates patient-reported experience measures.

DISCUSSION

Our results indicate that compared with patients with AIS under observation, those treated with brace had statistically significantly lower total SRS-22r scores (4.14 ± 0.38 vs. 3.98 ± 0.43, $P < 0.001$), poorer function (4.53 ± 0.50 vs. 4.35 ± 0.58, $P < 0.001$), self-image (3.66 ± 0.51 vs. 3.39 ± 0.58, $P < 0.001$), and mental health (3.96 ± 0.69 vs. 3.78 ± 0.73, $P = 0.003$). Although statistically significant, the differences in SRS-22r domain scores between our observation and brace cohorts were not clinically relevant when the minimum detectable measure differences (MDMD) for SRS-22r in AIS patients, as determined by Kelly *et al*, were applied (Figure 1).[9] For all the three categories of function, self-image and mental health, the differences in scores between the two groups were less than the MDMD. There was no statistically significant difference between our cohorts with regards to pain and management with satisfaction in the SRS-22r.

On the contrary, Meng *et al* reported in a meta-analysis of seven studies that brace-treated AIS patients had higher total SRS-22r (standardized mean difference = 0.312, 95% CI, 0.054–0.571, $P = 0.018$) and satisfaction with management scores (standardized mean difference = 0.393, 95% CI, 0.127–0.659, $P = 0.004$) compared with those under observation.[10] Hence, the authors concluded that those who underwent bracing for AIS had an improved quality of life. Meng and colleagues did not find significant differences in function, self-image, and mental health between the groups. In a study by Schwieger *et al*,[11] the authors studied the effect of brace treatment on body image and quality of life in adolescents with AIS and found no significant difference between those treated with a brace or under observation at two years follow-up. They concluded that wearing a brace did not have a negative impact on quality of life or body image.

The lower total SRS-22r scores in our brace cohort could be because of several factors, such as varying levels of

TABLE 4. Correlation Between PROMs (SRS-22r) and PREMs

Brace group

SRS-22r domain	Patient-centered care domains	Patient-reported experience measures (PREMs)	Correlation coefficient (Pearson r value)	P
Satisfaction with management	Providing supportive care	How often did you have confidence and trust in the doctors treating you?	0.32	<0.0001
Total score	Providing supportive care	How often did you have confidence and trust in the doctors treating you?	0.34	<0.0001
	Providing supportive care	How often did you have confidence and trust in the nurses treating you?	0.31	—
	Respecting preferences, needs, and values	How often did the doctor's assistant treat you with courtesy and respect?	0.30	—
	Respecting preferences, needs, and values	How often do you think that staff worked well and in an age-appropriate manner with you?	0.30	—
	Listening to patients	If you had worries or concerns during your treatment, how often did the doctor/nurse discuss them with you?	0.34	—
	Education and sharing information	Were you taught all you needed to know about how to care for yourself at home?	0.33	—

SRS-22r indicates Scoliosis Research Society-22 revised.

Adapted from Santana et al.[6] Adaptations are themselves works protected by copyright. So in order to publish this adaptation, authorization must be obtained both from the owner of the copyright in the original work and from the owner of copyright in the translation or adaptation.

stigma associated with wearing a brace in the local population or different patient experience during clinical care. Adolescence is a period of time in the life of pediatric patients where they establish their self-identity and confidence and the impact of AIS and brace therapy on their appearance and self-image may in turn, affect their treatment outcomes. Wang et al[12] identified self-image, followed by mental health, as the most commonly reported quality of life domains affected in patients with scoliosis undergoing brace treatment. Moreover, when the MDMDs published by Kelly et al[9] for SRS-22r were applied, we found that the differences in SRS-22r scores between those who were braced compared with patients under observation were likely not clinically relevant, although statistically significant (Figure 1).

Our results indicate that overall, the EQ-5D-5L index score is more favorable in the observation than brace cohort, whereas the two groups fared equally in domains of pain, self-care, and mobility, as well as, anxiety and depression. The brace group reported greater difficulty with their usual activities compared with the untreated group. Cheung et al[13] similarly studied 652 patients with AIS and reported better EQ-5D-5L scores in those managed with observation than those who were braced at the time of study (mean difference = 0.08, $P < 0.001$). Interestingly, Cheung and colleagues reported that patients who were previously braced had improved EQ-5D-5L scores (mean difference = 0.05) than those currently undergoing bracing ($P < 0.001$).

Within our observation cohort, we did not find any significant correlation between PREMs and PROMs. However, in the brace group, we observed that the greater confidence and trust in doctors and nurses were moderately correlated with improved total SRS-22r scores and satisfaction with management ($r = 0.31–0.34$, $P < 0.0001$). In addition, higher total SRS-22r scores were weak to moderately associated with being treated with courtesy and respect by the doctors' assistant and receiving age-appropriate communication ($r = 0.30$, $P < 0.0001$). Patients who reported having their worries and concerns addressed during treatment and being taught how to care for themselves were also more likely to have better total SRS-22r scores ($r = 0.33–0.34$, $P < 0.0001$).

To the best of our knowledge, no study which investigates the relationship between PREMs and PROMs in patients with AIS managed nonsurgically exists to date. Black et al[2] analyzed data from 4501 knee replacements, 4089 hip replacements, and 1793 groin hernia repairs and found weak positive associations between patient experience and reported outcomes ($r = 0.2$ for all three elective surgeries). The authors concluded that the aspect of patient experience most strongly associated with improved outcomes was having trust in the treating physicians—a similar conclusion we have made based on our results. Such a correlation indicate that patients who have higher level of trust and confidence in their treating team also tend to report better outcomes, although more studies are required to study the cause and effect between the two. Majority of

studies analyzing the relationship between PREMs and PROMs have been performed in primary and ambulatory care. Overall, these studies report weak positive associations (correlation coefficients ranging from 0.1 to 0.3) between improved patient experience and outcomes.[14–16]

Limitations

The present study has several limitations. First, bias may be introduced in the responses of younger participants who experienced difficulty comprehending key terms and questions in the surveys. For instance, it is difficult for an eight-year-old child to understand the term "attractive" in the SRS-22r question "Do you feel attractive with your current back condition?" and to respond appropriately to "Are you and/or your family experiencing financial difficulties because of your back?" without awareness of their financial status. If parents assisted the young children by asking leading questions and implying their personal opinions, this may lead to confirmation bias. As much as possible, we minimized interviewer bias by encouraging participants to complete the surveys on their own and provided those who required clarification with professional aid and neutral questioning from health care assistants and physiotherapists. Secondly, the positive associations we have found between PREMs and PROMs in the present study do not prove casualty. It is possible that factors associated with improved patient experience are also associated with better outcomes. For example, surgeons who are better communicators may also be more proficient in their management of AIS. Moreover, patients who had better outcomes may overlook minors concerns in their experiences at outpatient visits and hence, report higher PREMs scores. In the absence of an intervention study, it is not possible to determine the direction of influence between PREMs and PROMs or whether the association between the two is a casual relationship. Despite the above limitations, our study is the first to attempt to study the relationship between PREMs and PROMs in a population of patients with AIS managed nonsurgically.

CONCLUSIONS

In conclusion, our results demonstrate that there are intermediate positive associations between better patient experience and outcomes, with correlation coefficients of more than 0.3. Having confidence and trust in the treating physician ($r = 0.34$), having worries and concerns addressing during treatment ($r = 0.34$) and being provided with information for self-care ($r = 0.33$) were most strongly associated with improved PROMs. These positive associations were only observed in the brace group, but not in patients with AIS under observation. Hence, we conclude that positive clinic experiences are not associated with improved patient-reported outcomes in the pediatric population with AIS managed with observation. However, in those treated with a brace, special attention should be paid to addressing concerns that arise during treatment and

providing adequate information on aftercare beyond the clinic visit, in addition to age-appropriate physician-patient communication.

Moving forth, routine collection of PREMs and PROMs may be integrated in pediatric clinical settings to help inform decisions that improve processes in patient-centered care models, especially in the current health care setting where patient satisfaction is increasingly used to evaluate the effectiveness of care delivered.

> ## ➢ Key Points
>
> ❑ Better patient experience is not associated with improved patient-reported outcomes in the pediatric population with adolescent idiopathic scoliosis who were managed with observation.
>
> ❑ Improved patient experience is associated with better patient-reported outcomes, as evaluated by SRS-22r and EQ-5D-5L, in patients with adolescent idiopathic scoliosis who underwent brace therapy.
>
> ❑ In particular, key aspects in physician-patient communication including (1) being treated with courtesy and respect and (2) age-appropriate communication were associated with better outcomes reported by patients.
>
> ❑ Care should be given to (1) addressing worries and concerns raised during clinic consults and (2) providing adequate information and advice on self-care beyond the clinic visit in managing patients with adolescent idiopathic scoliosis who are treated nonsurgically.

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