

# Adolescent idiopathic scoliosis patients treated with bracing, surgery, or observation showed no difference in behavioral and emotional function over a 2-year period

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## Abstract

The purpose of this study was to assess if behavior and emotional function, as measured by the Pearson Behavioral Assessment Survey for Children, Second Edition (BASC-2) in patients and parents, changes with differing treatment protocols in patients with adolescent idiopathic scoliosis (AIS). One previous study showed abnormal BASC-2 scores in a substantial number of patients diagnosed with AIS; however, no study has assessed how these scores change over the course of treatment. AIS patients aged 12 to 21 years completed the BASC-2. The 176-item questionnaire was administered to subjects at enrollment, assessing behavioral and emotional problems across 16 subscales of 5 domains: school problems, internalizing problems, inattention/ hyperactivity, emotional symptoms index, and personal adjustment. Parents were given an equivalent assessment survey. Surveys were administered again after 2 years. Subject treatment groups (bracing, surgery, and observation) were established at enrollment. Patients were excluded if they did not complete the BASC-2 at both time points. Forty-six patients met the inclusion criteria, with 13 patients in the surgical, 20 in the bracing, and 13 in the observation treatment groups. At enrollment, 26% (12/46) of subjects with AIS had a clinically significant score in 1 or more subscales, and after 2 years 24% (11/46) of subjects reported a clinically significant score in at least 1 subscale (P = .8). There were no significant differences in scores between enrollment and follow-up in any treatment group. Similar to what was reported in a previous study, only 36% (4/11) of patients had clinically significant scores reported by both patient and parent, conversely 64% (7/11) of parents were unaware of their child's clinically significant behavioral and emotional problems. Common patient-reported subscales for clinically significant and at-risk scores at enrollment included anxiety (24%; 11/46), hyperactivity (24%; 11/46), attention problems (17%; 8/46), and self-esteem (17%; 8/46). At 2-year follow-up, the most commonly reported subscales were anxiety (28%; 13/46), somatization (20%; 9/46), and self-esteem (30%; 14/46). Patients with AIS, whether observed, braced or treated surgically, showed no significant change in behavior and emotional distress over the course of their treatment, or compared with each other at 2-year follow-up.

**Abbreviations:** AIS = adolescent idiopathic scoliosis, BASC-2 = Behavioral Assessment Survey for Children, second edition, PRS = parent rating scales, SRP = self-report of personality for adolescents, SRS-22 = Scoliosis Research Society-22r Patient Questionnaire.

Keywords: adolescent idiopathic scoliosis (AIS), psychosocial health, bracing, surgery, observation

None of the authors received financial support for this study. Dr Andras has received stock options from Eli Lilly and publishing royalties from Orthobullets. She is a paid presenter/speaker for NuVasive and a paid consultant for Zimmer Biomet. She has served as a board member for Pediatric Orthopedic Society of North America and Scoliosis Research Society and on an editorial board for the Journal of Pediatric Orthopedics. Dr Skaggs has received royalties from Wolters Kluwer Health, Zimmer Biomet, Globus Medical, and Medtronic; consulting fees from Zimmer Biomet, Globus Medical, Top Doctors, and Orthobullets; research funding from NuVasive; has ownership interest in Zipline Medical, Inc., Green Sun Medical, and Orthobullets; and has held leadership or advisory positions in the Pediatric Spine Foundation and CHLA Foundation. He has served as a co-editor in chief for Orthobullets and on editorial boards for Spine Deformity, Orthopedics Today, and Journal of Children's Orthopaedics. The rest of the authors have no funding to disclose.

The authors have no conflicts of interest to disclose.

The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

This study has been carried out with approval from the Institutional Review Board at Children's Hospital Los Angeles. Informed consent was obtained from participating patients and/or families. <sup>a</sup> Jackie and Gene Autry Orthopedic Center, Children's Hospital Los Angeles, Los Angeles, CA.

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How to cite this article: Jalloh H, Andras LM, Sanders A, lantorno S, Hamilton A, Choi PD, Skaggs DL. Adolescent idiopathic scoliosis patients treated with bracing, surgery, or observation showed no difference in behavioral and emotional function over a 2-year period. Medicine 2023;102:3(e32610).

Received: 15 September 2022 / Received in final form: 15 December 2022 / Accepted: 19 December 2022

Study Design: Prospective study of consecutive patientsLevel of Evidence: Ilhttp://dx.doi.org/10.1097/MD.00000000032610

## 1. Introduction

The impact of adolescent idiopathic scoliosis (AIS) on the mental and emotional status of patients has raised many concerns. Studies have assessed the psychological and emotional effects of scoliosis on adolescents particularly, as this is already a mentally and socially trying time for children and young adults.<sup>[1–3]</sup> One previous study has shown that 32% (29/92) of patients with AIS showed signs of clinically significant psychological distress after taking the Behavioral Assessment System for Children, Second Edition (BASC-2).<sup>[4]</sup>

The BASC-2 is an established questionnaire that has been used in hundreds of studies to assess changes in behavior and emotional well-being. The BASC-2 self-report of personality for adolescents (SRP) is validated for ages 12 to 21, and it seeks to understand the emotions and thoughts of the subject. It consists of 176 questions and 5 domains (school problems, internalizing problems, inattention/ hyperactivity, emotional symptoms index, and personal adjustment) with 16 subscales including anxiety, depression, and self-esteem.

The BASC-2 parent rating scales (PRS) is an assessment tool given to the parents to gauge behavioral and adaptive functioning of their children. This consists of 150 questions in 4 domains (internalizing problems, externalizing problems, behavioral symptoms index, and adaptive skills) with 14 subscales including anxiety, depression, and social skills.

Many studies have sought out to assess how mental health changes in patients with AIS over time,<sup>[2,3]</sup> and some have found that change to be associated with curve severity, treatment type, and duration of treatment.<sup>[5]</sup> These studies of patients with AIS have used assessments such as the Scoliosis Research Society-22r Patient Questionnaire (SRS-22)<sup>[6,7]</sup> and other health-related quality of life assessments,<sup>[3,8]</sup> but none have used as detailed of a measure as the BASC-2 Assessment. The purpose of this study was to assess the behavioral and emotional functioning of AIS patients with differing treatment protocol over a 2-year period using the BASC-2 patient and parent surveys.

## 2. Materials and methods

After obtaining IRB approval, patients were prospectively enrolled in this single-center study. All patients with AIS between the ages of 12 and 21 years were invited to participate. These ages were selected as the BASC-2 is validated over this age range. Patients with types of scoliosis that were not idiopathic and those who had already undergone operative treatment for their scoliosis prior to enrollment or who did not complete the 2-year follow-up survey were excluded from the study.

Patients were approached at routine follow-up visits by a research assistant or manager. The patient and parent were both informed of the study, the time commitment, and potential risks and benefits. After enrollment, the patients were given the survey along with their parents to fill out separately. Enrollment was from September 2014 to June of 2015.

Upon enrollment, both patient and parent were given BASC-2 questionnaires to complete separately. The patients received the BASC-2-SRP, while parents completed the BASC-2-PRS. Scores were entered using the Pearson BASC-2 Assist Scoring and Report System, and reports for each patient and parent, detailing *t* scores, percentiles, and clinical significance across subscales, were obtained. Two years after the initial survey, the patient and parent were again asked to complete the BASC-2-SRP and BASC-2-PRS in the orthopedic clinical setting, respectively. Patients and parents who did not have follow-up appointments in clinic received the surveys via mail.

Subject results were analyzed by factors including treatment group. These groups were defined by the treatment reported at the initial visit. The surgical group consisted of patients who were preoperative at the time of enrollment. Patients were considered to be in the bracing group if they were using a brace or had bracing initiated at the time of the initial survey. Patients who were being observed with no intervention upon enrollment were placed in the observation group. Participation in this study had no impact on what treatment was recommended.

Values from the reports collected included the number of clinically significant, at-risk, and normal scores in each subscale and domain, which were determined by patient t scores and compared against validated patient-matched normative data. Patient and parent scores of "clinically significant," "at risk" and "normal" were determined by t scores in each subscale that were compared to established age-matched normative data (lines 71–72).

Clinically significant and at-risk domains are identified based on comparisons to normative population date for each age across the range of 12 to 21 years. Statistical analysis was completed using STATA and included chi-squared tests to assess changes in the number of clinically significant and at-risk scores reported over time across treatment groups. Level of significance was defined as P < .05.

# 3. Results

One hundred thirty-seven patients with AIS were approached to participate in this study. Twelve declined to participate, and 5 enrolled but did not complete the survey. The remaining 120 patients completed the baseline survey, and 46 completed the follow-up survey comprising the study cohort. The mean age was 13.6 years (range: 12-18) at enrollment. Mean follow-up was 28 months, with the minimum follow-up at 20 months. Of the 46 patients, 87% (40/46) were female and 13% (6/46) were male. 28% (13/46) of patients were pre-operative at time of enrollment and were in the surgical group. 43% (20/46) were in the bracing group; 25% (5/20) of these patients initiated bracing at the enrollment visit, and the rest had been bracing for an average of 7 months. Of the 20 bracing patients, only 1 was still bracing at the 2-year follow-up visit. 28% (13/46) patients were in the observation group at the initial survey. Five of 20 patients in the bracing group and 3/13 in the observation group ended up having surgery before the 2 year follow-up. Across the surgical (N = 13), bracing (N = 20), and observation (N = 13) treatment groups at enrollment, the average Cobb angles were 59° (range: 45–95°), 30° (range: 16–43°), and 33° (range: 21–60°), respectively. Of note there was 1 patient in the observation group who had a Cobb angle of 60 degrees, but had declined surgery. At the time of the 2-year follow-up all patients in the surgical group had in fact undergone surgery.

# 3.1. Clinically significant and at-risk scores

At enrollment, 26% (12/46) of subjects with AIS had a clinically significant score in 1 or more subscales, and after 2 years 24% (11/46) of subjects reported a clinically significant score in at least 1 subscale (P = .8). There was no significant difference in clinically significant scores between enrollment and follow-up in any treatment group (Table 1).

Clinically significant and at-risk scores were combined, creating an at least at-risk category. At enrollment, 54% (25/46) of subjects had an at least at-risk score in 1 or more subscales. After 2 years, there were no changes in the number of patients, that is, still 54% (25/46), who were at least at-risk (P = 1.0). There was also no significant change in reported at least at-risk scores between enrollment and follow-up across treatment groups (Table 2).

At enrollment, patient Cobb angles were not correlated with the number of clinically significant (P = .37, R = 0.14), at-risk (P = .23, R = 0.18), or at least at-risk (P = .19, R = 0.23) scores reported on the BASC-2-SRP. After 2 years, Cobb angles were also not found to be correlated with the number of clinically significant scores reported by patients (P = .41). When considering

 Table 1

 Percent of patients reporting clinically significant scores in at least 1 subscale.

	All subjects	Bracing	Surgical	Observation	
	(N = 46)	(N = 20)	(N = 13)	(N = 13)	P value
Enrollment	26% (12/46)	20% (4/20)	46% (6/13)	15%	.14
2 year follow-up	23% (11/46)	20% (4/20)	38% (5/13)	15%	.33
P value	.8	1.0	.7	(2/13) 1.0	

#### Table 2

Percent of patients reporting at least at-risk scores in 1 or more subscales.

	All subjects	Bracing	Surgical	Observation	
	(N = 46)	(N = 20)	(N = 13)	(N = 13)	P value
Enrollment	55% (25/46)	45%	69%	54% (7/13)	.39
2-yr follow-up	55%	50% (10/20)	69% (9/13)	46% (6/13)	.44
P value	1.0	.8	1.0	.7	

at-risk scores and at least at-risk scores, these were also not significantly correlated with Cobb angle (at-risk: P = .07, and at least at-risk: P = .07, respectively).

At enrollment, 42% (5/12) of patients had clinically significant scores reported by both patient and parent forms. Similarly, after 2 years, 36% (4/11) of patients had clinically significant scores reported by both patient and parent forms, such that 64% (7/11) of parents whose children had clinically significant scores were unaware of their child's clinically significant behavior. When considering at least at-risk scores, at enrollment only 60% (15/25) of patients had at least at-risk scores reported by both patient and parent forms. After 2 years, 48% (12/25) of patients had an at least at-risk score reported by both patient and parent reports, meaning 52% of parents were unaware of their child's at-risk behavior.

## 3.2. Commonly reported subscales and domains

In patient responses at enrollment, the most commonly reported subscales for combined clinically significant and at-risk scores were anxiety (24%; 11/46), hyperactivity (24%; 11/46), attention problems (17%; 8/46), and self-esteem (17%; 8/46). Two years later, the most commonly reported subscales were anxiety (28%; 13/46), somatization (20%; 9/46), and self-esteem (30%; 14/46). Of the 11 patients who had at-risk or clinically significant scores in hyperactivity, 73% (8/11) no longer displayed issues in that subscale after a 2-year period. Conversely, the number of patients with at-risk or clinically significant scores in somatization more than doubled over the 2-year period, as only 9% (4/46) of patients reported these scores at enrollment.

The most commonly reported at-risk and clinically significant parent responses at enrollment were depression (17%; 8/46), withdrawal (17%; 8/46), and somatization (15%; 7/46). Two years later, activities of daily living (20%; 9/46), withdrawal (20%; 9/46), and somatization (17%; 8/46) were the subscales with the most at-risk and clinically significant scores. The combined number of at-risk and clinically significant scores in the activities of daily living subscale nearly doubled in the 2-year period.

The BASC-2-SRP (patient self-report form) and BASC-2-PRS (parent report) have 6 overlapping subscales: attention problems, anxiety, depression, hyperactivity, atypicality, and somatization. At enrollment, the most commonly flagged subscales by parents and patients did not overlap; however, the somatization subscale was one of the most common subscales for both patients and parents at 2-year follow-up.

# 4. Discussion and conclusions

In this study, we sought to assess the behavioral and emotional well-being of patients with AIS with different treatment modalities over a 2-year period. Patients who were either observed, braced, or underwent posterior spinal fusion completed BASC-2-SRP questionnaires upon enrollment and at 2-year follow-up. Our findings showed that whether patients were observed, braced, or underwent spinal fusion, there was no significant change in the number of patients with a clinically significant score in at least 1 subscale. Other studies have evaluated the quality of life and mental health of AIS patients across treatment groups. One study assessed the Polish Strength and Difficulties Questionnaire-25 responses in girls with AIS undergoing brace treatment and found that there was no significant change in the mental health of the patients over a 1-year period.<sup>[5]</sup> Another study measured AIS patient responses to the 36-item Short Form survey pre and postoperatively; while there was improvement in most categories such as functional capacity and physical aspects, there was no significant change in social aspects, mental health, and emotional aspects 2 years after surgery.<sup>[8]</sup> Another recent study assessed bracing females with AIS and found that brace-wear did not significantly impact quality of life and body image.<sup>[9]</sup> On the contrary, a study of 3400 AIS patients in the UK with a 10-year follow-up found that SRS-22 scores improved significantly in every domain over time; it is however notable that mental health scores were the slowest to improve from pre to postoperation in these patients.<sup>[10](p22)</sup> While these questionnaires are not as detailed as the BASC-2-SRP, these studies also revealed that the mental and emotional status of AIS patients over time was unchanged. We chose the BASC-2 as it provides a more granular assessment of the patient's mental health and behavior.

In addition, this study also looked at parent responses of each patient enrolled. Parents were given a BASC-2-PRS at enrollment and 2-year follow-up. Interestingly, 64% (7/11) of parents were unaware of their child's clinically significant behavior. When considering at-risk and clinically significant scores, 48% (12/25) of parents were unaware of their child's behavioral or emotional issues. Other studies have attempted to compare parent and patient responses with regard to quality of life and mental health with conflicting results. Kontodimopoulos et al used KIDSCREEN-52 and SRS-22 to assess quality of life in patients with AIS and found that parents actually underestimated their child's scores in the social support and peers category.<sup>[11]</sup> Conversely, another study found no significant difference between patient and parent perception of the mental health status of the patient.<sup>[5]</sup> In this series, our findings indicate a disconnect between patients and parents. This is true of both the amount of at-risk and clinically significant scores and the subscales most frequently flagged by patients and parents.

At 2-year follow-up, some of the most commonly reported subscales were anxiety, somatization, and self-esteem for patients, all of which fall within the internalizing problems and personal adjustment domains of the assessment. For parents, the most commonly reported subscales were activities of daily living, withdrawal, and somatization. Of these subscales, self-esteem and somatization are the only 2 that are on both the patient self-report (BASC-2-SRP) and parent evaluation (PRS). It is possible that problems with self-esteem and anxiety are more internalized than somatization. The items on the BASC-2-PRS that gauged somatization included statements like, "My child says, 'I'm sick'" and "My child complains of headaches" or "health" or "chest pain." Parents may be more aware of these symptoms in a child than those that are internalized like anxiety and self-esteem. Of note, BASC somatization items like feeling sick and chest pain are not symptoms that are typically associated with AIS.

There is certainly the possibility of selection bias in this study as many patients and families were not interested in participating in such a detailed and lengthy questionnaire at the 2-year follow up. With 176 items, the BASC-2-SRP comes at a cost, as it can take up to 30 minutes to complete, adding an element of survey fatigue and burnout that may have contributed to diminished follow-up. Additionally, it is possible that families with more concerns about the patients' psychosocial state may have had increased interest in participating. Conversely, it is possible that families with these concerns may have wanted to avoid participating in such a study. Among those who completed a baseline survey, there was no difference in age, gender, Cobb angle, or frequency of having at least 1 clinically significant subscale score between those who completed a second survey and those who did not. It is still possible, however, that these 2 groups may have had different behavior over the 2-year follow-up period. Nevertheless, for those who completed both surveys, the responses at enrollment and at 2-year follow-up were eerily similar. This suggests that while the percentage of clinically significant/at-risk patients may have been skewed somewhat higher or lower than it in fact was, one would not expect this to impact the conclusion that there does not seem to be a major change in the psychosocial state of AIS patients over the course of treatment.

Another potential concern is variability in the onset and duration of bracing, both at enrollment and during the study period. Initially, we had intended to include only those patients who could be enrolled at the onset of bracing. We broadened the enrollment criteria in attempt to capture more patients but even so had a smaller sample than the surgical group. It is consequently possible that there was some change at the onset of bracing that is not captured in this series. We do not suspect that is the case, however, as the initial values between the observation and bracing groups were quite similar. In addition, about a quarter of patients in the bracing and observation groups ended up having surgery which could affect the comparison between groups. Our main finding, however, was stability of psychosocial scores between baseline and follow-up with little difference between treatment groups.

Another potential limitation of this study is that the educational level of the parents was not assessed and may have impacted their interpretation of the questionnaire. Nevertheless, as educational differences were likely equally present at both enrollment and final follow-up, we do not think that the main conclusion of this paper would have been influenced by this factor.

Finally, due to the relatively small sample size, there is insufficient power to determine conclusively that there is no change in behavior and emotional distress over 2 years of treatment for AIS. A similar magnitude of results with a larger sample size would more definitively establish this preliminary conclusion. There are also several alternative questionnaires such as the SRS-22, SRS-7, and ISYQoL that are aimed at evaluating quality of life in patients with AIS. While these are nowhere near as detailed as the BASC-2, due to their more concise nature they can be given out regularly which is beneficial to look for any trends in this regard. The SRS questionnaires have been validated and are reliable tools for assessing quality of life, particularly as it relates to surgical treatment of scoliosis.<sup>[12]</sup> The SRS-22 can be utilized to assess changes in satisfaction and health status not only in AIS but also adult scoliosis patients.<sup>[13,14]</sup> Similarly, the ISYQoL offers another option for providers to assess the impact of scoliosis on patient quality of life. It has been shown to have high validity, correlate well with the SRS-22, and is composed of just 20 items.<sup>[15,16]</sup> While the SRS-22 is one of the most widely used questionnaires amongst scoliosis patients, and the ISYQoL is quickly being adapted for global use given its validity, with just 20 items these do not offer a comprehensive reflection of the behavioral and emotional health of patients. For instance, SRS-22 questions are specific to patients with scoliosis, but just 4 domains are assessed, with only 1 pertaining to mental health, as compared to the 16 subscales across 5 domains that the BASC-2 offers.

The BASC-2 questionnaire was generated with the use of a substantially larger normative data set with over 12,000 general population sample reports and 5000 clinical sample reports across the different rating scales. Established in 2004 with the help of responses from nearly 50,000 participants, the BASC-2 questionnaire has been utilized in >125 studies and can aid in diagnosis of behavioral problems in children and assess response to treatment.<sup>[17]</sup> The BASC-2 questionnaire has far reach, with multiple studies across varying pathologies including autism spectrum disorder, obesity, adolescent bariatric surgery, and eating disorders.<sup>[18]</sup>(p<sup>2</sup>)<sup>[19–21]</sup> While the length of the BASC-2 is certainly a limitation to its use and practicality in an office setting, it has proven useful across specialties and offers a robust representation of the behavioral and emotional health of patients.

In conclusion, our findings suggest that there is no significant change in the behavior and emotional well-being of patients with AIS regardless of treatment type over a 2-year period. Additionally, many parents remain unaware of their child's clinically significant or at-risk behaviors, especially when these are in the internalized domains. This underscores the importance of remaining vigilant of patient emotional and mental health status in AIS patients, especially since these issues do not seem to fade with time or improve with treatment. Although the findings suggest no change in behavior and emotional well-being over 2 years, most treated patients (50–69%) are at risk for psychosocial difficulties at 2-year follow-up. Physicians should consider this when counseling patients and should aim to increase parental awareness of these increased risks.

# Acknowledgments

This paper is dedicated to the memory of our colleague, Dr Paul D Choi.

## Author contributions

**Conceptualization:** Lindsay M. Andras, Stephanie Iantorno, Anita Hamilton, Paul D. Choi, David L. Skaggs.

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