



Development and validation of the scoliosis misconception scale (SMS) for assessing level of misconception of patients with adolescent idiopathic scoliosis

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Abstract

Background Little is known about patients' understanding of adolescent idiopathic scoliosis (AIS). This paper aims to develop and validate the Scoliosis Misconception Scale (SMS) and to explore patients' level of misconception about AIS.

Methods A total of 195 patients who were newly referred with newly diagnosed AIS were recruited to assess their levels of misconception and psychological distress before and after their first consultation with a specialist. The 17-item SMS was administered to assess patients' level of misconception about AIS and the Kessler Psychological Distress Scale (K10) was used to measure their level of distress.

Results According to the Item Response Theory, all items were within the acceptable range from -3.69 to 2.39 for difficulty parameters, which determined the difficulty of the scale, while most of the items were within the acceptable range from 0.11 to 1.54 for the discrimination parameters, which determined the rate at which the probability of endorsing a correct item changes given ability levels. Internal consistency by marginal reliability was 0.66. One-sample *t* test revealed that participants on average scored 6.79 (*SD* = 2.12) before the first clinic session and 6.45 (*SD* = 2.51) after the first clinic session, both significantly higher than 0 [*t*(75) = 27.86, *p* < .001; *t*(75) = 22.43, *p* < .001].

Conclusions Despite a longstanding clinical model that functions well to treat AIS, most patients still have significant misconceptions about the condition. This highlights the necessity to assess patients' knowledge level of a medical condition and potential generalisability of misconception–distress link to the forefront across other illnesses.

Keywords Adolescent idiopathic scoliosis · Misconception · Distress · School screening · Scoliosis misconception scale

Introduction

As an idiopathic progressive chronic illness that occurs most often after the age of 10 during puberty, AIS is a three-dimensional deformity of the spine defined as a lateral curvature on a standing coronal radiograph of > 10°. The overall prevalence of AIS from different epidemiological

studies indicates a rate of 0.47–5.2% [1–4]. Untreated scoliosis continues to deteriorate beyond adolescence and curves that progress beyond 50° can lead to chronic back pain, cardiopulmonary compromise, poor cosmesis and negative psychological impact [5]. Currently, the most effective non-operative treatment supported by high quality randomized controlled trial to prevent curve progression is by spinal bracing. In the Bracing in Adolescent Idiopathic Scoliosis Trial (BrAIST) study, bracing was effective in preventing curve progression to threshold for surgery in 72% cases [6]. For curves progress beyond 50°, surgical correction of the deformity by instrumented spinal fusion is recommended [7].

In Hong Kong, a territory-wide scoliosis screening program for AIS was jointly implemented by the Department of Orthopaedics & Traumatology of The University of Hong Kong and the Department of Health as part of the Student Health Service program to ensure physical and psychological

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health of school children since 1995 [2]. All participants with clinically detected scoliosis are referred to one of the two local spine specialist centres for long-term monitoring until skeletal maturity. Large population-based cohort studies showed that school screening was predictive and sensitive with a low referral rate, enabling early conservative treatment [2, 8]. While the current scoliosis intervention models mainly aim at addressing patients' medical needs through early screening and intervention, the psychosocial needs of patients have been overlooked.

Previous research has demonstrated the psychological impacts of AIS diagnosis and treatments. A population-based control study revealed that AIS was a significant risk factor for psychological issues such as suicidal thought, worry and concern about body image [9]. Studies have also suggested that adolescents with AIS had poorer body image perception than healthy control [10–12]. In particular, female AIS patients undergoing bracing treatment had a poorer body perception than males AIS patients and a poorer perception of happiness and satisfaction in comparison with female healthy control [13]. With regard to the paucity of patients' understanding of the chronic illness and how these misconceptions lower their insights into the disease, it is suggested addressing patients' psychosocial needs for better pre-emptive treatment, education and support.

In addition to the psychological implications of AIS, it is ubiquitous that patients demonstrate various aspects of misconceptions of AIS during clinical consultations. It was observed that only a minority of AIS patients had the opportunities to discuss their concerns regarding their medical conditions with health professionals [13], implying that most clinicians had limited time to establish rapport with their patients and were uninformed about patients' level of understanding regarding AIS. This suggests the need to assess patients' knowledge level about AIS because insight regarding the knowledge level and psychosocial functioning of the average patient is one way to help clinicians tailor the patient-provider experience without having to make considerable changes to their care implementation, such as time spent with each patient during intake and follow-up.

Taken together, the present paper described the validation of the Scoliosis Misconception Scale (SMS) with item response theory modelling (IRT) and employed the SMS to examine patients' level of misconception about AIS and determine whether the existing clinical model and the first clinic consultation were informative to provide sufficient AIS-related knowledge. Furthermore, patients' level of psychological distress following the first clinic consultation was also measured to explore the relationship between patients' level of AIS misconception and distress.

Methods

Participants

This study obtained ethical approval from the local Institutional Review Board and was done in compliance with the principles of the Declaration of Helsinki.

One hundred and ninety-five consecutive patients (Female = 53.1%) who were newly referred from the local student health screening program to a scoliosis specialist outpatient clinic in Hong Kong were invited to complete the SMS for scale validation. Participants ranged between aged 8 and 14 years (mean = 12.98, $SD = 2.14$), and had normal developmental cognitive functioning. Among 195 participants who completed the initial survey, only 76 participants (Female = 84.2%) were willing to participate in the follow-up study by completing the SMS and a psychological distress scale after their first clinic consultation with a spine specialist who was an orthopaedic surgeon blinded to the study protocol and development of the SMS. Participants ranged between aged 8 and 14 years (mean = 12.36, $SD = 2.12$). Participation was voluntary, and written informed consent was obtained from all participants' parent(s) or legal guardian, and assent from the patients.

Measures

Scoliosis misconception scale (SMS)

Scoliosis Misconception Scale (SMS) is a True/False scale which consists of 17 items about etiology, symptoms, effect and treatment of AIS (Table 1). The scale was developed in consultation with three orthopaedic scoliosis specialists, two physiotherapists and one orthotist who were invited to complete SMS, and the correct answer of each item was derived by the mode of respondents. Among the 17 items, question three (i.e. exercise and bracing can correct the back curve) received inconsistent responses among the participating health professionals and was therefore removed from analysis.

After the scale validation process, the 12-item SMS extracted from the original 17-item scale was used to measure participants' level of understanding of AIS. Individual score was computed by summing the number of incorrect items. Thus, the possible score ranged from 0 (i.e. participants endorsed all items correctly) to 12 (i.e. participants endorsed all items incorrectly). Higher SMS score indicated higher level of misconception.

Kessler psychological distress scale (K10)

The K10 is a self-reported 10-item questionnaire that measures psychological distress in the most recent four-week

Table 1 A scoliosis misconception scale of 17 True/False statements assessing patient knowledge and misconception of AIS (with model answers)

1. Scoliosis is unavoidable	True	False
2. Bearing heavy objects (such as putting on heavy backpack) results in scoliosis	True	False
*3. Exercising and bracing can improve the angle of back curving	True	False
4. Patients with scoliosis easily get tired	True	False
5. Patients with scoliosis should avoid exercise to prevent worsening	True	False
6. Inappropriate postures during working or rest (such as standing, lying, sitting) cause scoliosis	True	False
7. Back pain is the symptom of scoliosis	True	False
8. Physiotherapy can only improve the posture of patients but not correct the angle of curving to normal	True	False
9. Scoliosis can progress quickly during the growth spurt of adolescents	True	False
10. Scoliosis will stop progressing for patients with larger angle of curving during their adulthood	True	False
11. Patients undergoing scoliosis surgery cannot do exercise even after recovery	True	False
12. Correct bracing can prevent progression of scoliosis	True	False
13. Scoliosis can affect sense of balance and body coordination	True	False
14. Severe scoliosis can affect cardiopulmonary function	True	False
15. Scoliosis can affect pregnancy and reproduction ability	True	False
16. Some exercise (such as weightlifting) cause scoliosis	True	False
17. Not suitable bed mattress and pillow can cause scoliosis	True	False

*Q.3 received inconsistent responses among the participating health professionals and was therefore removed from analysis

period (Kessler et al. 2003). Participants were asked to rate how often they had the feeling described in each of the items (e.g. nervous, helpless and depressed) on a 5-point scale ranging from 1 (“None of the time”) to 5 (“All of the time”). The K10 score for each participant was calculated by summing all 10 items, and scores ranged from 10 to 50. A score under 20 indicates mental wellness, a score of 20–24 indicates a mild distress, a score of 25–29 indicates a moderate psychological stress, and a score of 30 and over indicates severe distress.

Procedure

One hundred and ninety-five participants first completed the SMS with 17 statements regarding common misconceptions of AIS. The average time of completion of SMS was 10 min. Participants were not allowed to ask questions about the items as the aim of the study was to measure their understanding of scoliosis. Their responses were then compared with those from the six healthcare professionals.

These participants were invited to complete the 12-item SMS after their first clinic consultation. Following the clinic

consultation, participants also completed the K10 scale in addition to the SMS.

Data analysis

The psychometric assessment of SMS involved the two-parameter logistic model of Item Response Theory (2-PL-IRT) which could determine the difficulty of the scale and determine the rate at which the probability of endorsing a correct item changes given ability levels. The 2-PL-IRT was computed with the *ltm* package of R software version 3.6.3. A difficulty index in the range of -3 – $+3$ and the discrimination index in the range of 0.35–2.5 were regarded as acceptable. Item fit was determined by the chi-square goodness-of-fit per item. For reliability analysis, the internal consistency according to marginal reliability was used in the IRT because the marginal reliability can be used to estimate the average reliability of the respondent’s knowledge.

After the scale validation process, misconception scores of patients before and after the first clinic session were computed using the 12-item SMS. The possible score ranged from 0 to 12. Higher SMS score indicated higher level of misconception. Summing up the number

of incorrect items, each participant ended up with a pre-clinic misconception score and a post-clinic misconception score. One-sample *t* test was performed to determine whether the misconception scores of patients were significantly different from 0 (i.e. all items attempted correctly) while a paired-samples *t* test was used to compare the SMS scores of patients before and after the first clinic consultation. Considering that patients' distress scores were not normally distributed, Spearman's rho correlation coefficients were then conducted to investigate the relationship between participants' misconception and psychological distress. The statistical analysis was done with the SPSS software 26.0.

Results

According to the 2-PL IRT analysis the difficulty parameter of all items were within or close to the acceptable range of -3 – $+3$ and ranged from -3.69 to 2.39 . In terms of the discrimination parameter, most of the items were within the acceptable range of 0.35 – 2.5 and ranged from 0.11 to 1.54 . Five items (i.e. item 8, 9, 12, 13 and 14) of SMS had a negative discrimination estimate ranging from -0.25 to -1.30 . These items were subsequently removed. The item goodness-of-fit showed that item 7, item 11 and item 16 did not fit well ($p < 0.05$). However, they were retained because they had acceptable difficult and discrimination values. The amount of total information trapped by the items between the -3 and $+3$ ranges of ability was 79.19% . Internal consistency by marginal reliability was 0.66 . The IRT analysis of SMS is summarized in Table 2.

One-sample *t* test of misconception revealed that participants on average scored 6.79 ($SD = 2.12$) before the first clinic session and 6.45 ($SD = 2.51$) after the first clinic session, both significantly higher than 0 [$t(75) = 27.86$, $p < .001$; $t(75) = 22.43$, $p < .001$], suggesting a considerable level of misconception both pre- and post-clinic amongst participants. A paired-samples *t* test was then performed and revealed no significant difference between the pre- and post-clinic misconception scores [$t(75) = 1.19$, $p = .237$] (Fig. 1).

Regarding the level of distress after the first clinic consultation, patients on average scored 15.76 ($SD = 15.67$) on the K10 questionnaire, suggesting a low level of distress amongst participants. Considering that patients' distress scores were not normally distributed, Spearman's rho correlation coefficients were computed and revealed no significant association between misconception and distress level for pre-clinic ($r_s(74) = -.13$, $p = .251$) and for post-clinic ($r_s(74) = -.11$, $p = .343$) (Fig. 2a, b).

Discussion

The present study validated the Scoliosis Misconception Scale (SMS), examined patients' level of misconception regarding AIS, investigated the relationship between misconception and psychological distress in AIS patients and provided preliminary evidence supporting the revision of the existing AIS clinical model. Results indicated that the SMS had good psychometric properties in terms of acceptable difficult and discrimination values of the items, high explanatory power closest to 80% of the total information and moderate level of internal consistency. Moreover, despite a longstanding clinical model that functions well to treat adolescent idiopathic scoliosis, most patients still had significant misconceptions towards their illness and such misunderstanding was not addressed properly and therefore persisted even after going through the medical system. This suggested that it is of importance to assess patients' knowledge level of a medical condition and potential generalizability of misconception-distress link to the forefront across other illnesses.

Substantial misconceptions were found in patients before and after their first clinic consultation with scoliosis specialists, indicating that they did not have adequate knowledge about the cause, symptoms, treatments and management technique of AIS and the first clinic consultation was not informative and effective to disseminate such relevant information. Importantly, studies across different chronic illnesses indicated the significance of illness-specific knowledge by revealing its positive relationship with disease outcomes. Confusion about illness and treatment [14] and increased medication concerns [15] were linked with low treatment adherence in patients with chronic obstructive pulmonary disease. Similarly, poor illness perceptions in patients with congenital heart disease predicted inferior quality of life [16]. These findings suggested that illness-specific knowledge may be a crucial determinant of self-management behaviour and health outcomes in a variety of chronic illnesses and insufficient understanding about the illness may constitute a barrier for medical regimen adherence. Drawing upon the current and prior findings, it is imperative to integrate AIS-related knowledge into the clinical care model to resolve misconceptions about AIS in order to address patients' information needs which may potentially improve patients' compliance to early treatment and as such lower the risk for surgery.

However, there was no significant correlation between the level of misconception and psychological distress, suggesting that patients' distress level might not be related to their extent of understanding about AIS. Prior studies revealed that accurate illness-related knowledge was linked with better psychological functioning and health-related

Table 2 Results of parameters estimate of scoliosis misconception scale from item response theory

Scoliosis misconception scale		Item parameters		S-X ² Fit index	
Item no	Item	Difficulty (SE)	Discrimination (SE)	X ²	P value
1	Scoliosis is unavoidable	1.7669 (3.5974)	0.1109 (0.2118)	4.6105	0.7983
2	Bearing heavy objects (such as putting on heavy backpack) results in scoliosis	2.0179 (0.8113)	0.7047 (0.3227)	7.2922	0.5055
3	Exercising and bracing can improve the angle of back curving	2.0231 (0.6121)	0.8564 (0.3058)	12.0088	0.1508
4	Patients with scoliosis easily get tired	0.4491 (0.2397)	0.7632 (0.2383)	12.9285	0.1143
5	Patients with scoliosis should avoid exercise to prevent worsening	− 3.6939 (1.9017)	0.4710 (0.2573)	11.2089	0.1901
6	Inappropriate posture during working or rest (such as standing, lying, sitting) cause scoliosis	1.5293 (0.3550)	1.5398 (0.5765)	12.7588	0.1204
7	Back pain is the symptom of scoliosis	− 0.0001 (0.1487)	1.2667 (0.3148)	16.8582	0.0316
8	Physiotherapy can only improve the posture of patients but not correct the angle of curving to normal	1.3719 (1.2011)	− 0.2536 (0.2006)	3.7006	0.8831
9	Scoliosis can progress quickly during the growth spurt of adolescents	1.6476 (0.3842)	− 1.1767 (0.3585)	7.9302	0.4403
10	Scoliosis will stop progressing for patients with larger angle of curving during their adulthood	− 1.0667 (0.8111)	0.3074 (0.1959)	6.6506	0.5748
11	Patients undergoing scoliosis surgery cannot do exercise even after recovery	− 0.2088 (0.2061)	0.8266 (0.2407)	20.1212	0.0099
12	Correct bracing can prevent progression of scoliosis	2.3933 (0.6319)	− 1.2951 (0.4827)	3.9269	0.8637
13	Scoliosis can affect sense of balance and body coordination	0.8568 (0.2215)	− 1.1756 (0.3223)	17.1175	0.0289
14	Severe scoliosis can affect cardiopulmonary function	1.4692 (0.4183)	− 0.9429 (0.3183)	12.5689	0.1276
15	Scoliosis can affect pregnancy and reproduction ability	0.6162 (0.3033)	0.6511 (0.2296)	5.5428	0.6983
16	Some exercise (such as weightlifting) cause scoliosis	0.0200 (0.1725)	1.0067 (0.2695)	18.5317	0.0176
17	Not suitable bed mattress and pillow can cause scoliosis	1.5226 (0.4000)	0.955 (0.2935)	14.4038	0.0718

S-X²: Item fit index for dichotomous item response theory models; X²: Pearson goodness-of-fit statistic

quality of life in adolescents patients with type 1 diabetes [17], cancer [18] and congenital heart disease [19]. The inconsistency could be due to the reason that although AIS was chronic, patients might not feel distressful when the symptoms were minimal at first referral. It could also be explained by the fact that the positively skewed distress level in which more than half of the patients expressed distress that was lower than the mean in the current study (i.e. 15.76) and the mean from a local adolescents epidemiological study (i.e. 21.57) [20].

There were several limitations to the current study. First, we tried to eliminate any selection bias by recruiting consecutive patients newly referred to the scoliosis clinic. Only 76 out of 195 patients agreed to complete the follow-up SMS and psychological scale after their consultation. We

could not exclude any bias and difference between those who agreed and those who declined to participate in the follow-up survey. Second, a specific limitation to the study pertained to the small sample size which was dependent on the recruitment of newly diagnosed AIS patients. Nonetheless, this study has revealed issues that physicians can address during their consultations or by providing additional patient education through other means after the consultations. Third, confounding variables such as the socioeconomic status of the family were not explored in the current study; but prior research has demonstrated that patients who had lower income were more likely to have lower health literacy [21, 22].

Considering that AIS necessitates early screening coupled with long-term monitoring, the current findings hold

Fig. 1 Misconception scores of AIS patients before and after the first clinic session. Participants on average scored 6.79 ($SD=2.12$) before the first clinic session and 6.45 ($SD=2.51$) after the first clinic session, both significantly higher than 0 [$t(75)=27.86$, $p<.001$; $t(75)=22.43$, $p<.001$], suggesting a considerable level of misconception both pre- and post-clinic amongst participants. No significant difference was found between the pre- and post-clinic misconception scores [$t(75)=1.19$, $p=.237$]

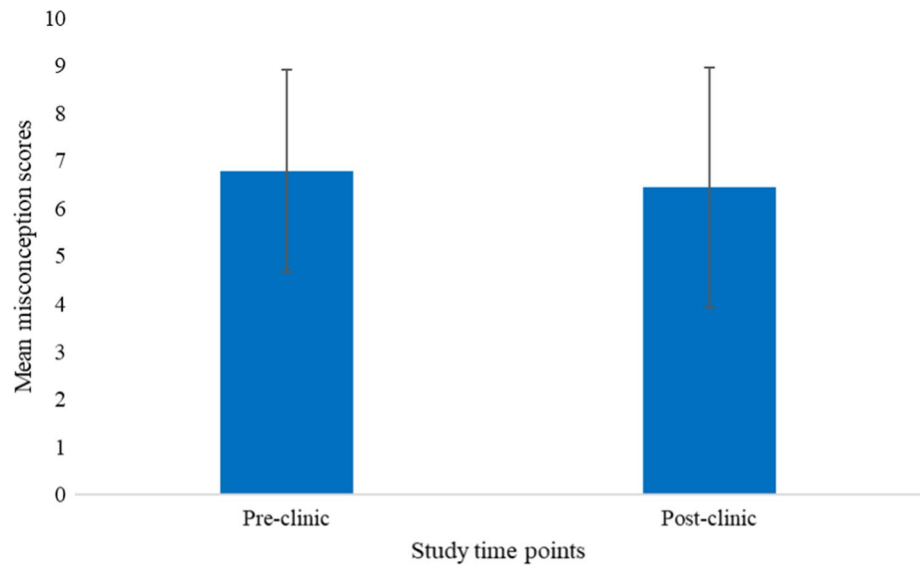
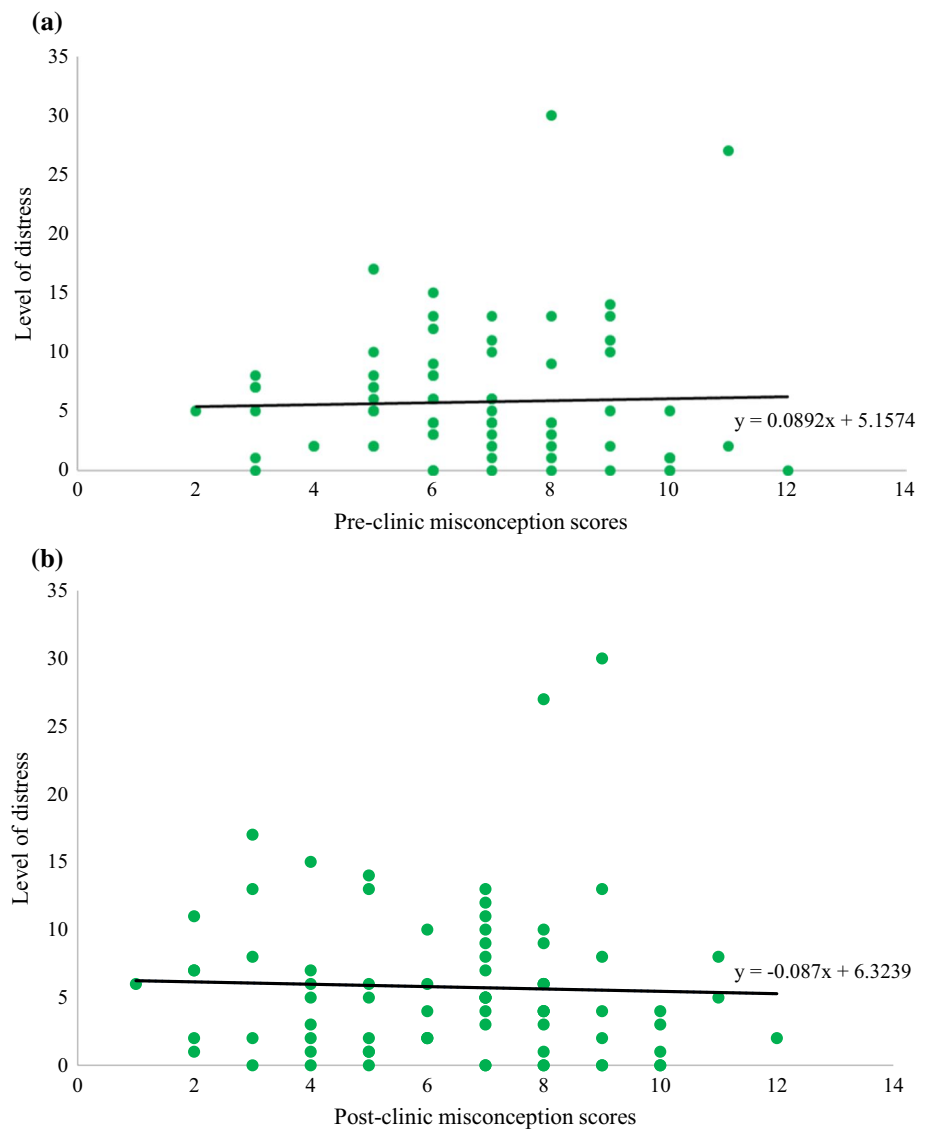


Fig. 2 a Association between level of distress and pre-clinic misconception scores. Spearman's rho correlation coefficients revealed no significant relationship between level of distress and pre-clinic misconception scores of patients ($r_s = -.13$, $p = .251$). **b** Association between level of distress and post-clinic misconception scores. Spearman's rho correlation coefficients revealed no significant relationship between level of distress and post-clinic misconception scores of patients ($r_s = -.11$, $p = .343$)



important implications for reviewing the current scoliosis clinical model. Specifically, a more comprehensive clinical care model integrating AIS-related health education with school screening may facilitate early identification of AIS and help to redress the misconceptions. Improving patients' knowledge about the causes, treatment and self-management of AIS may potentially improve the compliance to follow-up and early conservative treatment and coping skills of patients, this may in turn prevent progression of spinal curve and reduce the need for surgical intervention. Future studies could benefit from using a longitudinal design with a larger sample size and taking multiple measures such as demographics, social support and health-related quality of life into account to substantiate these findings and shed light on how the level of AIS-related knowledge and the psychosocial processes unfold over the course of monitoring and treatment. Another important future direction will be to examine the level of misconception and distress in caregivers of AIS patients. The impact of childhood chronic illness may extend to the entire family system [23]. While some families may demonstrate resilience in face of stressors such as the news of their child's diagnosis, the associated medical risks and treatment regimens, these stressors may negatively impact family functioning.

In sum, the current study provided preliminary evidence that a considerably high level of misconception of scoliosis was found before and after the first clinic consultation in AIS patients who were referred from a scoliosis school screening programme. Additionally, low levels of distress reported by patients after their diagnosis was in favour of the implementation of scoliosis school screening for the purpose of early detection of spinal curve and progression prevention.

Declarations

Conflict of interest No conflict of interest declared.

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