Patient and Parent's Knowledge, Emotion and Expectation Evaluation in Conservatively Treated Adolescent Idiopathic Scoliosis: A Prospective Randomized Study in 200 Children by a Simple Questionnaire

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Abstract

Objectives: To find out if any disparity of the knowledge regarding the scoliosis, treatment, psychological status and treatment satisfaction between different groups of children based on age, follow-up or treatment modality (bracing or observation) and, between patients and their parents.

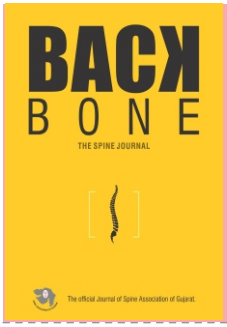
Summary of Background Data: There are numerous questionnaires available in scoliosis which specifically measures either operative outcome or bracing outcomes in terms of general appearance, psychological appearance or pain scores. There is no questionnaire available that evaluate the overall general knowledge, their psychological status regarding the treatment, knowledge regarding future such as progression of curve, marriage, pregnancy and health status as well as their expectations and choices from the treatment in conservatively treated AIS patients.

Methods: Study was conducted in 200 children with adolescent idiopathic scoliosis (AIS) with age between 10 and 16 years. All 30 questions were divided into four subgroups to evaluate 1) General knowledge (Q.1-9); 2) Emotional and psychological status (Q. 10-16); 3) Treatment knowledge (Q.17-25); and 4) Treatment satisfaction (Q.26-30). Results were evaluated based on treatment modality (bracing or observation); duration of follow-up (less than or more than 12 months), and age (less than or more than 13 years), and also between patients and parents.

Results: General knowledge remains the same ($p>0.05$) in all subgroups, while treatment knowledge was higher in parents ($p<0.0001$) and in patients with follow-up more than 12 months ($p=0.0009$) while age of patients didn't show any difference ($p=0.083$). Psychological disturbances were found more in parents ($p=0.046$), and patients with longer follow-up ($p=0.001$) and higher age ($p=0.002$). Similarly, parents ($p<0.0001$), and patients with follow-up more than 12 months (0.011) and age more than 13 years ($p=0.009$) had higher treatment dissatisfaction. However, the treatment modality (bracing or observation) didn't exhibit any difference ($p>0.05$) in any questionnaire.

Conclusion: We evaluated general and treatment knowledge, psychological and mental status and treatment satisfaction from a single and simple questionnaire in conservatively treated AIS subjects, which would provide useful information to handle the different issues involved with the disease.

Keywords: Adolescent idiopathic scoliosis, Conservative treatment, Questionnaire, Evaluation.



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Introduction

In adolescent idiopathic scoliosis (AIS), only a few percentages of patients undergo for the surgical correction while majority of them are being treated with conservatively [1]. Scoliosis by its term is not just the disease of spine with three dimensional deformities, but includes other specialties such as, psychiatry, pulmonology, physical rehabilitation and behavioral science etc. Thus, treating a scoliosis does not mean to treat an X-ray with bent spine, it is an overall treatment in

Submitted: 24/04/2022; Reviewed: 20/05/2022; Accepted: 19/08/2022; Published: 01/10/2022

Back Bone: The Spine Journal (The Official Journal Of "Spine Association of Gujarat") | Available on www.backbonejournal.com | DOI:10.13107/bbj.2022.v03i02.047

terms of general knowledge regarding the disease, improving the acceptability of the disease and psychological behavior in the patients as well as their parents, and making them closer to their expectations according to the knowledge of the treating physician. Psychological well-being (PWB) and Quality of Life (QoL), including actual and future Disability (Dis), were already clear in the mind of some pioneers such as Stagnara, who stated that we have to treat human beings with a deformity, not X-rays [2]. Along this path, the role of the physician and of the entire treating team is crucial [3]. Today, PWB is considered as determinant [4].

The AIS knowledge questionnaire is an inexpensive, brief, self-administered, and convenient test. The short answer question can be completed by individuals with minimal training, education, or literacy. Evaluation of the sources of information requires a measurement tool to appraise child and family knowledge [5-7]. A measure of patients' knowledge should be brief, understandable to the participants, and easy to administer and score [7]. Families who are better informed have less anxiety and a better operative experience [8]. Prior research, however, has found families have substantial need for information with regard to surgery and these needs may often not be met [5]. Approximately 10% of adolescents with idiopathic scoliosis will progress to a level requiring consideration of surgery [1]. Although the untreated clinical course of scoliosis is controversial [9], moderate to severe curves can cause worsening deformity, psychosocial impairments, and decreased pulmonary function [10].

Senders et al [11], in their article of comparing the spinal appearance before and after the surgery, agree with Bridwell et al [12] and Rinella et al [13], who found parents concerns and expectations higher than patients, but differed from those of Smith et al [14], who, using the Quality of Life Profile for Spinal Disorders [15, 16], found patients generally having a worse perception of their deformity than their parents. Thus, they emphasized that their spinal appearance questionnaire (SAQ) provides more detail than the SRS appearance domain and explanation of spinal deformity's concerns and improvements. There are numerous questionnaires available in scoliosis which specifically measures either operative outcome or bracing outcomes in terms of general appearance, psychological appearance or pain scores [17, 18].

Khetani et al [19] recently tried to develop the questionnaire that assesses the knowledge concerning risks, benefits, and complications of surgery for adolescent idiopathic scoliosis patients and their parents. Although majority of AIS patients are treated by conservative treatment, there is no questionnaire available that evaluate the overall general knowledge, their psychological status regarding the treatment, knowledge regarding future such as progression of curve, marriage, pregnancy and health status as well as their expectations and choices from the treatment. A single questionnaire that should be able to evaluate the information from patients and parents is important to modify the treatment in a particular patient by involving one of the associated specialties other than scoliosis doctor. Here we have tried to evaluate all possible reasons and knowledge in both patient and parent by creating a simple questionnaire in conservatively treated patients. The purpose of the study was to highlight some important issues along in conservatively treated (either bracing or observation) AIS patients that are generally not focused in the literature. Objectives were to find out if any disparity of the knowledge regarding the scoliosis, treatment, psychological status and treatment satisfaction between different groups of children based on age, follow-up or treatment modality (bracing or observation) and, between patients and their parents. We hypothesized that children who had longer follow-up, elder age group or different treatment modality have difference in knowledge, psychological condition, treatment knowledge or satisfaction from the other groups, and similarly parents have different knowledge and expectations from the patients. The objective of this study was to develop a reliable and valid questionnaire to assess knowledge (regarding the scoliosis in general and treatment knowledge), psychological and emotional status, and the treatment satisfaction in patients as well as their parents of conservatively treated AIS.

Materials & methods

A randomized prospective study was conducted in 200 children with adolescent idiopathic scoliosis (AIS) with age between 10 and 16 years. There were 175 girls and 25 boys in the study with an average age of 13.4±2.9 and 13.8±3.1 years respectively. We have selected patients group from our outpatient clinic for scoliosis with following selection criteria: 1. Minimum two visits should be completed; 2. only conservatively treated patients with either observation or bracing; 3. No prior history of any procedures; and 4. Parents should have education till graduation. We have excluded those patients who had prior history of surgery, or other systemic diseases and scoliosis other than AIS or whose parents had education less than graduation. Patients with above criteria were selected for the study during our outpatient clinic and were explained about the purpose of the study.

We have developed a simple questionnaire which comprised of simple 30 questions (see appendix for questionnaire with their scores). All questions were divided into four different subgroups that evaluate 1) General knowledge of scoliosis (Q 1-9); 2) Emotional and psychological status regarding the disease and beliefs regarding social issues such as marriage, pregnancy or self mage (Q 10-16); 3) Knowledge about

treatment and follow-up (Q 17-25); and 4) Expectation and treatment satisfaction (Q 26-30). Questions group 10-16 and 26-30 were evaluated by giving the points for each answer clue and thus, psychological status minimum 7 and maximum 28 points. Similarly, treatment satisfaction (Q 26-30) has minimum 5 and maximum 20 points. In both groups, going from minimum to maximum points suggested worsening in psychological status or treatment dissatisfaction. While other two groups, scoliosis general knowledge (Q 1-9) and treatment knowledge (Q 17-25) questionnaire were evaluated by either right or wrong answers and percentage were found out to compare it between different population parameters as well as between patients and their parent's knowledge. Prepared questionnaire were given to patients as well as their parents separately, and they were asked to fill out it separately. One nurse from our scoliosis clinic helped patients and their parents explaining the details about the forms and questionnaire. All questionnaire forms were collected between October and December 2008, within three months of period.

We have divided children in following groups: based on treatment modality- i.e. who were under bracing and who were under observation; based on duration of follow-up- children who had follow-up less than 12 months and who had follow-up more than 12 months; and, according to their age- less than 13 years and more than 13 years. Results were evaluated with a statistical software program (SPSS, version 12, Chicago, Illinois) by using student's t-test and chi-square test. P value less than 0.05 were considered as statistically significant.

Results

Between patients and parents: Our analysis in Table 1 suggested the percentage of different answers in patients and parents. Our results explained that there was no statistically significant difference (p=0.98, chi-square test) regarding the knowledge about scoliosis. However, there was significant difference (p=0.046, chi-square test) found in the anxiety level and psychological condition between patients and parents, showing that parents had higher anxiety and psychological disturbances by their children's disease. Our analysis also showed that 26% parents were in crying state compared to 12% of patients when they had to face scoliosis or new treatment for the first time. Analyzing treatment knowledge and treatment satisfaction scores, there is significant difference found between parents and patients. Regarding treatment knowledge questionnaire, almost 91% parents could answer the questions correctly as compared to 25% patients who answer correctly (p=0.0001, chi-square test). Similarly 71% parents were either not satisfied or finding other options for the treatment, compared to only 32% of patients. Only 8% parents and 29% patients were satisfied with the treatment showing that parent had significantly higher dissatisfaction rate with the treatment (p=0.0001, chi-square test).

Children on bracing and observation treatment: Table 2 showed the average scores with percentage of children in each group who were on bracing or observation treatment. There were 79 and 121 children on bracing and observation respectively. Analyzing general knowledge regarding scoliosis and treatment knowledge there were no significant difference found (p=0.597 for scoliosis knowledge and 0.833 for treatment knowledge, student's t-test). Similarly, there was no difference in the level of treatment satisfaction between children who were on bracing and who were on observation (p=0.775, student's t-test). And, there was no difference in the psychological status between these two groups (p=0.108, student's t-test).

Follow-up less than 12 and more than 12 months: There were 77 and 123 children with follow-up less than 12 and more than 12 months respectively (Table 3). Analyzing the general knowledge of scoliosis, there was no difference (p=0.276, student's t-test) between them. However the knowledge of treatment is significantly higher in the children with longer follow-up than the less follow-up (p=0.0009, student's t-test). Similarly analyzing treatment satisfaction scores, children with longer follow-up had higher dissatisfaction (p=0.011, student's t-test) and, anxiety and psychological disturbances (p=0.001, student's t-test) than those with shorter follow-up.

Age less than 13 and more than 13 years: There were 90 children with age less than 13 years and 110 with more than 13 years (Table 4). Analyzing the general knowledge and treatment knowledge, there was no difference found between both the groups (p=0.166 and 0.083, for general knowledge and treatment knowledge respectively, student's t-test). However, elder children were found to have more treatment dissatisfaction rate than the younger one (p=0.009, student's t-test) and, similarly there were higher anxiety and psychological disturbances (p=0.002, student's t-test) in them.

Discussion

Disease-specific scales are indices intended to measure those specific aspects of the disease important to clinicians and patients [20, 21]. Specifically in adolescent idiopathic scoliosis, there are many questionnaire developed by many authors as well as SRS (scoliosis research society) that evaluate the effect of surgery on the general appearance, psychological status, QoL and satisfaction with the surgical treatment [22, 23]. Although, only 10% of adolescents with idiopathic scoliosis will progress to a level requiring consideration of surgery [1], there is no questionnaire available that evaluate the general knowledge regarding the scoliosis, emotional and

	Patients (n)				Q No	Parents (n)			
	2	9	9	180	1	1	14	13	172
	126	1	9	64	2	144	1	8	44
	51	150	4	1	3	34	173	2	0
	175	56	91	6	4	179	58	85	8
General Knowledge	16	52	41	90	5	37	62	18	86
	82	77	24	18	6	86	62	19	23
	146	17	86	23	7	120	21	132	25
	179	0	0	17	8	181	0	2	17
	61	37	85	13	9	44	35	111	11
	41.9	**20.0**	**17.5**	**20.6**	**%**	**40.8**	**21.0**	**19.3**	**19.1**
	40	66	47	47	10	7	32	57	104
	33	30	42	35	11	4	26	36	64
	20	20	39	29	12	3	10	24	57
Mental Status	153	17	5	25	13	80	10	5	73
	165	28	2	5	14	158	32	0	1
	68	61	32	3	15	116	29	34	3
	76	113	14	0	16	101	93	6	0
	45.6	**27.5**	**14.9**	**11.8**	**%**	**40.4**	**20.0**	**13.9**	**26.0**
	138	49	1	3	17	132	53	2	0
	8	47	42	96	18	8	48	48	85
	8	97	68	13	19	10	100	71	6
	76	5	139	24	20	72	8	138	12
Treatment Knowledge	1	161	2	29	21	3	160	1	30
	0	17	148	74	22	2	15	135	57
	28	15	49	6	23	126	33	50	8
	39	43	21	13	24	44	34	26	22
	105	9	17	44	25	79	47	25	20
	24.6	**27.0**	**29.7**	**18.4**	**%**	**91**	**18**	**14**	**50**
	82	80	29	74	26	76	93	28	73
	57	9	45	56	27	94	15	39	28
Treatment Satisfaction	51	103	12	22	28	39	70	12	62
	10	131	43	2	29	16	94	71	3
	88	63	5	26	30	102	66	6	4
	29.1	**39.1**	**13.6**	**18.2**	**%**	**7.6**	**21.2**	**33.4**	**37.8**

Table 1: Number and percentage answers for each question in the questionnaire in patients and their parents

	Patients (n) With Bracing 79				Q No	Patients (n) with Observation 121			
	1	4	5	69	1	1	5	4	110
	45	1	5	28	2	78	1	4	28
	17	66	0	0	3	33	87	4	1
	68	24	40	3	4	106	32	51	3
General Knowledge	9	25	10	35	5	9	27	31	55
	34	32	9	4	6	47	45	15	14
	58	6	37	10	7	87	12	50	13
	73	0	0	10	8	112	0	0	9
	28	9	38	4	9	34	28	47	9
					%				
	14	22	17	25	10	26	44	30	22
	21	16	25	17	11	35	29	29	28
	8	11	18	16	12	11	9	22	12
Mental Status	54	8	3	13	13	86	8	2	17
	61	14	0	3	14	96	14	0	2
	34	19	18	1	15	44	43	19	2
	27	46	5	0	16	47	63	9	0
	16.5	**10.0**	**5.1**	**4.8**	**%**	**25.8**	**15.1**	**6.8**	**4.6**
	47	29	1	2	17	86	25	5	5
	4	24	19	32	18	7	24	24	67
	6	39	26	9	19	4	62	41	14
	35	1	54	8	20	41	4	85	15
Treatment Knowledge	0	74	0	5	21	1	96	2	22
	0	3	61	29	22	0	13	77	40
	4	6	21	4	23	79	9	28	2
	19	14	9	9	24	20	28	12	5
	48	3	6	19	25	62	6	10	25
					%				
	34	35	11	29	26	48	46	18	40
	22	3	25	21	27	40	6	19	35
Treatment Satisfaction	24	45	3	6	28	33	48	9	16
	45	25	3	2	29	86	18	7	0
	37	26	1	11	30	51	37	4	15
	16.8	**38.6**	**8.8**	**41**	**%**	**24.6**	**51.4**	**13**	**15**

Table 2: Number and percentage answers for each question in the questionnaire in patients with bracing and observational treatment

	Patients (n) with <12 months 77				QNo	Patients (n) with >12 months 123			
	1	0	4	72	**1**	1	9	5	109
	42	1	2	32	**2**	82	0	8	35
	20	57	4	0	**3**	31	97	0	1
	62	19	37	2	**4**	113	37	54	4
General Knowledge	5	21	22	29	**5**	12	31	19	61
	37	27	4	9	**6**	46	50	20	9
	61	7	27	8	**7**	85	10	60	16
	65	0	0	14	**8**	116	0	0	7
	16	18	33	7	**9**	45	19	52	6
					%				
	19	26	18	13	10	21	40	29	34
	16	18	19	24	11	41	27	36	20
	11	8	11	6	12	8	12	29	22
Mental Status	57	5	1	7	13	83	11	4	23
	59	8	0	3	14	98	20	0	2
	33	19	17	1	15	45	43	20	2
	26	45	5	0	16	48	64	9	0
	17.1	**9.3**	**4.3**	**2.5**	**%**	**25.3**	**15.8**	**7.6**	**6.9**
	50	22	1	4	**17**	85	34	1	1
	8	13	17	39	**18**	1	36	26	60
	6	46	17	9	**19**	4	54	53	15
	31	2	57	7	**20**	45	3	82	16
Treatment Knowledge	1	55	0	14	**21**	0	106	2	14
	0	8	49	23	**22**	0	8	89	46
	52	3	20	2	**23**	76	12	29	6
	14	20	6	5	**24**	25	22	15	9
	39	3	8	13	**25**	71	6	8	30
					%				
	32	30	10	22	**26**	50	51	19	49
	30	5	14	15	**27**	32	4	30	41
Treatment Satisfaction	19	33	3	10	**28**	38	60	9	12
	50	11	8	0	**29**	81	32	2	2
	36	17	3	7	**30**	52	46	2	19
	16.2	**32.6**	**7.6**	**37**	**%**	**24.8**	**55.8**	**14.2**	**19**

Table 3: Number and percentage answers for each question in the questionnaire in patients according to their follow-up in months

	Patients (n) <13 years 90				QNo	Parents (n) >13 years 110			
	2	1	2	85	**1**	0	8	7	95
	57	1	5	32	**2**	67	0	4	39
	25	67	3	1	**3**	26	87	1	0
	81	23	42	3	**4**	94	33	49	2
General Knowledge	4	31	19	35	**5**	12	21	22	56
	40	32	11	8	**6**	43	45	13	10
	70	7	0	0	**7**	76	10	87	24
	85	0	0	7	**8**	98	0	0	14
	26	15	39	8	**9**	35	22	46	5
					%				
	18	31	26	35	10	22	35	21	12
	34	19	16	21	11	23	26	38	23
	7	11	23	19	12	12	9	17	9
Mental Status	69	12	3	21	13	71	4	2	9
	84	16	0	3	14	73	12	0	2
	50	27	21	2	15	28	35	16	1
	40	60	8	0	16	34	49	6	0
	22.3	**13.1**	**6.8**	**6.7**	**%**	**20.0**	**12.0**	**5.2**	**2.8**
	62	25	1	2	**17**	74	31	2	3
	5	20	16	49	**18**	4	29	27	50
	7	71	1	11	**19**	3	25	69	13
	40	2	61	0	**20**	36	3	78	23
Treatment Knowledge	1	70	0	16	**21**	1	93	4	14
	0	8	64	34	**22**	0	8	74	35
	67	4	14	4	**23**	61	11	35	4
	19	19	5	4	**24**	20	23	16	10
	47	3	5	16	**25**	63	6	11	28
					%				
	46	42	16	42	**26**	36	39	13	29
	29	5	30	33	**27**	33	4	14	23
Treatment Satisfaction	25	54	10	12	**28**	32	39	2	10
	66	32	4	2	**29**	65	11	6	0
	47	35	3	18	**30**	41	28	2	0
	22.2	**42.2**	**9**	**48**	**%**	**19**	**46.6**	**13.2**	**0**

Table 4: Number and percentage answers for each question in the questionnaire in patients according to their age group

psychological status as well as knowledge regarding marriage, conception with scoliosis, knowledge of treatment and treatment satisfaction in conservatively treated (observation or bracing) children. Although there are few questionnaires available evaluating the QoL, stress evaluation under bracing, or spinal appearance separately in conservatively treated AIS patients, there is no questionnaire evaluating all information simultaneously in a single questionnaire. Our purpose of this study was to develop a reliable simple multiple choice based questionnaire that can evaluate all the information at a same time in conservatively treated AIS patients as well as their parents. In present paper we have successfully developed a multiple choice based simple questionnaire to solve this issue.

Wagner et al [7] found questionnaire's reading level is important. A high reading difficulty may cause questions to be answered incorrectly because the participant did not understand the question. Our questionnaire was very simple and based on multiple choice questions which were also very well understood by most patients. Additionally, one nurse from our institute continuously helped the patients to explain the questionnaire to patients and parents both while filling the form. Whati et al [24] suggested that low scores often reflect a lack of comprehension rather than lack of knowledge. Although higher scores may have been because of greater knowledge, educational level was higher in parents than patients [13]. In present study, we found that general knowledge regarding the scoliosis was the same between parents and patients (p=0.98, chi-square); however, there was definite difference in the treatment knowledge, mental as well as psychological status and treatment satisfaction level between patients and their parents. Additionally, we have enrolled only those children whose parents had completed graduation to avoid any bias in predicting the intelligence level of parents. Our findings suggested that parents had more knowledge regarding the treatment and treatment approach of scoliosis (p<0.0001, chi-square) which agreed with Khetani et al [19] who found that parent had higher general knowledge that the patients. Our general knowledge questions regarding scoliosis were really basic which might be one of the reasons showing no difference between patients and their parents' knowledge. Despite of higher treatment knowledge in parents, they had higher psychological and disturbances than their children (p=0.04, chi-square) that proved that parents are more anxious than their children. Another point to be noted is that parents were less satisfied with the treatment (p<0.0001, chi-square) than their children. There were only 7.6% parents satisfied with the treatment as compared to 29.1% of patients and similarly, there were 37.8% parents wanted to change the current treatment compared to 18.2% patients. Our findings proved that as education level increased (i.e. patients and parents) the knowledge of treatment is increasing and thus, anxiety level also gets increased while treatment satisfaction level would decrease. This is an important issue to suggest specific program for parent education along with their children who has scoliosis. This program may include healthy conversation between parents and treating doctor as well as psychiatrists.

Not only scoliosis itself but also conservative treatment may contribute to a decreased quality of life. Especially, braces in Adolescent Idiopathic Scoliosis (AIS) treatment seem to produce stress [25-27], however there is controversy whether health related quality of life issues of brace treated adolescents are affected negatively [27-29]. As reported in a previous study, in brace the patients seem to have more stress than just because of their deformity. Therefore it is essential to ease the psychological burden the patient has to bear, by using the appropriate psychological intervention for a patient under brace treatment, a conservative specialist in this field has to have the appropriate skills for [30, 31]. However, in our study, apart from the stress level we also wanted to compare the general and treatment knowledge as well as treatment satisfaction level in conservatively treated AIS patients who had bracing and who had not. And it is quite interesting to know that we could not find any significant difference in the general knowledge, treatment knowledge, psychological status and treatment satisfaction (p=0.597, 0.108, 0.833 and 0.775, respectively) between patients who were treated with bracing and who were treated with observation only. Thus we proved that among the conservatively treated AIS patients either observation or bracing treatment does not decide the level of knowledge or stress or treatment satisfaction. We think the education level and the age must be the deciding factors to judge the level of acceptability and satisfaction with treatment in such patients. Our findings are different with those who usually measured the difference in psychological status between bracing and operation which could be quite understood.

We have also analyzed the four parameters according to the follow-up period (<12 months and >12 months) and age (<13 years and >13 years) of the patients while collecting questionnaire. The purpose was to identify more follow-up or higher age of the patients make any difference in the questionnaire. Comparing the follow-up period we could find no difference in the general knowledge regarding scoliosis (p=0.276, student's t-test); however, there was statistically significant difference in treatment knowledge (p=0.0009), psychological stress and well-being (p=0.001) and treatment satisfaction (p=0.011) between the patients with follow-up >12 months and <12 months. Our findings proved that patients' knowledge regarding treatment increased with the

regular follow-up while their psychological stresses were also increased and treatment satisfaction gradually decreased. Similarly while comparing all parameters between patients who were <13 and who were >13 years, there was no statistical difference in general knowledge (p=0.166) and treatment knowledge (p=0.083) while there was higher psychological stress and disturbances (p=0.002) and less treatment satisfaction (p=0.009) in patients who had age >13 years. Linderman and Behm, [32] in their interesting article analyzing psychological well being and compliance to brace, suggested that noncompliant girls did not expect success of treatment, had low self-esteem and did not seek social support, while the contrary was true for noncompliant boys; in short time brace use, low compliance was best predicted by low reflective thinking and good body image, and again the contrary was true for patients who had used the brace for >6 months. Therefore both of our findings suggested that the general knowledge remains the same in each patient group but knowledge regarding treatment increased with longer follow-up as such patients usually have access to internet, books and other mediums. Similarly elder patients with longer follow-up have more psychological stress and less self image and treatment satisfaction than the younger patients with less follow-up. This typically suggests that the children entering into skeletal maturity would have more disturbances and often want to change the treatment. Our findings support the need of increasing psychiatric consultation and proper understanding the nature of the disease to such children during the regular follow-up. Such findings are not reported before which we think is a positive factor in our study.

We agree that there may be few lacunae in the study, such as in detail evaluations of all questionnaire were not possible because few questions (like general knowledge and few from treatment knowledge) were either write or wrong type and others were judging the scores (mental status and treatment satisfaction). A second limitation is that knowledge questionnaire can become outdated [6]. Therefore as the need for new knowledge becomes available, the existing questionnaire should be modified [6]. However our questionnaire involved only conservatively treated patients knowledge status which is a positive point. Additionally, we tried to evaluate the overall findings including general and treatment knowledge, psychological and mental status and treatment satisfaction from a single and simple questionnaire.

Conclusion

We think that our questionnaire would provide useful information to evaluate the patients of different age and follow-up as well as their parents and would guide to treat the different issues involved with the disease. And psychological counseling should be an integral part in the treatment of idiopathic scoliosis.

Scoliosis Questionnaire Information:

Name of Patient:

Who is Filling the Form (please tick): Patient [ ] Mother [ ] Father [ ]

ID no:

Age/ Sex: DOB (Date of Birth):

Date of first visit: Date of Questionnaire:

Education of patient/parent:

First visit Cobb angle: Cobb angle at Questionnaire:

Risser sign (not to fill): Menarchal age (if yes):

Treatment now (please tick): Bracing [ ] Observation [ ]

How long follow-up (months):

Signature: Patient: Parent:

Part I: General Knowledge

1. What do you mean by scoliosis?
a. Problem in spinal cord
b. Problem in spinal vertebra
c. Problem in both
d. Curvature of spinal column

2. What is Cobb angle?
a. Measurement of severity of scoliosis
b. Measurement of complications rate
c. To decide about treatment protocol
d. Don't know

3. Why do you take treatment? (Goal of treatment)
a. Curve correction
b. Stop progression
c. Pain control
d. Chest deformity

4. If you don't take treatment, what problems can happen?
a. Curve progression
b. Respiratory problems
c. Pain
d. Others

5. When did you listen about scoliosis- term?
a. When I had
b. Doctors
c. Listened before when friend or relative had
d. Others

6. Are you knowing any scoliosis patients similar to you and how?
a. No
b. Yes, by friends and relatives

c. Yes, by doctor
d. Others

7. How did you get information about scoliosis?
a. Doctor
b. Relatives and friends
c. Internet
d. Books

8. For how long you have to come for follow-up
a. Till maturity
b. Till marriage
c. Till pregnancy
d. Till life long

9. What size of curve can cause shortness of breath?
a. 80° to 100°
b. 30° to 50°
c. 50° to 80°
d. Every time

Part II: Mental and Psychological Status

		Score
10.	What was your mental condition when you heard for the first time about your scoliosis	
a.	No effect-	1
b.	Slightly tensed-	2
c.	Very tensed-	3
d.	Severely tensed and started crying or worrying about future-	4
11.	What was your mental condition when you received bracing	
a.	No effect-	1
b.	Slightly tensed-	2
c.	Very tensed-	3
d.	Severely tensed and started crying or worrying about future-	4
12.	What was your mental condition when you heard for operation for your curve	
a.	No effect-	1
b.	Slightly tensed-	2
c.	Very tensed-	3
d.	Severely tensed and started crying-	4
13.	Scoliosis and self image	
a.	Same-	1
b.	Decreased a little bit-	2
c.	Decreased that you can't play with friends or go out-	3
d.	Decreased to depression-	4
14.	Scoliosis and marriage	
a.	Doesn't matter-	1

b. Difficult- 2
c. Very difficult- 3
d. Impossible- 4

15. Scoliosis and pregnancy
a. It is normal- 1
b. Minimal risk- 2
c. More risk- 3
d. Not possible- 4

16. Scoliosis and your daily activity
a. Not difference- 1
b. Slight difficulty- 2
c. More difficulty- 3
d. Needs help from others- 4

Part III: Treatment Knowledge

17. What are the treatment steps
a. Observation, bracing, operation
b. Bracing, observation, operation
c. Operation, bracing, observation
d. Bracing, operation, operation

18. Knowledge about observational treatment
a. No need of observation
b. Require in curve <10°
c. Require in curve <25°
d. It is for identifying curve progression

19. How frequent you need to visit the doctor
a. Every monthly
b. Every 3-4 months
c. When curve increase
d. Every 6 months

20. Knowledge about bracing.
a. If observation not successful bracing should be done
b. It should be done when diagnosed
c. No need of bracing
d. Bracing will reduce curve

21. How long bracing…
a. Till life long
b. Till maturity
c. Till marriage
d. Till pregnancy

22. Surgery should be done when …
a. When curve >40°
b. When curve >100°
c. When it causes pain
d. When curve >40° and progresses

23. What is your main concern? Curve or rib hump?
a. Curve correction
b. Rib hump
c. Both
d. Others

24. If bracing not successful …
a. Still continue with bracing
b. Operation
c. Change the brace
d. Change the doctor

25. If scoliosis surgery is not done, how much can the curve increase in size (over a lifetime)?
a. Curves can increase from 0° to 150°
b. Curve will not increase
c. Curve becomes double
d. Curve life time increase

Part IV: Treatment Satisfaction		Score
26.	Do you any other activity for your curve	
a.	None-	1
b.	Exercise-	2
c.	Yoga & meditation-	3
d.	Quack treatment-	4
27.	What is your response regarding operation	
a.	I will follow my doctors' decision-	1
b.	I will undergo operation if curve progress-	2
c.	I will undergo operation if it is very severe-	3
d.	I won't undergo operation-	4
28.	Are you satisfied with your treatment	
a.	Yes, definitely-	1
b.	Little bit satisfied-	2
c.	Not satisfied-	3
d.	There is no other options except current treatment-	4
29.	How much curve correction can be expected from scoliosis surgery	
a.	>50%-	1
b.	<50%-	2
c.	100%-	3
d.	No correction-	4

30.	Would you recommend bracing or operation to other patients	
a.	Yes, I would recommend-	1
b.	If there is other options, I would choose that-	2
c.	It is better to accept scoliosis but not bracing or operation-	3
d.	No, not at all-	4

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Declaration of patient consent: The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient has given his/her consent for his/her images and other clinical information to be reported in the Journal. The patient understands that his/her name and initials will not be published, and due efforts will be made to conceal his/her identity, but anonymity cannot be guaranteed.

Conflict of Interest: NIL
Source of Support: NIL

How to Cite this Article

Modi HN, Suh SW, Hong JY, Yang JH | Patient and Parent's Knowledge, Emotion and Expectation Evaluation in Conservatively Treated Adolescent Idiopathic Scoliosis: A Prospective Randomized Study in 200 Children by a Simple Questionnaire | Back Bone: The Spine Journal | October 2022-March 2023; 3(2): 96-108.