Genij Ortopedii. 2021. Vol. 27, no. 6. P. 767-772.

Original article

https://doi.org/10.18019/1028-4427-2021-27-6-767-772

Family attitude to pediatric spine deformity

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Abstract

Introduction Analysis of psycho-emotional aspects in children suffering from spinal deformities demonstrates a high level of dysfunctionality in mechanisms of personal and intra-family adjustment. There is a paucity of publications on the problem. **Objectives** included multidimensional psychometric assessment of parents' attitude toward children with spinal deformities and the correlation with psychological characteristics of patients. **Material and methods** Results of a survey performed for 45 patients who underwent operative treatment for spinal deformities of different etiology and their parents were reviewed. The patients' age ranged from 7 months to 17 years inclusive. Validated questionnaires used as survey tools included the "DOBR" questionnaire, FACES-3, SDQ and DERS. Patients were assigned to two age-related groups, Juniors aged from 7 months to 6 years inclusive and Seniors aged from 7 to 17 years inclusive. An intergroup and correlation analyses were performed in the study groups. **Results** Multidimensional analysis showed that parents of children with spinal deformities tend to downgrade the severity of the child's condition neglecting postoperative prescription standards that was more common for Seniors ($p = 0.001$). Parents look toward the maximum intra-family cohesion but do not have the necessary knowledge to achieve it. Emotional problems and social adjustment difficulties are more common for Seniors ($p = 0.031$). **Conclusion** Lack of adequate parental knowledge about the child's disease is the key factor behind the imbalance in intra-family functioning. Therapeutic intervention and parent management training can facilitate to psycho-emotional well-being in the family and postoperative improvements for maladapting children with spinal deformities.

Keywords: spinal deformity, children, psychoemotional stress, psychocorrection

For citation: Grechanyi S.V., Gurenich A.D., Naumov D.G., Mushkin A.Yu. Family attitude to pediatric spine deformity. *Genij Ortopedii*, 2021, vol. 27, no 6, pp. 767-772. https://doi.org/10.18019/1028-4427-2021-27-6-767-772.

INTRODUCTION

Psychological issues of the treatment and rehabilitation of children with spinal deformities are an understudied yet important concern at the confluence of psychology and spinal surgery. Psychoemotional stress together with vertebrogenic pain syndrome, pulmonary dysfunction and cosmetic deficiency appear to significantly affect the quality of life of the child and the family [1–4]. Patients may exhibit a less positive outlook on life, suffer from lower self-esteem, and have more difficulty connecting with peers [5–9]. The study of the psychosocial status of children aged 6 to 18 years who are diagnosed with early onset scoliosis indicates a higher prevalence of depressive and anxiety symptoms that bring the dysfunctionality in many aspects of everyday life in comparison with healthy peers [10]. 32 % (29/92) of adolescent idiopathic scoliosis (AIS) patients scored in the clinically significant range in at least one of the subscales of the Behavioral Assessment System for Children (BASC-2) [11].

Identification and elimination of negative aspects of psychosocial functioning in children with spinal deformities can assist in the improvement of treatment results. Body Cathexis Scale (BCS, the degree of satisfaction or dissatisfaction one feels towards various parts and aspects of their own body)), Pediatric Quality of Life Inventory (PedsQL), Children's Depression Inventory (CDI), Piers-Harris self-esteem questionnaire (PH-SEQ) and state-trait Anxiety Inventory for Children were used to evaluate the patients [12, 13]. There are conflicting views on the attitude of parents in the issues of psychoemotional assessment of children with spinal deformities: on the one hand, parents painfully perceive the morphological defect of the child, on the other hand, they tend to overestimate the assessment of stress levels related to body deformity or are unaware that their child has clinically significant emotional or behavioral problems [14–17]. Despite the obvious importance of the family in treatment and rehabilitation, there is a paucity of publications that would describe all aspects of the problem. Twelve publications brought out between 1987 and 2021 could be identified through the PubMed search using the keywords "pediatric spine deformities", "family psychology".

Objectives included multidimensional psychometric assessment of parents' attitude toward children with spinal deformities and the correlation with psychological characteristics of patients (behavioral profile and emotion regulation) and family (family cohesion/ adaptation) to identify the main tendencies of the problem and describe psychocorrective and psychoeducational practices. This is a pilot study that suggests a preliminary assessment of the problem to include patients with a wide range of diagnoses that feature the presence of spinal deformity verified by radiographs and a wide age range (children and adolescents aged from 7 months to 18 years).

MATERIAL AND METHODS

The study was performed at the Clinic of Pediatric Surgery and Orthopaedics of the St. Petersburg Research Institute of Phthisiopulmonology. Clinical material was collected from October 2020 to January 2021 using online testing mode. An informed consent form was developed at the planning stage and filled out by the parents of patients. The number of observations required was determined using the Sample Size Calculation method with a confidence level of 95 %, a confidence interval of 15 % and an estimated number of children with spinal deformities registered annually in the Russian Federation was 30 thousand cases [18, 19].

Inclusion criteria:

• surgery performed for spinal deformities of various etiologies;

• age of patients ≤ 18 years;

• consent of parents and the child older than 14 years to be included in the study.

Exclusion criteria:

• lack of technical capacity to fill out questionnaires online;

• duration of postoperative catamnesis of ≤ 3 months;

• misunderstanding of the questions.

The final cohort consisted of 45 patients who underwent initial surgery at the age of 7 months to 18 years; M, 6 years 5 months (Me, 4 years 8 months). There were 27 males (60 %) and 18 females (40 %) examined ($x^2 = 1.800$; $p = 0.180$). The mean age of males and females was 6 years (Me 4 years 6 months) and 7 years (Me 5 years) ($t = -0.697$ $p = 0.490$), respectively.

Patients were assigned to two age-related groups, Juniors aged 0 to 6 years (n=28; 62.2 %) and Seniors aged from 7 to 17 years (n = 17; 37.8 %) ($x^2 = 2.689$, $p = 0.101$) for objective assessment of the attitude of parents to children disease. The study received a favorable opinion from the relevant research ethics committee.

The survey tools included:

• DOBR questionnaire consisting of 40 statements with the degree of agreement assessed on a 6-point scale (from -3 to +3) [20];

• FACES-3 questionnaire (cohesion and adaptability of the family) aimed at studying 2 main fundamental characteristics of family functioning: family adaptability and cohesion [20];

• Strengths and Difficulties Questionnaire (SDQ), a screening tool for measuring psychological adjustment in children and adolescents and aims to detect any emotional or behavioural problems, hyperactivity, peer difficulties, etc. [20];

• The Difficulties in Emotion Regulation Scale (DERS), a Russian-language adapted version used for senior children [21].

The survey results were evaluated by children's mental health professionals qualified as a "psychiatrist" and "clinical psychologist" with 30-year experience.

General characteristics of the patients

Distribution of children considering the etiology of the underlying disease is presented in Table 1.

The majority of patients underwent surgery for congenital deformities of the spine ($x^2 = 3.756$, $p = 0.053$). There was no significant difference between the diagnosis and the sex of the child ($x^2 = 2.594$, $p = 0.458$).

Statistical analysis was performed using Statistical Package for the Social Sciences (SPSS), version 22.0 (SPSS Inc., Chicago, IL, USA). Verification of the normality of the distribution of the variables was produced using descriptive statistics (histogram with a normal distribution curve) and the Kolmogorov-Smirnov tesr. For all quantitative parameters, the level of bilateral significance was $p < 0.01$ that indicated the abnormality of the distribution, and the results were presented in the form of M ± m and Me (min, max). The Mann-Whitney U–test was used to assess the statistical significance of the differences in quantitative parameters and the Pearson χ^2 test was used for qualitative variables. Spearman's rank correlation test was used to assess the strength and significance of intergroup correlations. The differences were regarded as significant with bilateral $p < 0.05$.

Table 1

Etiological distribution of patients

Diagnosis	Total	Males	Females
Congenital malformations and anomalies including scoliosis, kyphosis, kyphoscoliosis, hemivertebrae	29 (64.4 %)	17 (37.8 %)	12 (26.7 %)
Consequences of the infectious process including tuberculosis and BCG-spondylitis, nonspecific spondylitis, spondylitis secondary to late-onset neonatal sepsis (LONS)	7 (15.6 %)	3 (0.07 %)	4 (0.09 %)
Vertebral fractures	2 (4.4 %)	2 (0.04 %)	–
Deformities of other etiology: spondylolisthesis, Gorham-Stoat syndrome, non-bacterial spondylitis	7 (15.6 %)	5 (0.11 %)	2 (0.04 %)
	45 (100.0 %)	27 (60.0 %)	18 (40.0 %)

RESULTS

The attitude of parents and children to the disease.

Attitudes to the Child's Illness Questionnaire:

1) the Internality scale: the predominance of the external attitude of parents to the child's illness. The disease is perceived as a condition that depends on objective circumstances. Parents are not inclined to believe that they can influence and control the disease, are not inclined to experience responsibility for its

manifestations and blame themselves in case of an unfavorable course;

2) the Anxiety scale is the predominance of anxiety and concern of parents, as well as the lack of a clear idea of the outcome and consequences of spinal deformity in a child;

3) the Nosognosia scale is parents' understatement of the severity of the disease, underestimation of the objective consequences of the disease;

4) the Activity Control scale: parents' understatement of the importance of the therapeutic and protective regime and restrictive measures prescribed, more pronounced in senior group (p = 0.001);

5) the General Tension scale is the prevalence of a calm, balanced attitude of parents to the child's illness, a low level of mental tension and a hypoergic position with no search for new ways to solve the problem.

Cohesion and adaptability of the family questionnaire

1) Cohesion and adaptability of the family: regardless of the age of the child families of patients were characterized by relatively similar mechanisms of functioning and by a linked, extreme level of interaction. Parents looked forward to maximum family cohesion, but demonstrated a lack of appropriate knowledge for its implementation (no established habits, family rules, constant and stable emotional relationships noted);

2) Emotional Problems scale: higher rates noted in senior group (p = 0.031).

In general, the family system was rated to a semi-functional (unbalanced) level and tended to dysfunctional (extremely unbalanced) interaction according to maternal aspirations (ideal cohesion, the idea of "due"). Questionnaires scores are presented in Table 2.

Table 2

Questionnaires scores

Questionnaire	Study groups (n = 45)	Junior (n = 28)	Senior (n = 17)	p
	Me [25 %; 75 %] (min-max)			
Attitude to child disease (DOBR)				
Internality	2.00 [-2.00; 5.50] (-8, 12)	2.50 [-2.00; 5.50] (-8, 9)	2.00 [-2.00; 7.00] (-8, 12)	*P = 0.071*
Anxiety	3.00 [-1.50; 9.50] (-18, 22)	0.50 [-2.75; 9.50] (-8, 16)	5.00 [-0.50; 9.50] (-18, 22)	*P = 0.332*
Nosognosia	-2.00 [-7.00; 5.00] (-22, 13)	-3.50 [-6.75; 3.00] (-16, 9)	-1.00 [-10.00; 7.00] (-22, 13)	*P = 0.946*
Activity Control	-9.00 [-15.00; -4.00] (-28, 16)	-8.00 [-14.00;-2.25] (-28, 16)	-12.00 [-20.00; -6.50] (-28, 8)	*P = 0.001*
General Tension	-1.50 [-4.75; 2.25] (-14.75, 10.25)	-1.50 [-4.75; 2.00] (-10.50, 7.50)	-1.00 [-4.6250; 2.25] (-14.75, 10.25)	*P = 0.431*
Cohesion and adaptability of the family (FACES-3)				
Real cohesion	41.00 [35.50; 46.50] (23–50)	41.00 [34.50; 47.50] (23–50)	41,50 [36.00; 43.75] (27–49)	*P = 0.649*
Real adaptability	33.50 [30.25; 37.00] (26–41)	32.00 [30.00; 36.00] (26–41)	36.00 [31.50; 38.50] (28–41)	*P = 0.114*
Ideal cohesion	48.00 [43.25; 50.00] (27–50)	48.00 [44.00; 49.00] (27–50)	47.00 [41.00; 50.00] (29–50)	*P = 0.981*
Ideal adaptability	38.00 [33.50; 41.00] (29–50)	37.50 [33.25; 40.00] (29–44)	38.00 [33.00; 41.50] (29–50)	*P = 0.639*
Strengths and Difficulties Questionnaire (SDQ)				
Emotional problems	2.00 [1.00; 4.00] (0–6)	2.00 [1.00; 3.00] (0–6)	3.00 [2.00; 5.00] (0–6)	*P = 0.031*
Behavioural problems	2.00 [2.00; 3.00] (0–7)	2.00 [2.00; 3.75] (1–7)	2.00 [2.00; 3.00] (0–6)	*P = 0.835*
Hyperactivity	4.00 [3.00; 5.00] (1–7)	5.00 [3.00; 6.00] (1–7)	3.00 [2.00; 4.00] (1–5)	*P = 0.007*
Peer difficulties	4.00 [3.00; 5.00] (1–8)	4.00 [3.00; 5.00] (1–8)	4.00 [3.50; 5.50] (3–8)	*P = 0.351*
Pro-social behaviour	600 [5.00; 7.00] (2–9)	6.00 [5.00; 7.00] (2–9)	7.00 [5.00; 8.00] (3–9)	*P = 0.166*
The Difficulties in Emotion Regulation Scale (DERS), Seniors only (n = 17)				
Rejection of emotional reactions	12.00 [10.00; 18.50] (10–23)			
Difficulties associated with purposeful behavior	13.00 [10.75; 17.25] (8–22)			
Difficulties of impulse control	12.00 [10.00; 19.00] (8–26)			
Awareness of emotions	17.00 [14.00; 20.25] (13–28)			
Lack of emotion regulation strategies	19.00 [14.50; 26.50] (12–29)			
Understanding your emotions	13.00 [10.75; 14.25] (10–18)			

Correlation analysis

The most significant correlations in the junior subgroup were observed between the "activity control" and the "ideal family adaptability" (p = 0.936) and "behavioral problems" scores (p = 0.719). The score of "real family cohesion" directly correlated with the severity of "hyperactivity" (p = 0.740) and "pro-social behaviour" (p = 0.894), and the "ideal family cohesion" with "emotional problems" (p = 0.968) and "peer difficulties" (p = 0.878). The findings showed that most significant correlations were seen in the family cohesion / adaptability that indicated the leading role of the family factor in the adaptation of patients to the disease.

Seniors showed significant correlations in "internality" and "problems with peers" (p = -0.805). The latter had a strong correction with "understanding of your emotions" scale (p = 0.735). Attitude to the disease "anxiety" scale directly correlated with the type of emotional dysregulation "difficulties associated with purposeful behavior" (p = 0.722). Two important components of the attitude to the disease were found to be correlated with behavioral characteristics and the way of emotional regulation in seniors.

A diagram of intergroup correlations in Juniors and Seniors is presented in Figures 1 and 2.

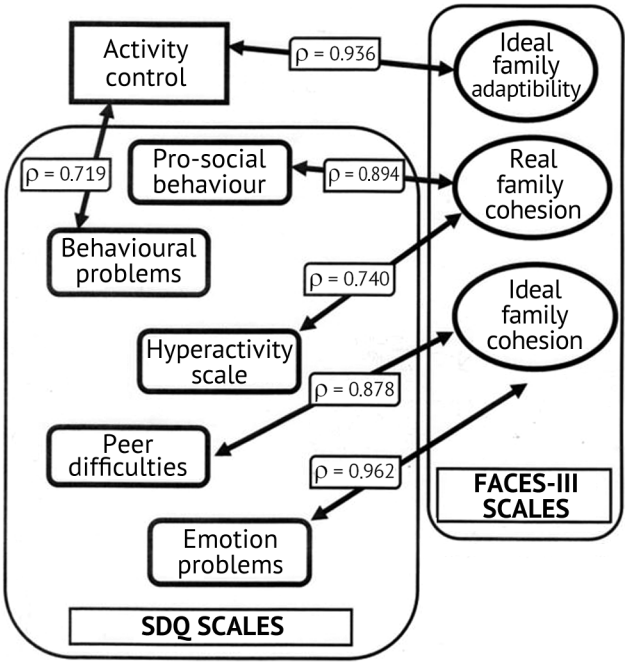

Fig. 1 Correlations in Juniors

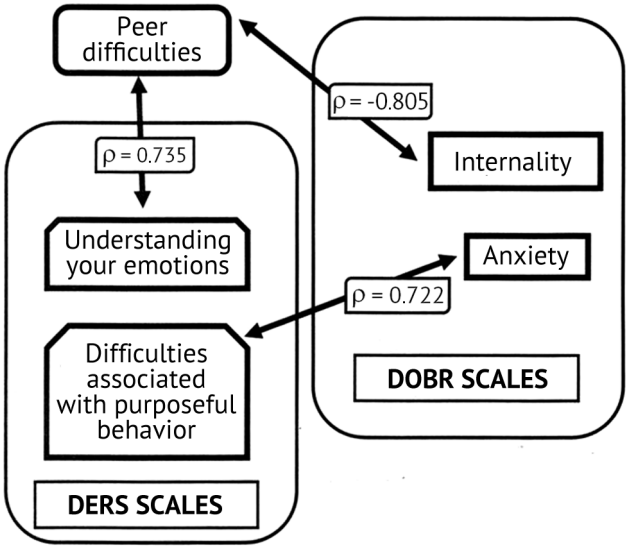

Fig. 2 Correlations in Seniors

DISCUSSION

Multidimensional psychometric assessment of parents' attitude to the problem of spinal deformity in children is an integral part of an integrated approach to the treatment of the disease spectrum [22–27]. Spinal surgeons often focus exclusively on surgical aspects of the child's treatment, neglecting communication with parents [28–30]. Aspects of family interaction play a key role in the social adaptation and functional rehabilitation of children in the postoperative period.

Previous publications reported on this topic focused on the correlation of the family and anxiety and depressivon [4], self-esteem [10], cosmetic perception of a morphological defect [12], and this study is one of the first aimed at studying the attitude of parents to the disease in children with spinal deformities. A new aspect discussed is the use of such evaluation criteria as family cohesion and adaptability (the FACES-3 questionnaire) that showed significant correlations with the behavioral characteristics of preschool children. The ability of emotional regulation (DERS) appeared to be an important psychological component of the emerging personality in schoolchildren. The study revealed important patterns concerning individual components of the attitude to the disease. The severity of internal control when the parent experiences greater responsibility for the child's illness, was associated with peer difficulties, and anxiety associated with the child's illness correlated directly with difficulties of purposeful behaviour.

Both internal control and the anxious attitude to the child's illness are a kind of educational overprotection, and the higher rate of family adaptability including seniors can be a kind of specific parental attitude to the child's illness. This would be a natural reaction of parents in response to the child's health problems first to be followed by established behavioural policy in the future with a willingness to subordinate all their interests to the needs of the patient, and keep up with him when solving important issues. With the obvious benefits of this

approach there are still negative aspects of a high level of emotional stress and rapid depletion of coping resources.

The findings suggest that the most important and obvious learning point for a practical specialist is the lack of objective information about the disease among parents concerning the treatment and restrictive regime, in particular. The patients and the families make high demands to the effectiveness and quality of surgical treatment, and educational programs providing disease awareness information are essential for parents. Radiographic and physical measures of deformity do not correlate well with patients' and parents' perceptions of appearance. Patients and parents do not strongly agree on the cosmetic outcome of AIS surgery [23]. Specific features of emotional regulation identified in this study also allow us to develop strategies for therapeutic intervention aimed at psychocorrection of the family cohesion, adaptability, emotional stress, etc.

CONCLUSION

1. The attitude of parents toward the disease of children with spinal deformities is not associated with specific knowledge they might have about the condition during postoperative period. Parents are often unaware of treatment and restrictive postoperative regime and educational programs providing objective information about pathology are essential for the parents.

2. Families of children with spinal deformities are characterized by an unbalanced level of functioning, including an extreme level of chaotic family adaptation and contributing to the development of pronounced family stress.

3. The importance of the family factor in postoperative rehabilitation and adaptation of children with spinal deformities is confirmed by numerous strong correlations between cohesion and adaptability of family functioning and various aspects of parents' attitude to children's illness, characteristics of children's behavior and leading types of emotional regulation, that is, complex components of patients' mental health.

4. Psychotherapeutic intervention is aimed at disease awareness communications with parents explaining the role of critical attitudes, permanent control, persistence to the child's condition, interaction with psychological "focus" on his needs. Establishing psychologically safe communication with the child would facilitate an optimal balance of freedom and responsibility.

Limitations

1. A wide age range of the patients.

2. Absence of a comparison pediatric group with other musculoskeletal diseases.

3. The preliminary pilot nature of the study that did not aim at validated practical recommendations of psychotherapeutic intervention.

The prospects of the research include narrower selection criteria, the use of comparison groups of patients with other nosological forms to evaluate the effectiveness of the methods of psychotherapeutic intervention used.

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The article was submitted 05.04.2021; approved after reviewing 25.06.2021; accepted for publication 19.10.2021.

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