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## Psychological Aspects of Scoliosis Treatment in Children

Ryszard Tomaszewski<sup>1</sup> and Magdalena Janowska<sup>2</sup>

<sup>1</sup>*Silesian Medical University, Katowice,*

<sup>2</sup>*Upper Silesian Child Health Centre, Department of Pediatric Orthopedics  
and Traumatology, Katowice,  
Poland*

### 1. Introduction

Scoliosis in children is a serious therapeutic problem. Generally, scoliosis can be divided into several categories: congenital, neurological idiopathic etc occurring in children, adolescents [1].

In prenatal or after birth case, parents learn about their child's diagnosis soon after his or her birth or even in a prenatal period during fetal ultrasound examination [2] - This information is always difficult for a parent. How they will cope with the problem of their child's illness largely depends on the support they receive and give to each other, their personalities and the way the information is forwarded by their doctor. Information in the prenatal period may allow a child's parents to be better prepared for this situation, seek medical and psychological help.

In the case of idiopathic scoliosis parents experience a shock having learnt about the illness of their child, but a shock of a different kind. They often cannot believe that their children's spine being normal at birth, suddenly began to develop incorrectly. The problem of idiopathic scoliosis also applies to children who, at their teenage years, may mentally suffer from a very strong deformity of their shape. The cause of idiopathic scoliosis is generally unknown. Treatment of scoliosis primarily relies on rehabilitation, but if the curvature reaches a certain angle (about 20 degrees), then the rehabilitation treatment is complemented with brace treatment [3, 4,5]. The aim of treatment of scoliosis with the use of a brace or surgery is to stop the progression and possible correction of the curvature.

Coming to terms with wearing a brace is usually difficult and often a lengthy process. As it is known every surgical procedure (including the one associated with scoliosis) is a difficult situation for patients and either their parents. If one wants a child to accept this method of treatment, it needs to be accepted by a child's parents. Due to stress they have the right to feel the negative emotions like anger among others. In some patients' case, anger may be externalized more in a direct manner, for example by shouting, raising voice tone (as it is in the case of external anger), while in others anger may be hidden, repressed, not shown to the object of a situation (internal anger) [6]. A difficult situation, a long-term illness, physical deficiency or hospitalization and surgery can often trigger reactions of anger which can be expressed directly or suppressed. The cause of such reactions is usually fear of the disease

itself (respondents described it as a fear of how they will function, what they will be able to do, how they will cope with school situations such as not being able to carry books to school or participate in sports activities) or surgery (with the most frequent question: are you sure I will wake up?, how much will it hurt?). The mere awareness of the fact that a person is ill can create a source of nagging anxiety. A sick child's imagination suggests everything in his or her mind which can be connected with the concept of a disease such as a heart failure, physical disability, being rejected by others. A negative image of the disease, its course and effects may increase a child's anxiety [7]. We must not forget that anger is one of the stages prior to the acceptance of a prolonged illness without the expression of which it is usually impossible to reconcile with the situation and thus to find strength to fight the illness [8]. Deciding on the method of treatment patients must know that this is best for them and often the only form of help. It is important that they know the initial treatment plan which will allow them to take a little control over the process. It is vital that both doctors and patients and their parents bear in mind that a positive attitude towards treatment has a huge impact on its results. The very way of information transfer is of the utmost importance. It is important that the information should be received by both parents and the children (Their age, intellectual level and already observed sensitivity must be taken into account. Talking with parents and a child or a teenager about the disease and the proposed method of treatment the principle of finding the positives in difficult situations should be implemented (eg a brace will be worn for a specified time, the operation is to shorten the time of wearing the brace and to accelerate the healing process)[9].

Restrictions to physical capabilities and even functional disturbances of individual organ systems are possible consequences of scoliosis. Following diagnosis, there is a need for a certain amount of adjustment to the new situation. Regular repetition of specific exercises, visits to the family doctor and to specialists, adaptation to a brace and rehabilitation measures all have a lasting impact on the life situation of an adolescent. The initial shock that frequently follows a diagnosis of scoliosis may result in emotional uncertainty; feelings of fear, depression, helplessness or hopelessness need to be overcome. These symptoms are usually most severe at the beginning of the treatment. However, even if a patient comes into terms with it, they may repeatedly re-appear during the long process. Very often does it happen that other difficult life situations make the depressed mood associated with the need to treat by means of a corset and difficulties in reconciling with this fact return. Uncertainty produced by scoliosis about the further progress of the illness may result in changes in the attitude of the patient to himself and his body. Knowing that one will never have a perfect body can lead to doubts about self-worth and a lessening of self-esteem. [10].

The study (Botens-Helmus C, Klein R, Stephan C) using the BSSQ questionnaire (Bad Sobernheim Stress Questionnaire) have shown higher scores in these areas. Patients wearing orthopedic corsets evaluated the following events as being stressful (scale 0-3, 0-most stressful, 3-least stressful):

I feel conspicuous by the appearance of my back

1. I find it hard to show my back public
2. I feel embarrassed in situations, in which other people can see my naked back
3. I don't feel embarrassed showing my back
4. I try not to get too close to other people to avoid that they become aware of my scoliosis
5. When deciding what kind of clothes to wear or how to wear my hair, I take care my back is hidden

6. Scoliosis is a part of me, people have to accept me the way I am
7. Because of the scoliosis I avoid activities/hobbies, which otherwise I would love to do[10].

BRQ is another questionnaire which illustrates the quality of patients' life very well. The questions of the questionnaire were grouped into eight specific domains: general health perception, psychical functioning, emotional functioning, self-esteem and aesthetics, vitality, school activity, bodily pain, social functioning. The subscales of these eight dimensions can be combined to produce a total score. Higher scores mean a better quality of life. In the studies (Vasiliadis E et al) which made use of the BRQ questionnaire, a reduced quality of life of children and adolescents affected by scoliosis were demonstrated. There are minor differences as far as specific domains are concerned among the authors, however, they all stress that patients achieved the lowest results in psychical functioning[11,12,13,].

This problem applies in particular to girls during puberty period. They are ashamed to undress before physical education lessons, go to the pool or even leave the house wearing T-shirts. These difficulties are also very pronounced in male-female relationships which begin to form in that time. Their negative experiences in this area may affect relations with the opposite sex and lead to difficulties in the sphere of intimacy throughout the whole life. Brace wearers may feel unattractive, ugly, unworthy of interest of the opposite sex and this, in consequence, may lead to closing within oneself and to reluctance as far as establishing any new social contacts is concerned, not to mention the emotional and physical intimacy.

Changes in lifestyle and life plans due to giving up particular sporting or leisure interests or limitations to the choice of career represent further burdens for the patient. The relation of the patient to the parental home is affected to the extent that adolescents are usually restricted in their movement towards autonomy by necessary treatment measures. Contact with his own age-group may be hampered by his special role as a scoliosis patient and separations from his social circle by periods in clinics or hospitals are detrimental to the process of orientation towards the peer group[14,15].

Observing people of both sexes with scoliosis would seem that boys will deal with this problem much better. [16].Obinwanne F Ugwonalu and the coworkers' study evaluating differences in the functioning of the gender(CHQ domains: Psychical Functioning, Role/Social Limitation, Bodily Pain, Behaviour, Mental Health, Parental Impact - Emotional, Parental Impact-Time, Family Activities, Family Cohesion) have shown that there were no differences between braced boys and girls, except for Family Activity, which was significantly higher among boys [17]. One can suppose that the boys in question have, in fact, tried not to show inconveniences they experienced.

Teenagers do not want to look different from their peers and, although bracing is not associated with pain, it is disturbing for patients. There is evidence that bracing tends to affect them psychologically due to disturbances of their perceptions of self and body image [17,18].

A lot of scientific research and observations [19,20,21,7]point at a lower life quality of children and teenagers being treated due to scoliosis. Although this kind of treatment is not associated with pain, it is a disturbing one for patients and tends to affect them psychologically due to disturbances of the perceptions of self and body image [6]. Adolescence is a difficult psychological period in its own right and, when it is compounded

with scoliosis and bracing, can produce immense psychological stress, resulting in altered body image [6]. The study (Parent EC, Hill D, Moreau M, Mahood J, Raso J, Lou E ; Freidel K, Reichel D, Steiner A, Warschburger P, Petermann F, Weiss H, Aulisa A, Guzzanti V, Perisano C ) explored differences in perceptions of body image, happiness and satisfaction between adolescence with scoliosis wearing a Boston brace and a control group. The main results obtained is that girls with scoliosis had a statistically significant poorer perception of happiness and satisfaction in comparison to girls in the control group have a better body image perception as well as a better perception of happiness and satisfaction in comparison to the control group . The study shows that adolescence with scoliosis had a poorer body image perception than adolescents in the control group. [6]

However, brace-based treatment significantly interferes with several aspects of patients' life , which may determine high levels of stress and negatively impact on every-day life . In fact, AIS patients, especially those subjected to conservative treatment, may experience social isolation, depression and reduced participation in leisure activities. As a result, the prevalence of psychological disorders may be as high as 19% . Therefore, scoliosis is currently recognized as an important risk factor for psychological discomfort and poor QoL, especially in brace-treated patients [21].

Clinical variables that may affect overall quality of life include severity of the condition, skeletal maturity(Risser Sign), duration of brace treatment and degree of correction (conservative and/or surgical). However, the extent to which all these factors influence a particular patient's ability to benefit from the brace will depend on his/her physical, emotional and social wellbeing [7].High correction bracing has been shown to have favorable outcomes when the patient is compliant . However, bracing is considered to be a traumatic experience which may leave lasting emotional scars. The condition may itself precipitate social problems, with brace treatment further affecting self and body image , interactions with others ,overall quality of life and generally being a stressful experience for patients [7]. L. Rivett, A.Rothenberg and al. explore two patients group.on the basis of their compliance histories. For the purpose of this study, compliance was defined as wearing of the brace for 20–23hours per day and compliance to a prescribed exercise routine, ideally carried out at least four times per week. Non-compliant subjects wore the brace for fewer than 20 hours per day and exercised less than four times per week. Each patients were described using BrQ test concerning 34 question about general health perception, physical functioning, emotional functioning, self esteem and aesthetics, vitality, school activity, bodily pain and social functioning.[7].It is noteworthy that non-compliant subjects do not regard themselves as being in poor general health or experiencing bodily pain (differences between the groups not significant for these two domains), but they clearly lack vitality , have low self esteem , and physical , emotional and social function is at significantly lower level.

Personal observation of children and adolescents wearing orthopedic braces confirm the depressed mood in this group. The group also seemed to cope worse with the difficulties typical for their peers. It had been expected that young people with scoliosis would possess higher levels of neuroticism when compared to healthy children (neuroticism, being neurotic is a personality feature which consists of a strong emotional instability, low resistance to stress, a tendency to feel anxious easily). The opposite of neuroticism is emotional balance. Eysenck was the first to have used this notion in temperament theory

PEN [22, 23,24]. A study on a group of 34 children (aged 11-16,5 ) treated for scoliosis and wearing braces (Open anxiety test by E. M. Choynowski and E. Skrzypek: What are you like? [22] did not confirm the hypothesis that children wearing a brace exhibit a neurotic personality type. Instead, the test did, however, show a different relationship - this group attempted to present themselves in a better way than they really are. It is highly likely that the reason for this was low self-esteem of the subjects. People with a positive self-image evaluate themselves the way they are, along with their advantages and disadvantages, they do not need to worry about being thought of only in positive terms by others. It is worth noting that similar results occurred when testing children suffering from enuresis [25]. Only 1 / 3 of them rated elevated neurotism while 73% of the children in this group showed elevated scores on the lie scale. An important observation seems to be obtained on the basis of Z. Juczyński's KompOs Scale [25] that children wearing a brace showed great persistence in action. This feature is probably very useful in all accomplishments occurring in those children's lives, as well as in treatment by means of a brace. It is therefore a very good predictor in the treatment and rehabilitation of scoliosis.

Our own observations of patients with scoliosis indicate that, very often, do they feel inferior to a group of their healthy peers. Not rarely do such people move away from social life. They do not meet with their peers after school, they do not participate in social events, birthday parties organized by others. Unfortunately, this is the case of the vicious circle principle (eg I'm not going to someone's birthday party despite being repeatedly invited and, in the result, I am not invited any more).

For patients being operated on several times, limited school attendance and its related problems may seem to be a big issue. For this reason, some parents and children decide on an individual course of learning, which in most cases, has a negative effect on self-esteem of hospitalized people. Very often does it deepen the sense of isolation and the feeling of being rejected by peers. A person not involved in daily life of the class ceases to feel as if he/she was treated as a part of it. Not knowing the course of everyday events in the life of the class, they may have trouble finding common topics to talk about with other students.

Aulisa A, Guzzanti V et al in their analyses did not show differences in QoL depending on the curve type (data not shown). However, patients with thoraco-lumbar curves were less satisfied with management than those with thoracic curves at the SRS-22 [21].

Teenagers (aged 14.5-18) awaiting scoliosis surgery who were examined by means of Anger Expression Scale (AX) [19] showed, in most cases (except for one person), much greater intensity of internal anger rather than external one. This information would suggest that such people deliberately do not express anger. One can assume that they are afraid to express negative feelings in order not to face disapproval and rejection, especially by their peers, as it was confirmed by the results obtained in the study described above - the lie scale.

Assessing pain control, (Beliefs About Pain Control Questionnaire (BPCQ) by S. Skevington and Z. Juczyński [25] young people from the same research group a month before surgery mostly associated the pain they experienced accidentally which means that neither them nor doctors had influence on the pain. In the second place they pointed their own opportunity to help and then the influence of the doctors. Those who were able to master severity of the pain and trusted their doctors in this respect, found their mood elevated. They felt they could have impact on their own life (or felt cared for by the doctors) which made them feel

better. Those, however, who believed that their pain was accidental did not usually do anything to reduce it ("it won't work after all") [26].

Surgical treatment of scoliosis often turns out to be a difficult experience for patients and their families.[24]. Initially, at parents and older patients (teenagers) there usually appears anxiety associated with the operated site. Many times can one hear them frightfully say: What will it be like if it doesn't work? May the spine during surgery be damaged? However, the most frequent second-reaching emotion is the hope that the rigors of rehabilitation, wearing a corset and other related problems will come to an end. Young patients seem to like the fact that the treatment will shorten the time they have to wear the orthopedic corset . It is important that both patients and parents believe that this method of treatment will bring benefits. It is also necessary to keep them informed whether there is going to be one or more surgical procedures because such information will allow patients and their families prepare for this situation. Patients would also like to inquire how much time is expected to make them return to their full efficiency.

Our own experiences [4] indicate that patients' and parents' positive attitude towards operation, feeling influence upon this difficult situation and having confidence in doctors is extremely important. The study showed that patients who believed that they could help themselves endured the pain they experienced after the surgery better and they assessed it as lower when compared to those who declared that they had no influence on the situations in their lives. Such a correlation also applied to having trust in doctors and medical personnel as well as the trust that these people are able to help them. The vast majority of respondents judged that the mood a few weeks before the surgery had an effect on the one assessed several days after. People positively oriented to treatment felt much better after the surgery than those who assessed their mood before the operation as low.

Psychological support should always be provided to AIS patients, through group therapy as well as individual counseling, in order to promote disease and treatment acceptance and minimize psychological discomfort [27].

It is therefore legitimate to provide patients suffering from scoliosis and their families with the contact with a psychologist, especially in difficult stages of the illness (at the time of diagnosis, before operations, immediately after their completion, and in difficult situations). It is particularly worth working on gaining greater control over pain before the surgery which would allow to reduce the pain. Working on expressing one's emotions, especially anger which is a natural part of experiencing the disease as well as working on self-esteem, would also be very helpful [28].

It is concluded that patients with scoliosis and their families need to be provided with psychological support through the whole period of the treatment.[29] Patients and parents should make contact with a psychologist prior to orthopedic treatment in order to gain mutual trust before this difficult and stressful event. It is also important because a psychologist may notice additional family problems earlier (eg a child's emotional situation, family conflicts), or pay attention to the sensitivity of the patient. These are factors which can increase stress and anxiety associated with awaiting treatment.

Particularly important is the contact between the psychologist and the patient who will undergo surgical treatment. Both the patient and parents should be prepared for it. It would be very helpful if the patients were able to help relieve stress and pain by means of capability of positive thinking and relaxation techniques.

In case of very strong fear of the patient, the psychologist could have influence on the shift of operations, recognizing that the patient should be given more time to get familiar with this difficult situation.

Psychological help should be primarily based upon the support of the acceptance of the disease, the ways of its treatment as well as finding positives in this difficult situation. It is also important that patients and their parents should have the opportunity to request a psychologist's help in case of other difficulties that may arise in their lives.

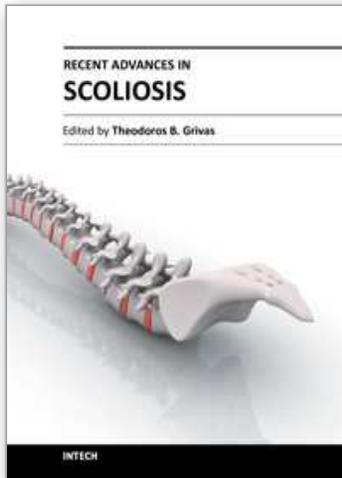
A support group would be extremely beneficial (for people with scoliosis of both sexes), where patients could gain support from other patients, who were faced with similar problems and managed to overcome them.

It is generally discouraged that patients with scoliosis should have an individual course of learning. Such a situation (especially in case of learning from home) may increase the sense of lower self-esteem, and the feeling of isolation from the peer group.

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## **Recent Advances in Scoliosis**

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This book contains information on recent advances in aetiology and pathogenesis of idiopathic scoliosis, for the assessment of this condition before treatment and during the follow-up, making a note of emerging technology and analytical techniques like virtual anatomy by 3-D MRI/CT, quantitative MRI and Moire Topography. Some new trends in conservative treatment and the long term outcome and complications of surgical treatment are described. Issues like health related quality of life, psychological aspects of scoliosis treatment and the very important "patient's perspective" are also discussed. Finally two chapters tapping the untreated early onset scoliosis and the congenital kyphoscoliosis due to hemivertebra are included. It must be emphasized that knowledgeable authors with their contributions share their experience and enthusiasm with peers interested in scoliosis.

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