Mini-Review

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Evaluation of quality of life and risk factors affecting quality of life in adolescent idiopathic scoliosis

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Summary **Adolescent idiopathic scoliosis (AIS) is a common disease leading to spinal deformity in children ages 10 and over. With advances in the study of health-related quality of life (HRQoL), greater attention has been given to the quality of life (QoL) of patients with AIS and their perception of deformity instead of just focusing on improving the rate of surgical correction. This article provides an overview of the methods of evaluating HRQoL and it analyzes several main factors affecting QoL, such as severity of disease, method of treatment, gender, and social environment, based on previous studies of patients with AIS. The authors believe that radiological studies should no longer be taken as the only indicator of postoperative therapeutic evaluation and hope to build a new evaluation system with assessment of QoL for patients with AIS.**

Keywords: Adolescent idiopathic scoliosis, quality of life, evaluation, questionnaire, risk factors

1. Introduction

Adolescent idiopathic scoliosis (AIS) is defined by the Scoliosis Research Society (SRS) as an unknown spinal deformity with a coronal Cobb angle > 10 degrees occurring in a child over the age of 10 whose skeleton is still developing. AIS occurs frequently in teenagers.

The rate at which AIS is corrected has greatly improved with the formulation of the theory of three-dimensional scoliosis correction and rapid advances in internal fixation, such as multi-level pedicle screw fixation. Changes in healthcare models and constant advances in research into health-related quality of life (HRQoL) have led to the realization that greater attention should be paid to the quality of life (QoL) of patients with AIS and their perception of deformity instead of just focusing on improving the rate of surgical correction.

Although scoliosis is far from life-threatening, social, family, and surgery-related factors might lead patients to develop mental disorders (*1*) or even attempt suicide (*2*). In order to improve patient QoL and satisfaction with treatment, attention must be paid to research on QoL in patients with AIS.

2. Advances in methods of evaluating HRQoL in patients with AIS

HRQoL refers to health status and is an individual's level happiness or satisfaction with personal life events in the face of disease, accident or injury, or medical treatment. HRQoL reflects a patient's subjective assessment of his or her QoL. Dimensions like health status, function, pain, and satisfaction can be evaluated using comprehensive scales and questionnaires that assess general health or the state of a specific disease. Common HRQoL scales are divided into two categories, general instruments to evaluate HRQoL and specific instruments to evaluate HRQoL.

2.1. *General instruments to evaluate HRQoL*

The questionnaire most commonly used to evaluate general health is the Short Form-36 Health Survey (SF-36). Other instruments include the Pediatric Outcomes Data Collection Instrument (PODCI) and the Child Health Questionnaire (CHQ).

The SF-36 covers the 8 aspects of physiological functioning (PF), bodily pain (BP), physiological

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functioning (RP), general health (GH), social functioning (SF), vitality (VT), mental health (MH), and emotional functioning (RE), and the SF-36 can be used to evaluate the QoL of patients with various diseases (*3*). Although the SF-36 is widely used in clinical practice, it is a general instrument to evaluate HRQoL and it not specific to scoliosis. Other drawbacks are problems like repeated questions and the long time needed to administer the questionnaire. Moreover, evaluation of self-image, which is of particular significance in patients with AIS, is not included in SF-36.

2.2. *Specific instruments to evaluate HRQoL*

Specific instruments to evaluate HRQoL are specifically designed for a specific disease like spinal deformity. Instruments to assess QoL in patients with scoliosis include the Scoliosis Research Society Outcomes Instruments (SRS-22 and SRS-24), the Quality of Life Profile for Spinal Deformities (QLPSD), the Spinal Appearance Questionnaire (SAQ), the Scoliosis Quality of Life Index (SQLD), the Walter Reed Visual Assessment Scale (WRVAS), and the Bad Sobernheim Stress Questionnaire (BSSQ) (*4-7*).

2.2.1. *SRS-24*

Haher *et al*. (*8*) created the simple and practical SRS-24 HRQoL questionnaire for patients with scoliosis in 1999 and they contended that a child's HRQoL and subjective satisfaction should also be assessed as part of the evaluation after surgery for scoliosis. The SRS-24 is divided into two parts. The first part includes assessment of pain, functioning, self-image, and activity, and this portion can be used to evaluate any patient with scoliosis. The second part includes postoperative self-image, functioning, and satisfaction with treatment. This portion can only be used to evaluate patients after surgery for scoliosis.

2.2.2. *SRS-22*

The SRS-24 has several advantages like being distinct and concise and having a high response rate. However, the second part of the scale is limited to patient evaluation after surgery. In 2000 and 2003, Asher introduced a modified SRS and SRS-22 questionnaire including five aspects of functional status, self-image, pain, psychological status, and satisfaction with treatment. This modified scale is also more accurate in some dimensions than the SF-36.

In addition, the SRS-22 can be used to evaluate QoL in patients after surgery for scoliosis as well as QoL in patients receiving conservative treatment of scoliosis. The SRS-22 is the world's most widely used scale to evaluate the QoL of patients with scoliosis. The SRS-22 has been translated into numerous languages such as Spanish, Japanese, and Turkish. Based on the English version of the SRS-22, Li *et al*. (*9,10*) created a Chinese (simplified) version of the SRS-22 that is culturally adapted. They concluded that it has good reliability and validity and can be used to clinically assess patients with AIS after surgery in China.

2.2.3. *SAQ*

Based on the WRVAS, Sanders *et al*. (*11*) created a new HRQoL questionnaire called the SAQ in 2007. The SAQ combines standardized images with a questionnaire to assess how patients and their families subjectively feel about a spinal deformity. Sanders also found that the SAQ was more sensitive and reliable in distinguishing an improvement in QoL after surgery than the SRS-22. Wei *et al*. (*12*) created a Chinese (simplified) version of the SAQ that was culturally adapted in accordance with international guidelines. They demonstrated its good reliability and validity in gauging how patients with AIS in China rated their appearance.

3. Analysis of the factors affecting QoL in patients with AIS

With the development of the Bio-Psycho-Social model of human behavior (*13,14*) and continuous revisions to relevant questionnaires, greater importance has been attached to factors that affect a patient's QoL. A study by Payne *et al*. (*3*) indicated that the presence of a spinal deformity was a risk factor for psychological depression regardless of the treatment the patient received. Adolescence is a sensitive period of personal and psychological maturity, so many factors like a deformity and physical discomfort can affect the QoL of patients with AIS.

3.1. *Disease factors: Severity of scoliosis*

Patients with AIS are most often seen for an abnormality such as incorrect body posture or left-right asymmetry of the shoulders. Since adolescence is a critical period of psychological development, the deformity caused by scoliosis may place a certain degree of social and psychological pressure on patients, and a more severe deformity will cause greater psychological stress.

AIS is a complex three-dimensional deformity. Spinal deformity in any plane can affect a patient's results on an HRQoL questionnaire. For postoperative patients with AIS, the Cobb angle of the instrumented thoracic curve is the main factor influencing QoL. A study by Helenius *et al*. (*15*) examined 98 consecutive patients who underwent surgery with a Harrington distraction rod and posterior spondylodesis. They found that the magnitude of thoracic curvature as assessed during follow-up an average of 21 years later was significantly inversely correlated with scores for cosmetic aspects on the SRS-24. A study by Watanabe *et al*. (*16*) found that general self-image was inversely correlated with the Cobb angle and the rotation angle of the thoracic curve and that self-image after surgery was correlated with the extent of correction of the thoracic Cobb angle. These results indicate that the Cobb angle of the thoracic curve and radiographic parameters for evaluation of scoliosis in the axial plane greatly affect patient outcomes, and particularly how patients with AIS gauge perceive their appearance.

A study by Shang *et al*. (*17*) scored 46 patients with AIS using the Symptom Checklist 90 (SCL-90), Self-rating Depressive Scale (SDS), and Self-rating Anxiety Scale (SAS) as recommended by the Psychology Department of the 4th Military Medical University. They compared those scores to those of 50 healthy adolescent volunteers of the same age. They found that patients with severe AIS were more likely to have psychological problems, thus affecting their QoL, than patients with medium or mild AIS.

3.2. *Treatment factors*

3.2.1. *Conservative treatment*

Brace therapy is an important form of conservative treatment for patients with AIS, and this therapy can significantly reduce the severity and slow the progress of AIS (*18,19*). However, bracing is likely to cause adverse psychological stress that affects QoL. A study by Climent *et al*. (*20*) used QLPSD to assess the effect of various types of braces on QoL, and they found that patients treated with a Milwaukee brace scored significantly higher than patients treated with a Boston brace, especially in terms of psycho-social functioning. This which means that the Milwaukee brace has a greater impact on QoL. A study by Maruyama *et al*. (*21*) used the SRS-22 to evaluate the QoL of patients treated with a Milwaukee brace and they reached the same conclusion. Matsunaga *et al*. (*22*) used the Maudsley Personality Inventory to assess 145 adolescent females with idiopathic scoliosis to compare changes in personality after brace therapy. Of the 134 patients rated as normal before the start of therapy, 108 were rated as abnormal when tested 1 month after the start of therapy. After psychological intervention, 47 patients were finally rated as abnormal, which suggests that psychological testing combined with psychological treatment may reduce the negative psychological effects of brace therapy and facilitate modified bracing.

Some researchers believe that patients with AIS who undergo brace therapy may feel shy and have internal pressure as a result of lifestyle or studying. Therefore, the mental health of patients with AIS should be evaluated and monitored to reduce the negative psychological effects of brace therapy. Possible approaches include psychological testing to assess patient personality types before bracing and formulating personalized treatment plans for individual patients to provide a better QoL.

3.2.2. *Surgical treatment*

The effect of surgery on a patient's social and psychological functioning has received less attention in the literature than the effects of brace therapy on that functioning. Surgery is a major challenge for patients with AIS due to problems like pain and emotional distress during hospitalization, worries about surgical complications, and the disruption to one's social life during post-surgical recovery (*23*).

A complex disease, AIS is not readily treated with surgery and patients with AIS also have a high risk of suffering psychological illness, particularly as a result of characteristics like preoperative trait anxiety and a low level of cognitive development. Therefore, close attention must be paid to a patient's psychological state and psychological intervention must be provided when necessary in addition to correcting scoliosis.

3.3. *Individual factor: Gender*

Gender is a factor that affects the psychology of patients with AIS. Payne *et al*. (*2*) used the Adolescent Health Survey (AHS) to study 685 patients with AIS, 269 males and 416 females ranging in age from 12-18 years. The AHS is a comprehensive assessment of health status that attempts to ascertain all medical, social, and family circumstances that might have an impact on the health status of adolescents. The study's results indicated that scoliosis was an independent risk factor for more frequent suicidal thoughts, more concern about abnormal body development, and a greater worry and concern about peer relations. Male adolescents with scoliosis were 60% more likely to think they were underweight while female adolescents with scoliosis were 52% more likely to have suicidal thoughts than their peers. This implies that the impact of scoliosis and gender differences in patients may be greater than previously thought.

3.4. *Social factors*

3.4.1. *Differences between urban and rural areas*

China is a developing country with unevenly developing regional economies. There are considerable disparities in living conditions, income, and medical systems in urban and rural areas. Compared to rural areas, urban areas allow a more open lifestyle with a higher income and a better medical insurance system. These social factors are sure to affect the evaluation of a patient's QoL and these differences will be reflected in SRS-22 scores. A study by Wang *et al*. (*24*) used the SRS-22 to study the regional factors that affected patient QoL, and they found that urban patients had significantly higher scores in satisfaction with management of their disease and lower scores in self-image than did rural patients. This indicates that differences between urban and rural areas affect the evaluation of QoL.

3.4.2. *Family environment*

For patients with AIS, the family environment is also a factor that affects QoL. Kahanovitz and Weiser (*25*) studied 72 female adolescents with scoliosis ages 12-16 years, and they found that patients from single-parent families had a lower QoL and that the mother's attitude towards her child's illness had a highly positive effect on a child's attitudes toward treatment, thus improving his or her QoL. Unlike adults, most children fail to comply with the treatment and recovery process because of their specific physiological characteristics. The psychological state of parents directly affects their children, who are likely to adopt the behaviors and opinions of their parents. Therefore, the parent-child relationship should be emphasized when treating adolescent patients.

4. Discussion

In conclusion, the QoL of patients with AIS can be directly or indirectly affected by factors like disease, treatment, individual traits, and social circumstances. This fact is being realized by spinal surgeons. Comprehensive and effective questionnaires or scales for the specific disease (scoliosis, in this case) must be used to follow-up on a patient's QoL and early psychological intervention must be provided when needed. Radiological studies should not serve as the only method of postoperative evaluation in patients with AIS and evaluation should include assessment of QoL.

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