

# Health Related Quality of Life in Adolescents with Idiopathic Scoliosis

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## 1. Introduction

The great number of articles about Health Related Quality of Life (HRQOL) in adolescents with Idiopathic Scoliosis (AIS) as well as the creation of measuring instruments indicates the emerging interest present in the health world, at the moment.

This work has come into being as a reflection between two researchers from Barcelona (Spain): Elisabetta D'Agata and Carles Pérez Testor. Besides, they both have collaborated with Manolo Rigo, director of E. Salvà Institute.

The present study is meant to deepen the concept of HRQOL and to understand how it is used, its strong and weak points.

Besides, the authors intend to complement the medical model with the *psychological one*, in a bio-psycho-social framework. They consider that the integration of the two perspectives could help to better understand AIS, in order to open the way to new research avenues. They hope that these reflections can have a practical impact on the process of *humanizing* health.

The present study is organized into four parts: at the beginning, the authors explore the historical origin of the HRQOL construct and its definition correlating it to the concepts of body image, stress and family function. The second part is about the impact of the scoliosis diagnosis and conservative treatment on the patient. The third part is a brief description of the measuring instruments and the last one discusses authors' contribution to the field.

## 2. Health related quality of life in adolescence

Happiness and wellbeing have been important themes of reflection since the ancient Greek philosophers' time. Nowadays, they have been considered the origins of the present concept of Quality of Life (QoL).

The QoL had its origin in the USA after the Second World War, when the Country was concerned to build up a Welfare State. The idea at first was that the QoL correlated with the possessions of material goods. However, with the progressive economic development of the 1970s, the concept changed and opened the way to social themes. In the 1980s, as sickness evolved from „severe“ to „chronic“ thanks to the technological and pharmaceutical improvements, the new concept of HRQOL began to be employed.

Its definition came from the *World Health Organization's* statement (1948), that "health is a state of complete physical, mental and social well-being, and not just the absence of disease". This concept has influenced a progressive process of understanding *health* in a subjective way, not only considered as a "state" or a "functional capacity" of patients (*biomedical model*), but also as the patients' perception and the personal representation of the disease (*bio-psycho-social model*) (Galán Rodríguez et al., 2000).

Thus, in 1995 the Group of the *World Health Organization* dealing with the QOL (WHOQOL) developed a definition of HRQOL. Since then it has been considered as a **multidimensional construct** that includes the patient's perception and the different levels of his life (physical, emotional, interpersonal, etc.); this new model emphasizes the **dynamic temporal dimension** (depending on age, patient's life stage and phase of the disease), and stresses the importance of **cultural factors** in a **subjective process of self-evaluation**.

Furthermore, this concept implies the presence of positive aspects (*quality*) in people's life and not only the absence of negative ones. As a consequence, it breaks with the former ideology of intervening only in case of troubles while it embraces a preventive principle: it justifies intervention **before** problems are present (Casas, 2000).

At the same time, in the 80s some publications about children HRQOL (CHRQOL) appeared in literature, although in smaller proportion than in studies related to adult population (Quiceno & Vinaccia, 2008). Until recently, children were considered patients without power. In the research field, the younger they were, the more the researchers relied on their parents into account (Andelman et al., 1999). Moreover, Frisén (2007) considered not to evaluate adolescents with the same parameters used for adults. In the specific case of adolescence, HRQOL study has to include such aspects as physical maturation and body image, peer relationships, intimacy, sexuality and autonomy.

However, in the past the concepts of HRQOL and CHRQOL were criticized for the lack of a clear, robust, consensus-based theoretical framework (Pane et al., 2006), for confusing the QoL just with health (Verdugo et al., 2006), and for the lack of definitions as these concepts were considered „self-evident“ (Andelman et al., 1999).

Nowadays, despite these limitations, the above stated concepts seem very important as they underline the emergence of the *bio-psycho-social paradigm* into the health field. It expresses a huge epistemological shift: it is a systemic model, which integrates bio-physiological systems with mental levels. According to this model, the disease arises as an interference in the systems' interaction while a single system may not be considered responsible for it. (Solano, 2001).

Considering the widespread debate and its interdisciplinary aspects, the authors intend to investigate some psychological dimensions, choosing three main concepts correlated with adolescent HRQOL: **body image, stress and family**.

## 2.1 Body image

Body image is considered relevant when a body falls ill.

At the beginning, body image was only studied by neurologists in cases of brain damages, then, neurologist Paul Schilder (1886-1940) widened the perspective through psychoanalysis and sociology.

However, an entity called *Body image* does not exist per se (Fisher, 1990); it is more accurately to define it as a multidimensional construct which includes the following three aspects (Raich, 2004): 1. a *perceptive* dimension, meaning the precision through which a person distinguishes size, weight and shape; 2. a *cognitive-affective* dimension, encompassing thoughts, feelings and values related to the body.; 3. a *behavioural* dimension, comprising inhibition, avoidance, obsessive checking, rituals, camouflage.

Body image has been studied in psychopathology, above all in the cases of eating disorders where its alteration is evident. However, it is a property belonging to the human being and it is *dynamic* in the life process, influenced by physiologic bodily changes. **Adolescence** is the period when the changes in body image are experienced with more intensity (Markey, 2010) because of the hormonal influences. Therefore puberty is considered a risk factor in terms of body dissatisfaction (Toro, 2010). Moreover, there are several intervening factors affecting body satisfaction as it is unrelated to the actual real weight or to the Body Mass Index, and it is more predictable in the case of a history of teasing, for example (Toro, 2010).

It has also been observed (Cahill & Mussap, 2007) that a protective factor for the body image is **self-esteem**. Self-esteem is considered the value that the person assigns to him/herself, in the process of self-evaluation (Rosenberg, 1965). But in the opposite direction, as in adolescence a great part of self-esteem is determined by body satisfaction, if the person does not accept his/her own body, it is difficult for him/her to accept the person living in it (Raich, 2004). For all these reasons, the influence of body satisfaction could have dramatic consequences during adolescence, such as poor self-esteem, depression, social anxiety, inhibition, sexual dysfunction, eating disorders, onset of cosmetic and surgical treatments, and so on (Salaberria et al., 2007).

Finally, in this context, it is important to underline that a disease may play an important role in body satisfaction, above all when it is an *acquired* disease, which could alter identity dramatically.

## 2.2 Stress

Stress has been studied in relation to HRQOL as it deteriorates the QoL (Schwartzmann, 2003). The concept of stress originated from the field of physics where it refers to those forces applied to an object which leads it to a breaking point (Buendia & Martinez, 1993). Similarly, McGrath (1970) defined it as an imbalance between environmental demands and individual responsiveness. The concept has been re-defined several times and has been changing over the time. At the moment, there are different definitions of stress, mainly divided into three categories: 1. *Stress* as a physiological, mainly hormonal, response to environmental demands (Selye, 1956); 2. *Stress* as a stimulus caused by the environment (Holmes & Rahe, 1967); 3. *Stress* as a relationship between the person and the environment (Lazarus & Folkman, 1984).

In this last theory, through a cognitive appraisal, the person has an active role in evaluating situations. Lazarus and Folkman (1984) called "coping strategies" the individual's cognitive and behavioural efforts aiming to minimize, reduce, tolerate and dominate environmental demands. Coping strategies could be divided synthetically into two groups: *approach* and *avoidance*. The first is an active strategy, orientated towards problem-solving and/or actively

seeking support; the second is a passive strategy, involving denial of the situation and withdrawal from it (Seiffge-Krenke & Klessinger, 2000).

Stress and disease have a two-way relationship, as stress may have direct effects on health while the impact of a disease could generate stress.

Two of the most difficult phases in a state of disease are the diagnosis and the treatment (Espina & Ortega, 2003). In the acquired diseases, the diagnosis may provoke emotional responses of shock, anxiety, feelings of loss and grief in the patient (and in his/her family). In the course of the treatment, the patient and his family could become aware of the problem. They are in *mourning* for the lost functions and habits (Espina & Ortega, 2003). This process (Bowlby, 1983) consists of four phases: 1. *Numbness* (slumber and denial of reality); 2. *Searching and yearning* (anger, anxiety, fear, disorientation, etc.); 3. *Desperation* (apathy, absence of emotion, etc.); 4. *Acceptance* (self redefinition and life reorganization).

### 2.3 Family with an ill child

Any illness is not confined only to the patient's body, but has an impact on the whole family; similarly in the opposite direction, family may influence the course of the disease and/or rehabilitation. These connections are possible as the family is a system (Bronfenbrenner, 1976), a unique "body" (Cigoli & Scabini, 2006), a set of internal, social and generational relationships where their components influence one another.

With the disease, the entire family may feel a loss of identity as a "healthy family" and face a process very similar to the mourning one. In the initial phase, there is a state of confusion over the diagnosis while later a state of depression may follow. There are different possible stages of adaptation to the disease (Gómez & Flores, 1999). Usually the family may alter its structure with a reorganization of the roles, the creation of new alliances, coalition, changed hierarchy, isolation (Ferrari & Adami, 1997). Familiar relationships may sometimes change so much that, although they seem helpful, they become part of the problem as a maneuver of the complex family game (Ferrari & Adami, 1997).

A main caregiver, that culturally is the mother, appears. But the main caregiver can have a so close relationship with the patient (exclusive dyad) that the rest of the family can live feelings of jealousy, abandonment, and even potential couple problems; the main caregiver can also gain power as the patient loses it, but, on the other hand, the total and exclusive dedication leads her/him to exhaustion and isolation within the family (Espina & Ortega, 2003).

## 3. HRQOL in adolescents with idiopathic scoliosis

The peculiarity of having a scoliosis places the patient in an undefined region between illness and health, as a scoliosis is a spine deviation but also a deviation from normality, a feature that could be lived either as a deformity or not, depending on whether the posture stoops, the person has to wear a brace or to be operated, and generally how to deal with it.

It has been shown that scoliosis is a risk factor in adolescence and may produce psychosocial issues (Payne et al., 1997).

Moreover, the issue of a *poor body image* is an almost universal evidence found in studies of adolescent scoliosis (Tones et al., 2006), although it seems to the authors of the present study insufficiently investigated. Several researchers (Payne et al., 1997; Weinstein et al., 2008) observed that patients who develop a disease that alters their physical appearance during adolescence, such as scoliosis, arthritis, diabetes, psoriasis or other, have a poorer body image compared to patients with an acquired disease in childhood or adulthood. In adolescence, scoliosis may threaten the integrity of body image and attack self-esteem; so, it could hinder the creation of a new image, with the appearance of feelings of insecurity and of inferiority (Saccomani et al., 1998). The research detected two levels about body image: on a conscious level, the 63% of patients minimized the impact of scoliosis on their body experience while, on an unconscious level, the 45% expressed anxiety about the experience of a bodily deterioration (Saccomani et al., 1998). In addition, considering a possible relationship between body image problems and eating disorders, Smith et al. (2008) observed that the 25% of the patients with scoliosis were severely underweight.

Besides, Forstenzer and Roye (1988) referred to the mourning process which the patient has to go through after the diagnosis of scoliosis. Like the patients, also parents live the mourning of the perfect and healthy daughter/son (Forstenzer & Roye, 1988). A further complication is present if these patients injured are daughters of mothers with scoliosis (Forstenzer & Roye, 1989). Consequently, a diagnosis of scoliosis may represent a double attack towards these mothers: in relation to their own imperfection and to their daughter's.

### 3.1 Conservative treatment

In literature there are contradictory results on the impact of brace in adolescent HRQL, due to a variety of factors present in the researches, such as the type of the orthoses, the daily use (part-time/full-time), cultural differences among patients (Cheung et al., 2007) or the measuring instruments used.

Surely, the kind of brace has a different impact on HRQOL: Milwaukee brace is considered the most stressful for its impact on the psychosocial area and back flexibility (Climent & Sánchez, 1999). Milwaukee-treated patients have a worse body image and worse experience with the hospital staff in comparison with the group of operated patients (Fällström, et al., 1986). However, low values in vitality and physical functioning have been observed also in adolescents treated with a modified Boston brace for a minimum of two years (Vasiliadis et al., 2006).

Since the beginning of the treatment and for six months later, in these patients, researchers have observed feelings of fear and anger (against the parents, the doctor, her/himself); in addition, denial is often used (Sapountzi-Krepia et al., 2006). Because of the feeling of being different, a lot of patients may develop a sense of shame. The fear that others can discover their "secret" may lead them to be more stressed, anxious, with a less positive attitude towards life and with feelings of body inferiority (Reichel & Schanz, 2003). As a consequence, the threat to body image and the social integration difficulty can guide the adolescent towards activities that isolate him/herself, developing the building of neurotic personality with depressive aspects, emotional coartation and relational difficulties (Saccomani et al., 1998). Although stress decreases during the first months of treatment, at the end of the treatment, a significative worsening in different areas (physical, emotional

and social functioning, self-esteem, pain and body image) has been assessed (Vasiliadis and Grivas, 2008).

At the opposite, a Swedish study (Olafsson et al., 1999) concluded that brace treatment has no negative effect on the image of the teenager, although a half of the sample believed that brace may affect the muscles.

Psychological stress due to the treatment is a concern among professionals, as it is also negatively related to the compliance with the treatment (Olafsson et al., 1999, Burkhart & Sabaté, 2003). For these reasons, a shorter brace type or a part-time wearing modality were proposed. Indeed, a 64% of high-school teens do not wear the brace as they should or long enough to be effective (Vandal et al., 1999), and this can interfere with the treatment effectiveness (Yrjönen et al., 2007).

Generally the reported compliance is less than the admitted one and it does not increase when the patient is prescribed to wear the brace in a part-time modality respect to a full-time one (Takemitsu et al., 2004). However, compliance can be considered a dynamic behavior, which is reduced with the age (increasing among patients aged 11-14 and worsening in older adolescents) and in relation to the duration of treatment (Takemitsu et al., 2004). It improves after school and during the night, while it worsens during summertime and on weekends (Nicholson et al., 2003). In addition, Lindeman and Behm (1999) underlined a relationship with sex: non compliant girls were anxious and expected to fail in facing scoliosis; non compliant boys, in contrast, had high self-esteem and high expectation of success.

Finally, also about the long-term treatment effects there is not always consensus on results. The study carried out by Haefeli et al. (2006), in monitoring HRQOL, showed no differences comparing patients treated with braces, with a control group, after a period of time *between 10 and 60 years*. The patients of the study, reporting psychological problems due to scoliosis, had a low self-esteem problem related to the feeling of no appeal and relational problems. Despite the negative effect of the brace, this does not develop a psychopathology (MacLean et al., 1989).

However, another research (Freidel et al., 2002) does not confirm these results: brace-treated patients are more unhappy with their lives; they report more physical problems and score higher in depression compared to a control group. Despite these feelings of depression, they appreciate more positive events in their lives. Moreover, in a *10-year-long study* after Boston treatment (Andersen et al., 2002), the 24% of patients who had worn a brace over the age of 16 had problems with the opposite sex, compared to the 7% of those who had started wearing the brace before they were 16; a difficulty in the sexual area was confirmed in another study with Milwaukee brace patients (Apter et al., 1978), who showed anxiety and rigidity. Finally, *22 years after* the treatment, there were no differences in relation to marriage and to the number of children among brace-treated patients and control group; only the mean age of brace-treated patients at their first child was higher (28 years) compared to the average (25.9) (Danielsson & Nachemson, 2001).

However, as the conservative treatment is long and affects the daily lives of almost asymptomatic patients, some psychological interventions have been implemented with the aims of sharing experiences, enhancing self-acceptance and learning strategies to manage

social life. Different techniques of art therapy, relaxation and games have been used (Reichel & Schanz, 2003; Weiss, 2003), while in case of pain, groups of handling pain have been set up (Weiss, 2003).

#### 4. HRQOL measuring instruments

Although health has always interested researchers, the HRQOL history is quite recent and as a result, a large amount of questions can arise (Climent et al., 2009). The problem is wider, as difficulties appear in the use of HRQOL measuring instruments either in the research or in the clinic fields.

In the AIS, the debate focuses on the possibility of using generic, specific and super-specific questionnaires (Climent et al., 2009).

##### 4.1 Tools in AIS

**Generic questionnaires** are valid for the general asymptomatic population, widely used in epidemiological general studies (as in the case of health surveys); they are usually well validated but they lack of sensitivity to detect clinically important changes throughout the time or the treatment. Instead of a global measure of HRQOL, the most authors break down the concept in various domains; among these, there are still important discrepancies about the appropriate dimensions of the concept.

In the AIS, **Short Form Survey-36** (SF-36) and Short form-12 (SF-12) have been widely used.

SF-36 (Ware & Shebourne, 1992) consists of 36 items covering 8 dimensions: physical functioning; role limitations due to physical problems; bodily pain; general health perceptions; vitality; social functioning; role limitations due to emotional problems; mental health. This questionnaire, translated into 15 languages, has good psychometric properties, valued in more than 400 articles (Vilagut et al., 2005).

A limitation found in this type of assessment refers to the fact that it has been validated for the adults. To take more appropriate areas into account, the following two questionnaires have been used: the **Paediatric Outcomes Data Collection Instrument** (PODCI) and the **Child Health Questionnaire** (CHQ).

The PODCI, created by the Pediatric Orthopaedic Society of North America in the late nineties, aims at measuring paediatric orthopedic problems. It consists of three instruments: the pediatric questionnaire (for parents of children between the age of 2 and 11), the questionnaire for parents of teens (aged 13 and 18) and the questionnaire for adolescents (between 11 and 18 ) (Furlong et al., 2005).

The latter from the U.S.A is the CHQ, with three versions for parents (CHP-PF 28, CHP-PF50, CHP-PF98) to assess the HRQL of children aged 5-10 and a version (87 items) for adolescents (between the age of 10 and 18 ) (HealthActCHQ, 2010).

The **specific instruments** measure the impact of a particular disease and have a greater sensitivity to change (Clarke & Eiser, 2004).

The most widely used questionnaire remains the **Scoliosis Research Society-22** (SRS-22), developed in its first version in 1999 (SRS-24) by the Scoliosis Research Society (Haheer et al.,

1999). At the moment, SRS-22 measures the HRQOL of patients with scoliosis, has 22 items and a structure of 5 factors: function/ activity (5 items), pain (5 items), self-image, appearance (5 items), mental health (5 items) and satisfaction with treatment (2 items). Each question has 5 possible answers, scored from 1 to 5. The higher the score is, the higher the quality of life of patients is. The results for the concurrent validity, using as criterion the SF-36 ( $r \geq 0.70$  for 17 comparisons), internal consistency (Cronbach's  $\alpha = 0.86$ ) and test-retest reliability ( $\rho = 0.90$ ) are significant (Asher et al., 2003). The questionnaire was constructed and evaluated using patients undergoing surgery as samples.

The original English version has been translated and adapted into many languages. It has been suggested that SRS-22 would not work well with younger patients or the ones with mild scoliosis because these patients scores present a higher ceiling effect (Feis et al., 2005).

Another questionnaire is the **Quality of Life Profile for Spinal Disorders (QLPSD)** (Climent et al., 1995), previously created and less widespread than SRS-22. This instrument has good reliability (test-retest:  $r = 0.91$ , internal consistency:  $\alpha = 0.88$ ) and construct validity. The questionnaire was specifically designed for adolescents only with IS, but then used for any kind of spinal deformities. Its final version consists of 21 items and 5 dimensions: function, sleep disturbances, pain, body image, trunk flexibility. There are currently three versions: Spanish, English and French.

Finally, there is the **Bad Sobernheim Stress Questionnaire (deformity)** (Weiss et al., 2006), a specific questionnaire that measures the stress particularly due to spinal deformity. The questionnaire consists of 8 items, evaluated from the highest stress (0) to no stress (3), so the final score indicates different stress levels: 0-8 for high stress, 9-16 for average stress, 17-24 for minimal stress. The questionnaire has good test-retest coefficient ( $r = 0.95$ ), a good criterion validity ( $r = 0.78$ ), while possibly due to the small number of items, Cronbach's  $\alpha$  is less than 0.7. Currently, there are the German original version and the Polish validated one (Misterska et al., 2009).

Another specific questionnaire is **Oswestry Low Back Pain Disability Questionnaire** (Fairbank et al., 1980), which is used in cases of low back pain. It consists of 10 items. A similar scale is the **Roland-Morris Disability Questionnaire** (Roland & Morris, 1983) which consists of 24 items describing situations of pain.

The **superspecific instruments** can belong to two types: the ones which study only one HRQOL dimension and the others that consider a very specific clinic situation in AIS (Climent et al., 2009). **Walter Reed Visual Assessment Scale (WRVAS)** and **Trunk Asymmetry Perception Scale (TAPS)** belong to the first type.

The WRVAS was created to deepen into the relationship between body image and spinal deformity (Sanders et al., 2003). It is a visual test, composed of 7 items related to: 1. spinal deformity, 2. rib prominence, 3. lumbar prominence, 4. thoracic deformity, 5. trunk imbalance, 6. shoulders asymmetry and 7. scapular asymmetry. Each aspect is shown with 5 progressive levels of severity from the least (1) to the maximum (5). The result is the sum of 7 items. The images show a person from behind and thus the scales measure the subjective perception from how the others see the patient's back. The instrument is able to discriminate between patients who notice the deformity and those who do not. In addition, there is a high correlation between parents and patients' scores ( $r=0.8$ ). The scale

has an excellent reliability (internal consistency: Cronbach's  $\alpha = 0.9$ ), a good discriminant validity (using Cobb angle,  $r = 0.69$ ) and a convergent one (using SRS-22,  $r = -0.5$ ). However, as the scale has some limitations (for example related to the lack of stratification of different curve patterns), another scale has been created: TAPS (Bago et al., 2010). The scale has a good reliability (Cronbach's  $\alpha = 0.89$ , test-retest = 0.92) and validity (convergent validity, using the SRS-22:  $r = 0.45-0.52$ , discriminant validity, using Cobb degrees,  $r = -0.55$ ).

#### 4.2 Tools for AIS conservative treatment

A super-specific questionnaire that measures HRQOL in brace-treated patients is the Greek questionnaire, **Brace Questionnaire (BRQ)** (Vasiliadis et al., 2006), which has the merit of measuring HRQOL in a very specific situation. This questionnaire consists of 34 Likert-scale items and can be used with people aged between 9 and 18. Minimum score is 20 and maximum is 100; higher scores indicate better HRQOL. The psychometric properties are good: high reliability ( $\alpha = 0.82$ ) and convergent validity ( $r \geq 0.40$ ). It measures 8 areas: general health perception, physical functioning, emotional functioning, self-esteem and aesthetics, vitality, school activity, bodily pain and social functioning. BrQ has been validated in Italian (Aulisa et al., 2010) and in Polish (Kinel, 2011).

Finally, a questionnaire derived from BSSQ (deformity) is the **BSSQ (mit Korsett)** which assesses the stress due to the brace impact (Weiss et al., 2006; Weiss et al., 2007). Like BSSQ (deformity), a maximum score of 24 indicates the lowest level of stress while 0 means the highest level of stress. The questionnaire has good psychometric properties: test-retest reliability is high ( $r = 0.88$ ) as its internal consistency ( $\alpha = 0.97$ ), although there is not any validity measurement. It was translated and validated into Polish (Misterska et al., 2009), Spanish (D'Agata et al., 2010) and into Italian (Aulisa et al., 2010).

In an Italian study (Aulisa et al., 2010), BrQ had the highest capacity among SRS-22 and BSSQ (mit Korsett) in detecting changes in HRQOL in relation to the sex of patients, brace type and severity of curve. This finding could be related to the higher BRQ items number, allowing to explore more areas than the other instruments.

Finally, it is worthy to mention an instrument which is a personality test. Although it does not belong to the HRQL ones, it can give an important contribution to the research. This test is called "Drawing a Person" (DAP) and it is a graphic and projective instrument. It has been studied by several authors (Goodenough, 1926; Machover, 1969; etc.). These authors have underlined that the non-conscious component is projected in the drawing: children project what they see and feel and what they can not verbalize (Hammer, 2005). According to Machover, the body with its visceral tensions and muscle tones is the battleground between needs and pressures. The drawing of a person refers to the body and this, in turn, represents his/her inner world. People with orthopedic problems have complex reactions to the images of their bodies, which are usually plastic and sensitive to diseases and cures (Machover, 1969).

#### 5. Our contributions

The authors of this work are willing to show two researches presented with Dr. Rigo; the former, communicated in SOSORT Congress (2010), was about the psychological impact of a

Rehabilitation treatment; the latter, referred to the Spanish validation study of the Bad Sobernheim Stress Questionnaire (brace), was published in *Scoliosis Journal* (D'Agata et al., 2010). They present a further contribution which is a reflection relating to the professional help.

## **5.1 Psychological changes during one-month course in Barcelona Scoliosis Rehabilitation School (BSRS)**

### **5.1.1 Background**

The studies about physiotherapy effects on AIS HRQOL opened to interesting questions. A research in Bad Sobernheim Clinic found an increase in self-esteem and social skills (Weiss & Cherdron, 1994) as a result of a Schroth rehabilitation group program. The authors explained that patients learn they can actively influence their symptoms; as a consequence, self-esteem improves with a more positive attitude toward deformity. It has also been observed that patients who attribute responsibility for their musculoskeletal disorders to themselves are more likely to report an improvement in the results of physiotherapy (Larsson et al., 2010). Fox (2000) studied a circular relationship between physical activity and self-esteem, showing that regular exercise may increase self-perceived competence and body image. By contrast, adolescents with scoliosis, who do not practice physical activity, have a poorer body image, especially among boys (Dekel et al., 1996).

The mentioned research aims at studying the personality aspects of adolescents treated with a rehabilitation program as there are no researches in this sense.

### **5.1.2 Methods**

The study was a pre-post, quasi-experimental design with the aim of assessing differences at an emotional level, before and after an intensive course of Rehabilitation.

The materials used were a Socio-demographic Questionnaire, created *ad hoc*; and the test of the **Drawing a Person**, according to which a person constantly expresses him/herself in drawing. There are examples of the use of this test in literature (Saccomani, et al., 1998).

Through this test, the authors assessed 5 emotional categories (aggressiveness, impulsiveness, insecurity, shyness and anxiety), sexual identity and defence mechanisms.

The sample was composed of 35 young people, 33 girls and 2 boys, aged 11 - 26 ( $M= 16$ ,  $SD=4.2$ ). Twenty-two of them were treated by bracing (11 part-time, 11 full time).

There was no control group.

The treatment consisted of one-month Rehabilitation, according to the protocol of Barcelona Scoliosis Rehabilitations School (BSRS), with a frequency of 5 days per week, 4 hours per day.

The setting had a group modality and was located in a private centre, E. Salvá Institute (Barcelona, Spain).

To analyze the nominal data, a non-parametric test (McNemar's test) was used.

### 5.1.3 Results

In pre-test and post-test, the sample showed a low level of aggressiveness (pre-test: 11%; post-test: 26%), of impulsiveness (pre-test:34%; post-test: 31%) and of insecurity (pre-test and post-test 43%). On the contrary, a high percentage of shyness (77%) and anxiety (83%) was assessed in the pre-test while in the post-test shyness decreased in a significant way (51%,  $p=0.035$ ); anxiety maintained the same value.

About the sexual identity, before the treatment, the 66% of the sample drew a person of the same sex; in the post-test, the percentage of the sample who represented the same sex increased (86%) although not in a significant way ( $p=0.06$ ).

Finally, at the beginning the 51% of the sample represented a blank outline without any treats (Figure 1) while in the post-test the percentage decreased (29%) in a significant manner ( $p=0.008$ ) (Figure 2).

### 5.1.4 Discussion

From the results it is possible to observe that the rehabilitation program had an impact on the reduction of shyness, but not in anxiety. These data could be explicated, considering that the setting had a group modality. After one month this method activated a process of socialization, reducing the initial shyness, due to the first-day session. With regard to anxiety, it seemed that the treatment had no effect in reducing it.

An interesting datum was about the massive use of **evasion and withdrawal** mechanisms that had these *ghost* drawings as consequence. The extremely poor body representation is possibly related to the use of this mechanism, as the person is escaping from his/her own reality.

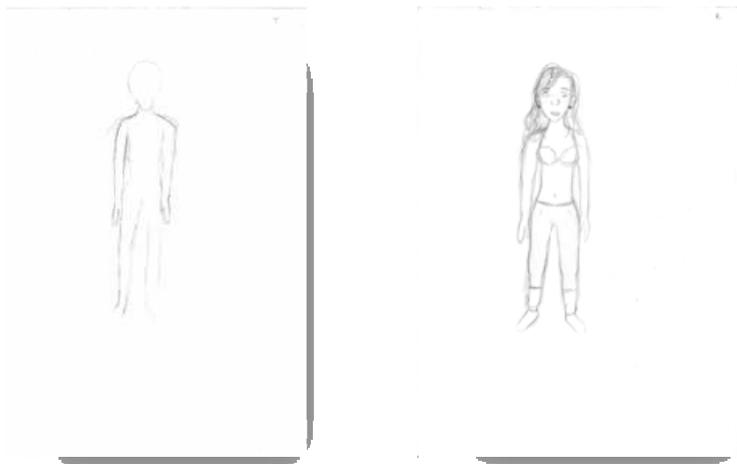


Fig. 1. 12-year-old girl's pre-test and post-test.

### 5.1.5 Conclusion

Further researches will aim at increasing the sample size to confirm these results. Besides, it would be interesting comparing different kinds of physiotherapy methods and different modalities (group/individual) to detect other impacts on a psychological level. Finally, to the rehabilitation treatment the authors would like to associate a specific psychological one, aiming at reducing anxiety.

## 5.2 Spanish validation of Bad Sobernheim Stress Questionnaire (BSSQ (brace).es)

The authors reported a synthesis of the research published in *Scoliosis Journal* (D'Agata, Pérez-Testor & Rigo, 2010).

### 5.2.1 Background

Owing to the recent attention among the clinicians towards the impact of brace on adolescent life, the aim of the present research was to validate into Spanish the German questionnaire Bad Sobernheim Stress Questionnaire (mit Korsett), applied to an adolescent population undergoing bracing treatment.

### 5.2.2 Methods

It has been followed the methodology used in trans-cultural adaptation (translations and back translation).

The sample consisted of 35 adolescents, in the 10-16 age range, with AIS, wearing Rigo System Chêneau Brace. Mean Cobb angle of the major curve was 35.42° (SD= 11.28°; Range: 20°-68°). Patients had been wearing the brace for 14 months (SD= 21) on average.

The setting was the private centre, E. Salvá Institute(Barcelona).

The materials used were a socio-demographic-data questionnaire, the SRS-22 and the Spanish version of BSSQ(brace).es.

The statistical analysis calculated the reliability (test-retest reliability and internal consistency) and its validity (convergent and construct validity).

### 5.2.3 Results

Average value was 11.7 (SD=4.8) in a score between 0 (maximum stress) and 24 (minimum stress); there were neither floor nor ceiling effect.

Test-retest reliability was satisfactory ( $r=0.9$ ,  $p<0.01$ ) as well as its internal consistency ( $\alpha=0.8$ ,  $p < 0.001$ ).

The questionnaire demonstrated convergent validity with SRS-22 since the Pearson correlation coefficient was 0.7 ( $p < 0.01$ ). Pearson correlation coefficient between BSSQ (brace).es and SRS-22 scales were the following: function 0.4 ( $p = 0.05$ ), pain 0.4 ( $p = 0.05$ ), Self Image 0.6 ( $p = 0.01$ ), health mental 0.6 ( $p = 0.01$ ) and satisfaction 0.5 ( $p = 0.05$ ).

By undertaking an Exploratory Principal Components Analysis, they found out a latent structure based on two Components which explicate the variance at 60.8%.

### 5.2.4 Discussion

The statistic properties assessed were satisfactory. However, the structure of the concept below does not appear really clear, possibly due to the small number of patients. Nevertheless, it could be explicated considering Factor 1 as Presence of stress and Factor 2 as lack of stress.

Besides, the sample presented a medium level of stress produced by the brace. The authors chose SRS-22 for the negative correlation between stress and HRQOL. In addition, it was interesting to observe its correlation with BSSQ(brace).es, specifically those referred to SRS-22 subscales. The highest correlations were found with self- image and mental health. These statistical correlations indicated that the stress roused by brace is connected to the patient's body image and to suffering.

### 5.2.5 Conclusion

BSSQ (brace).es is a reliable and valid test that can be used in clinic as it is easy to employ.

### 5.3 Help relationship in AIS: a reflection

In literature some psychological interventions aimed at patients with scoliosis have been described (Reichel & Schanz, 2003; Walker, 2003; Weiss, 2003), as well as self-help groups among parents and adolescents (Hinrichsen et al., 1985). However, the authors consider that the psychologist's attention is not greatly addressed yet to this direction and they desire to promote their participation both in the research and in the clinic field.

In this paragraph they intend to point out the relevance of the help relationship by professionals in the area of scoliosis and the potentiality of a psychological work next to the essential work of the doctors and physical therapists.

#### 5.3.1 The reasons for the help relationship

When a person gets sick, the problem is not limited only to one part of the body but the whole organism is weakened. It is not possible to consider the dimension of the *disease*, which means the physiological malfunction, without considering the *illness* that expresses the subjective dimension, the patient's inner experience (Kleinman, 1980). Considering the human being as a a psychological, social and spiritual structure, sickness is a fact that demolishes this "construction" and breaks the balance of life on all the levels (Cánovas, 2008).

In this sense, to highlight the dimension of the illness, it seems appropriate the message left at a forum on scoliosis (ISICO, 2010) by a teenager who writes: "Please help! I am a girl of 14 years old. I have scoliosis. Who can I contact? I think my life is useless. Sometimes I wish to kill me: but I think I will. Sorry "

The sick person claims care since suffering a process of global disintegration (Torralba, 1998). Understanding this destructuring process, it is important to help the patients re-build their world, using personal resources; so the task of caring has a relationship with the ones of *edifying* and re-building (Torralba,1998). It is impossible to cure the physical body, without considering all the other dimensions: it would be an incomplete work. The healing

process involves a rethinking of values, behaviours, relationships with others and a style of living (Chadifour, 1994).

### 5.3.2 Characteristics of the helping relationship

The teenager with IS should be accompanied by an empathic attitude, which means "going down into the well of the other" and getting wet, getting involved. The only way to find the patient is sailing in the same boat, embarked on the same project, beside and not above (Planella, 2006). But for this, it is important to recognize the patient, calling him/her by his/her own name and giving voice, allowing its expression through words authentically.

The relationship with the physicians or physical therapists may be helpful, though the difference is that professionals such as psychologists and psychotherapists have a deeper understanding of the person and are equipped with a proper set of skills acquired through training and experiences.

### 5.3.3 Helping relationship phases

The helping relationship supports the patients in finding solutions to the problem that affects them. Difficulties may be of different natures and it is always important to take the family into account as the patient's system (Bronfenbrenner, 1976).

According to the phase in which the patient is, the issues presented will be different: in diagnosis, the difficulty may occur in accepting scoliosis; in the conservative treatment, in accepting the brace. Transversally to the two phases, a common task may help the patient and family to express their emotions (fear, aggression, guilt, rejection, etc.); to make him/her aware of his/her active role as *agent* and not patient, encouraging the progression of autonomy; to help accept a difficult situation, promoting self-care.

In the diagnostic phase, the psychologist makes an assessment of patients and their families, integrating his work with the physician's and physical therapist's. According to the specific needs of the patient and his family, a planning intervention can follow. The setting can be individual or familiar, according to each case. Professionals (doctor, physiotherapist and psychologist) work together to integrate their vision in a complex way.

Finally, answering to the question that an intervention like this could mean a psychopathologization of the stress, Buendía, Ruiz and Riquelme (1999) argued that intervention should be preventive. If stress is considered not as a disorder, but as a challenge which, if poorly resolved, can lead to disorders, a brief but in time intervention can help the "stressed person" to develop appropriate coping strategies to face with the situation.

## 6. Conclusions

### 6.1 General conclusions

With the present work the authors have tried to outline a theoretical framework on the issue of AIS HRQOL. Referring to scientific literature and from a psychological perspective they can conclude that:

- HRQOL is a multidimensional concept including the physical, psychological and social life of a human being (bio-psycho-social model). Teenage HRQL is different from the corresponding one for adults (Frisen, 2007).
- Body image is a multidimensional construct comprising the perceptual, cognitive-affective and behavioural dimensions (Raich, 2004). In AIS, the most universal evidence is the poverty of body image (Payne et al., 1997).
- With reference to conservative treatment, among the possible reactions described in the first months caused by brace, there are fear, anger, shame, and a high use of denial and isolation (Sapountzi-Krepia et al., 2006). *Compliance* is a dynamic behaviour (Takemisu et al., 2004).

Finally, the authors' contributions refer to different areas: the rehabilitation effects on HRQOL; the Spanish validation of the BSSQ(brace).es; a reflection on a system of professional help relationship in AIS.

## 6.2 Limitations of the study

The authors are aware that their reflections are limited and that the present study does not cover all the researches on HRQOL in AIS. The work they present is meant to be an attempt to detect coherent lines in the researches. Besides, they do not mention HRQOL in case of surgery, because it would take up much space for its importance. So they have decided to focus their attention completely on the experience of scoliosis and the conservative treatment.

## 6.3 Future researches

As psychology is new in AIS, there are several areas that should be explored. At this stage the authors select only four points:

1. Paying attention to HRQOL impacts of those rehabilitation treatments which exalt respiration and movement. Theory as mindfulness in psychology and the use of respiration have been studied for the preventive effect of depression, the increasing of awareness and of wellbeing (Brown & Ryan, 2003).
2. Studying the AIS family, its structure to find any common patterns.
3. Questioning about the effectiveness of the questionnaires used so far. The great challenge in AIS HRQOL measurements is to create a complex instrument specifically addressed to the essential aspects of adolescents' lives, to their conscious aspects of the body and to those who fail to reach consciousness.
4. Deepening the relational aspects of adolescence: peer relationship and intimacy.

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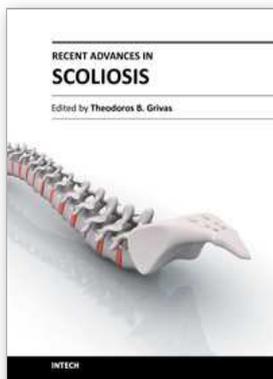
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## **Recent Advances in Scoliosis**

Edited by Dr Theodoros Grivas

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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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