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IDIOPATHIC ADOLESCENT SCOLIOSIS: LIVING WITH A PHYSICAL DEFORMITY

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ABSTRACT: A qualitative, phenomenological, hermeneutical study with the aim of explaining the experience of having a body deformity diagnosed as idiopathic adolescent scoliosis. A semistructured interview conducted with scoliosis patients admitted to the unit of spinal cord at the Vall d'Hebron Hospital was used. The youth defined their scoliosis based on how they perceived their deformity. They spoke of pain and deformity as characteristic symptoms of suffering, and explained how this symptom affected their social relationships. Their deformity was associated with words such as "horrible", "shame", "complex" and "problem." It is concluded that the symptom most referred is pain and the biggest concern of the youth was their body aesthetic and feelings associated with it. They attempt to solve this problem by adapting the way they dress and through surgery. Surgery can resolve the body deformity but not self-perception of their body image.

DESCRIPTORS: Scoliosis. Adolescent. Body image. Self-perception. Emotions.

ESCOLIOSIS IDIOPÁTICA ADOLESCENTE: LA EXPERIENCIA DE PADECER UNA DEFORMIDAD FÍSICA

RESUMEN Estudio cualitativo, fenomenológico desde la perspectiva hermenéutica, cuyo objetivo es conocer la experiencia de padecer una deformidad corporal en jóvenes diagnosticadas de escoliosis idiopática. Se utiliza una entrevista semiestructurada y dirigida a pacientes con escoliosis, ingresadas en la unidad de raquis del Hospital Vall d'Hebron. Las jóvenes definen su escoliosis según perciben su deformidad. Hablan del dolor como síntoma característico de la deformidad que padecen, y explican cómo este síntoma influye en sus relaciones sociales. Asocian a su deformidad palabras como "horrible", "vergüenza", "complejo" y "problema". Se concluye que el síntoma por excelencia referido es el dolor y que la mayor preocupación de las jóvenes es la estética corporal y los sentimientos asociados a ella. Intentan solucionar este problema adaptando su forma de vestir y mediante cirugía. La cirugía puede solucionar la deformidad pero no la autosatisfacción corporal.

DESCRIPTORES: Escoliosis. Adolescente. Imagen corporal. Auto percepción. Emociones.

ESCOLIOSE IDIOPÁTICA DO ADOLESCENTE: A EXPERIÊNCIA DE TER UMA DEFORMIDADE FÍSICA

RESUMO: Estudo qualitativo, fenomenológico, localizado na hermenêutica, cujo objetivo é explicar a experiência de ter uma deformidade corporal diagnosticada em jovens com escoliose idiopática. Foi conduzida uma entrevista semiestruturada com pacientes portadores de escoliose, internadas na unidade de coluna vertebral do Hospital Vall d'Hebron. Os jovens definiram sua escoliose conforme percebem sua deformidade. Eles falam de dor e deformidade, como sintoma característico do sofrimento, e explicam como este sintoma afeta suas relações sociais. A deformidade é associada a palavras como "horrível", "vergonha", "complexo" e "problema". Conclui-se que o sintoma dor é o mais referido e a maior preocupação dos jovens é a estética corporal e os sentimentos associados. Tentam resolver este problema por adaptação das vestimentas e pela cirurgia. Esta pode corrigir a deformidade, mas não a auto percepção de sua imagem corporal.

DESCRIPTORES: Escoliose. Imagem corporal. Adolescente. Auto-percepção. Emoções.

INTRODUCTION

Scoliosis is a deformity of the spine in three dimensions, where the coronal plane exceeds ten degrees, and the lateral displacement of the vertebral body crosses the midline and is regularly accompanied by some degree of rotation.¹⁻² Thus, it should be noted that scoliosis itself is not a disease but a structural alteration that can be taken as a sign, that is, an objective manifestation which can be measured clinically and radiologically in the patient.¹ The natural history of scoliosis is variable and depends on the etiopathology and the type of curve. Idiopathic scoliosis may progress to be painful, limiting physical function and mobility, and negatively affecting mental self-image or psychological function and health, thus causing problems for the development of friendships and the ability to socially adapt, for the individuals who have it.³⁻⁵

Studies mainly used for assessment of the different dimensions that comprise scoliosis are quantitative; several methods to measure the magnitude of the deformity have been used for these studies. One approach is to request the personal impression of the patient regarding his or her deformity through questionnaires.⁶ Patients are told that the questionnaires are designed to tell physicians how they see their bodies in relation to the curvature of their spines.⁷ The most important dimensions used in these questionnaires are pain, body image, mobility, sleep disorders, and a combination of factors that relate to overall functionality,^{2,8} highlighting the reduced quality of life in patients suffering from scoliosis and relating specifically to depression, back pain, limited physical ability, and a negative body self-perception from the deformity.⁹ The purpose of the questionnaires is to try to measure and quantify the perception of body deformity of those women affected with idiopathic scoliosis, but no studies with qualitative methodology have been found that show how these young women see themselves, or how the pain and image are, or the mobility they feel or have with their deformity prior to definitive treatment.

The questionnaires have some limitations; first, it is important to consider that body image dissatisfaction is common in all adolescents, even those without scoliosis, and self-image depends partly on the perception of facial features and body mass. Secondly, self-image scales show a significant but moderate correlation with radiological magnitude of the curve. This may indicate that there are other factors that influence the way patients with spinal

deformity perceive of their body image. Therefore, the perception of body image and deformity of the torso would be complementary but not equivalent dimensions. Studies show that scoliosis decreases psychosocial function, diminishes self-esteem and life energy, and produces difficulties in the perception of the physical health of patients with an idiopathic adolescent scoliosis (IAS) diagnosis. Probably the most definite effect of scoliosis on quality of life is increased back pain compared to the general population.^{8,10-11}

The sight of imperfection in the human body produces ambivalence in the viewer, including rejection of the sufferer and compassion towards their deformity.¹² When it comes to body image in relation to the stage of adolescence in humans, what characterizes puberty and adolescence is a spectacle of body changes. This outer body evidence is always accompanied by an intrapsychic component. The discovery of the body is embodied in teenagers with unforgettable experiences that will mark the rest of their lives.¹³ Clearly, the emergence of a physical deformity during this period of growth and identity construction will involve the living of experiences that will influence self-esteem and mental health.

To date, the main outcomes of treatment effects on aesthetics are associated with significant changes and/or improvement of vertebral rotation after brace treatment, and reduction of the Cobb angle after surgery, or the improvement in the perception of the deformity evaluated by questionnaire.¹⁴

The aim of this study is to know how to explain the experience of having a structural alteration young people diagnosed with idiopathic adolescent scoliosis.

METHOD

A study of qualitative, phenomenological, hermeneutical orientation was completed, with the aim of deepening an understanding of the human experience¹⁵ of young people affected by IAS.

The target population was composed of young women between 15 and 22 years of age, diagnosed with idiopathic scoliosis, who entered the spinal surgery care unit of the Vall d'Hebron Trauma and Rehabilitation Hospital, to undergo surgical treatment for their deformity.

The sample selection criterion is not intended to represent a population from which results can be generalized. The sample is always intentional, and its selection was determined by the extent,

variety and integration of the various realities that converged in the object being studied.¹⁶ It is an opinion sampling method, where personal strategic criteria have been followed in the selection of participants, such as being hospitalized at the time of the interview.

Inclusion criteria: all of the young women diagnosed with IAS, aged between 15 and 24 years old, admitted to the specialized in spinal cord unit in the Vall d'Hebron Trauma and Rehabilitation Hospital for surgical treatment of their deformity.

Exclusion criteria: patients diagnosed with IAS younger than 15 years or those who exceeded the age of 24 years, also those patients whose scoliosis is associated to another pathology, for example, cerebral palsy or psychological deficiency. Patients with interventions for recurrent infections or rupture of osteosynthesis material were also excluded.

The study was completed during the period of June of 2012 to September of 2013. The sample size was 12 young women who met the inclusion criteria. The sample was determined by the criterion of saturation from the data obtained, after previous analysis.¹⁷ According to this theoretical saturation criterion, the sample size was increased until it attained the saturation level.¹⁸ A total of two nurses connected to the specialized in spinal cord unit who were provided with the characteristics of the subjects to study, and inclusion and exclusion criteria, were used for data collection.

Once the cases were identified, interviews were conducted, explaining the objective of the study and requesting voluntarily participation. Confidentiality of the information collected was ensured, in accordance with the recommendations of the research center ethics committee where the study was conducted, by providing the patient and her guardian a model of the free and informed consent, and a fact sheet on studies without invasive procedures, both recommended by the committee. Information on the treatment of the information collected and on the destruction of audio recordings made during interviews was also provided.

Data collection was performed using recorded, semi-structured interviews. The purpose of phenomenology is to describe the essence of the lived human experience;¹⁵ in this manner, the researcher believed the collection of data through taped interviews would be an accurate way to collect that experience from the mouths of participants, and transcribe them in full. A semi-structured interview method was used, with the aim of trying to focus

the subject under study with very specific questions to facilitate the expression and explanation of the answers. The questions were prepared in advance, and were raised with the participants without any predetermined sequence; they were open-ended questions, for which the respondent had to construct the answers.¹⁹ The previous development of the script for the interview was done, taking into account the objectives of the study; questions about the experience of the scoliotic deformity were raised. During the interview, communication tools such as active listening or therapeutic silence were used; the goal was for participants to freely express their feelings and perceptions about their experiences with scoliosis.

The recorded interviews were transcribed verbatim for analysis. For data analysis, the computer program, Atlas Ti® 6.2, was used. For data analysis, categories were established, taking into account the objectives of the initial study.

This study was part of a larger study on body perceptions and emotional aspects of affected patients with idiopathic adolescent scoliosis. This study was part of a doctoral dissertation at the *Universidad de Alicante*, which is pending presentation to the defense committee.

RESULTS AND DISCUSSION

In an attempt to define scoliosis or explain what it is, these young women had a unique concept of the deformation of the torso, because it is something that can be seen and which draws others' attention; none of the patients spoke exclusively of characteristic symptoms or future complications, they simply referred to their current physical deformation as a defining aspect of their scoliosis.

A crooked spine, not having it straight or like ... having a deformation, is what I understand ... (P 6).

The.... the curve is...one... half my body is different from the other... if you have a body... and you cut it in half, you have a part that is different from the other... because you're curved...more (P 7).

[...] ugh a problem... but one that can be solved... (P 10).

Scoliosis definitions that have been collected indicate a structural alteration and deformation as a hallmark of this pathology; it is this aspect that was pointed out first by the young women when they tried to explain what scoliosis meant for them. They described their scoliosis as a problem and lived with a clear degree of body dissatisfaction

due to the observed deformation; deformity that has repercussions in the social sphere and that requires a "solution".

Definitions of scoliosis indicated exclusively those aspects of body deformity in scoliosis and did not mention the influence this deformity brought to aspects of quality of life and social interactions.¹⁻²

When the young people were asked how they discovered their scoliosis, all of them associated scoliosis with a body deformity that arose with the observation of their back by an unaffected person, usually a family member; or after self-examination, when they observed body areas that were not where they should be or did not look the way they should. In this sense, patients saw every millimeter of their body, hips and breasts were observed, they controlled or attempted to control the view outside those areas, with and without clothes. They examined how the body looked with clothes, how clothes disguised these areas, hiding the deformity.

[...] that you have a breast larger than the other, the hips, and it depends on which dresses I couldn't wear because the back was too open or... this little bone here...is more sunk than the other one [...] I had a shoulder blade larger than the other one and when I sat down...in class... when... depending on how I was sitting, if you sit with your back straight there's a lump popping out... (P 7).

In some cases, the lack of self-perception of the deformity or the fact that other people may notice it upon observation of their back seemed to favor a better adjustment to the situation, because the deformity was outside their visual field; the deformity was located on the back and its discovery seemed to be a unintentional one which did not affect quality of life and did not influence the everyday life of the patient.

Well I don't know, I don't know when it happened because I... well no... I didn't know I had it... it didn't hurt and I couldn't see it... I found out last August. [...] My mother saw it... she was behind me and my hair was pulled back... and she saw that... I wasn't completely straight... and she told me to stand straight and when she saw I couldn't, she took me to the doctor and they told me (P 6).

When perception comes from self-discovery, there is a constant visible memory from a mirror that causes a negative self-concept. Body image represents an important part of self-esteem for a lot of people, especially during the adolescent years.²⁰⁻²² The biggest concern for the young women was the physical aesthetics and the feelings of "embarrassment" and "inferiority" caused by their deformity. This translated into absolute control over every inch

of the body, observing an asymmetry in constant and growing evolution which resulted in a deterioration of social relationships. Patients reduced the amount of time they go out, so they can hide what they do not want to display before other people's eyes. Adolescents are in a critical time period regarding the development of self-concept, having their scoliosis as a frequent reminder of their body's imperfection, and they realize that their body is not as perfect as their friends'. These patients tended to have a negative concept of themselves, they experienced anxiety because they felt different and they had feelings of guilt and embarrassment due to their condition.²³

[...] but I was ashamed or if I noticed it or if someone said anything... people who would see it... but no... luckily it wasn't that evident... (P 6).

My whole problem was aesthetic [...] I had a really bad time ... (P 9).

It very evident, because I'm very skinny so it showed a lot... so one of my bones was higher than the other and I couldn't wear some dresses (P 7).

Some studies show that scoliosis patients perceive themselves as less healthy and have a social restriction that also includes a lower physical activity. Untreated patients are unhappy with their body image and appearance in clothes or swimsuits. About a third of patients believe their curvature has limited their life in some way, such as having difficulty in buying clothes, lower physical capacity, and lower self-awareness.^{11,24}

One way to solve an aesthetic problem is to hide that which is not liked; it is about covering it, attempting to hide that body part which is disliked. Adolescent girls try to hide and conceal their deformed body, changing their dressing habits and trying postural rectifications to conceal their deformities. Fashionable, socially accepted clothing in this age group, such as light or tight clothes, is replaced with wide, loose t-shirts that hide that which is not accepted. It is mostly limited to tight clothing. Patient attempted to walk straight and avoided lazing on beaches or pools, because the defect is evident in the eyes of others and they "had a hard time".

I would wear loose t-shirts... but those that are one-sided you could see one shoulder blade but not the other... I was covered and... it's one-sided... so it covered me up... [...] the holidays in the last year of high school... where we had to go to the pool I would wear a t-shirt... but many other girls would do it too... but I did it mostly because of the scoliosis (P 7).

I don't know... it wasn't that evident only if you really looked... but... I would wear loose shirts so it didn't really show [...] I also tried to walk a bit more straight up... and like that... (P 6).

Body image and health-related quality of life are important issues for patients with scoliosis, due to cosmetic deformity, physical and psychological symptoms, and treatment factors.²⁵ The experience of having a deformity has social repercussions. When the person is aware of her physical deformity, some social and cultural restrictions are obliged, except in the case of patients who do not report pain associated with their deformities; in these cases, the activities are not restricted except those involving exposure of the deformity to others or to people outside the family. Classically, the aesthetic commitment has been considered a critical factor for patients with idiopathic scoliosis. Psychological distress experienced by these patients is often attributed to the appearance of the deformity of the torso. The questions evidence the idea that these patients regularly suffered psychological conflicts, and when conflicts manifest a cause, it usually is the cosmetic effect.^{6,9,26} In the studies consulted, psychological distress was observed, caused by body deformity, but none of them gave importance to social pressure at a corporal aesthetic level, or referred to in some way to the preset aesthetic standards culturally imposed on these young women.

Oh... I had a hard time because I had to wear a swimsuit and it showed everything... I was always lying down... I... when I stood up or when I laid on a side, you could see my hump. [...] wider because you could see my hump here on my side and even if you don't want to, you can't help lying on your side because it shows... it's a hard time... a really hard time (P10).

In general, all the studies reviewed used simple questionnaires, such as the type SRS-22, CAVI-DRA, PHCSS, to expand the knowledge of some factors that highlighted the reduced quality of life of patients suffering from idiopathic scoliosis, and that are specifically related with depression, back pain, limited physical ability, and a negative body perception. Following this study, it is understood that body perception is the most subjective aspect that patients share, feelings and verbal expression of how they viewed themselves indicated, in some cases, a psychological deficit that should have professional support.

The deformity was understood as something wrong, something not accepted that produces a vision and rare body sensations, patients are described as horrible in appearance, expressing

shame and inferiority, they need to correct that aspect to feel better.

I looked horrible... I had a hard time (P 10).

An inferiority complex [...] (P 7).

Yes... I felt deformed... broken... how not to? (P 9).

Thus, in the line of body image, coinciding with some studies,^{23,27-28} it can be said that patients with IAS had a greater propensity for developing feelings of dissatisfaction with their body appearance, therefore, they tended to lack self-confidence, to have a sense of inferiority and even shame. This is a disturbing experience that forced patients to cope with stress, denial, fear, anger and shame. This lack of confidence could lead to pessimism and growing anxiety, and the result was a deterioration of social functioning and overall psychological isolation, therefore physical and social rehabilitation may be necessary.^{23,27-28} This containment of feelings and sensations would condition and at the same time facilitate the surgical decision, where there would be a prior and thorough assessment of the risks of surgery. Young women have the unique purpose of being like others, to be accepted by the group, to succeed in their social relationships, and that success is provided by an attractive view of the body; a vision that they did not have in their current condition. They described their situation as "horrible" and they understood it among the many perceived in their pubertal or maturational age, thus the difficulties of this age are added together to express and / or show their feelings and emotions.

I'm a girl who keeps to herself and swallows problems... and well... on Thursday at Uni I felt a bit down... and I exploded and such but oh well... [...] I have always been like this... I have never expressed my feelings... (P 7).

And I was worried and I would stop and think (P 6).

Well... scoliosis in my life has been nothing but more problems... more inferiority complex, and that's it (P 7).

Scoliosis has given me many problems... I have fallen and it's been a deadly fall and... if I could push away the word scoliosis it would be better... but I have to live with it all my life (P 10).

As some authors point out, adolescence is accompanied by physical and psychological perception of bodily changes that are perceived as problems for an individual in constant change, and this new problem, scoliosis, adds to all the existing ones. Body image represents an important part of self-esteem for a lot of people, especially during the adolescent years.²⁰⁻²²

The symptom reported by the young women, when asked about their physical state other than the deformity, was par excellence the presence and absence of pain. There were adolescents who experienced not having pain; they spoke of a complete absence of pain where detection of scoliosis was caused by physical deformity and what it meant for their body aesthetics. When there was no reference of pain, it was when the young people discovered their scoliosis through their parents' observations of their backs, and not by self-observation from the patients themselves.¹

I got worried... and I thought that [...] being so young and having this which would bring me problems but no... it didn't hurt at all [...] yes... I used to do everything I wanted because it didn't hurt... I would go out... and they told me that... if it was ok, if it didn't hurt I should do what I wanted (P 6).

The most important dimensions found in the area of scoliosis are pain, body image, mobility, sleep disorders, and a combination of factors that relate to overall functionality.^{2,8}

Pain is a subjective personal experience, and it is strongly mediated by external factors in the individual's life. It is a variable symptom, according to the demographic characteristics of the person, and it is difficult to evaluate. Interviewed patients who report pain note that this is, in some cases, disabling. Pain makes them unable to consider a normal life for an adolescent, according to them, it does not let them "even leave their house", the talk about their pain as "exaggerated" and hard to control, even when taking medication. A pain that precludes them from their social relationships because it does not enable them to participate in activities characteristic of this age, since pain is limiting.

I... [...] have had a hard time because of the pain [...] and the pain during the previous year... it was too much... no matter how much medicine I took (P 9).

I had a hard time, I would walk home for an hour and my ribs would hurt so much and sometimes I couldn't leave my house (P 10).

The presence of pain was described as pain associated with adult scoliosis, due to a combination of muscle fatigue, torso imbalance, joint disease or osteoarthritis, and in most cases due to a degenerative disc process.¹ There is no mention at any time of the existence of pain in young people with scoliosis, or the influence such pain can have on their quality of life.

In cases of patients who reported pain, manifested limitation was precisely the inability that causes pain itself.

[...] I have been able to do everything thank God and then I've had a whole day in bed with pain [...] because it was too painful... I haven't gone out as much as I would like to... (P 10).

When the person is not aware of their physical deformity because there is no pain or because it is not visible from the front or back side, no social restriction occurs; this may be because the deformity is not consciously present because it has not been seen on a frontal plane.

I used to do everything I wanted before because it didn't hurt... I would go out... and they told me that... if it was ok, if it didn't hurt I should do what I wanted (P 6).

Overall, the analyzed quantitative studies note that correction of the deformity is observed by patients with an improvement in pain scores and self-image. Self-image is the hardest domain of spinal deformity to measure, especially because the prospects of a person can change in different decades of their life. This makes it a difficult parameter to assess, although self-image is one of the most important characteristics related to the spinal deformity.^{10,29-31}

The solution given by these young women to the symptoms expressed was the adaptation of clothing in order to hide the deformity, or correction of said deformity using a corset or brace which was supposed to increase the problem of body image, as wearing a brace would show there was a problem. Another option was to undergo surgery. In the case of surgery, the young women do not explain it to be a prevention for future health, but an improvement of the current deformity; patients expressed the feeling of "relief" when surgery was scheduled and it was time to have the procedure. They did not express a fear of said surgery because they were "young and it's fine", an assessment of the risks that accompany such surgery seemed to be superfluous, it seems that these risks may not affect the young women, as it is a release from hidden feelings and sensations, mostly negative, affecting mental health and that implied a special outfit, a garment that excluded them from a social group and reminded them that their appearance involved not succeeding. The surgery will relieve the heavy burden of deformity.

Well because... because they told me that the older I get the worst it gets... my scoliosis was already progressed... I was told that if I wore a corset... it wasn't gonna get better, it was only gonna stop it because it was too advanced and they told me that as I got older it would get worse, and of course... when you're older you have a lot of back problems... and even more so if

you have scoliosis and then if you get pregnant and all... more back problems, they told me that so I said I rather do it now when I'm young and it was all right and not in a few years and I have things to do... and when I don't have the time. So I said the sooner the better, and I had to wait for a year... and so when they called me it was truly a relief because it's big news but... when you know it's gonna happen... it's a relief (P 7).

When the patient made the decision about the surgery, she did so weighing the risks of surgery in relation to the perception that her family had about the current deformity and the possibility of such deformity progressing in the future.³² To evaluate the outcome of any therapeutic intervention, either conservative or surgical, it seems essential to measure the perception the patients have of their deformity of the torso, in addition to their self-image, since the cosmetic disfigurement is a major concern and a primary objective in treatment.³³ Surgical correction in the adolescent population may have a limited impact on their self-image, mental health and satisfaction due to the role of physiological, sociocultural and biopsychosocial factors.³⁴

CONCLUSION

Young women with scoliosis deformity try to provide an explanation for their scoliosis, referring to their physical deformity and the presence and absence of pain simultaneously. There were adolescents who had no experience of pain, it was an absence of pain where detection of scoliosis was caused by physical deformity in the first instance, and what that meant for their body aesthetics. At the same time, there were teens who talked about an "exaggerated" pain that was difficult to control, despite taking medication, pain that affected social relationships because it precluded any normal social relationship in adolescence.

The biggest concern for these young women was physical aesthetics and the feeling of "embarrassment" and "inferiority" caused by the deformity. These young women attempted to solve this physical problem by hiding that part of the body which was not liked, they attempted to hide and conceal their deformed body, changing their dressing habits and trying to conceal the curvature with postural rectifications. Another option was to try to solve their problem through surgery, which can partly solve the deformity but not satisfaction with self-perceived body image with the results obtained, because the body is marked by unaesthetic scars

and society continues to demand what the aesthetic canons have established. Surgery, for them, means disappearance and relief from the heavy burden of physical deformity.

The negative experience of the deformity has social repercussions that result in a decrease in social relationships. Society influences the adaptation to and perception of the deformity; it prioritizes an aesthetic canon imposed on all young people.

Beginning within society, we must be aware of the values instilled in young people, given that in present times, they prioritize body image over the risk of a loss of health due to surgery.

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