Psychological Implications of Scoliosis: Perspectives from Adolescence to Adulthood

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Abstract

Adolescent Idiopathic Scoliosis (AIS) is a spinal condition diagnosed in early adolescence which can have significant psychological ramifications throughout the lifespan of a sufferer. This paper provides an overview of the issues AIS sufferers face and psychological implications across the lifespan for those sufferers with progressive cases or where there are multiple corrective surgeries involved. This article offers a refined understanding of AIS from adolescence to adulthood by encompassing the author’s experience of this condition. Psychological and emotional support is centred on positive psychology principles: the promotion of acceptance; hope; courage and determination to face adversity. Adaptation will inevitably be impacted by patient variables such as: personality style; coping skills and resilience. Identification with peers undergoing the same experience and normalisation of feelings should be emphasised as these are major protective factors which buffer from mental health problems especially, at the vulnerable stage of adolescence. Over time, most sufferers can make necessary adjustments and live full creative lives.

I was diagnosed with AIS in 1973, at the age of 13 years and at the time of the initial diagnosis, neither my parents nor I had any understanding of AIS or its eventual implications on our lives. Treatment for Scoliosis in the 70’s was extensive and required convalescence in various body casts for periods of up to one year. AIS is first evident in early adolescence therefore, when a “till then normal” child is diagnosed with AIS with no apparent curve deformities, parents can experience a response similar to a grief response. My parents suppressed their grief from the time of the initial diagnosis to the extensive treatment in 1974. Treatment involved undergoing corrective surgery involving spinal fusion and Harrington rod implants (a stainless steel surgical device to treat curvature and instability of the spine). Later in life, I underwent multiple surgeries (2006, 2008 & 2010) for curve progression of the scoliosis and further corrective surgery.

For the initial surgery, I travelled as an unaccompanied minor to Australia. Post-surgical convalescence was as an inpatient in a rehabilitation hospital with ten other adolescent females who had also undergone surgical treatment for AIS. Typical convalescence started with a “bed plaster cast,” requiring confinement in bed with the full body cast for three months, followed by a second cast, “the walking plaster cast” for three further months, whereby walking and lying down was permitted with only limited periods of sitting. The third stage, involved wearing a polythene jacket for a further six months where walking and lying down was allowed with only limited periods of sitting.

Scoliosis sufferers are reminded of the considerable advances in medical science since the 70’s. Surgical treatment no longer takes a year to recuperate and now involves a hospital stay of only a week to ten days- an

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important consideration for parents and adolescents undergoing surgery. Furthermore, pain control and post surgical recovery technologies have come a long way.

For the duration of my extensive treatment my parents who resided overseas at the time were unable to be by my side. The positive side of this was that with no parents, I had no parental anxiety to absorb. This traumatic experience early in life impacted my personality in many positive ways. Facing this challenge built my resilience allowing me to discover the ability to help others undergoing psychological and physical pain eventually leading to my career as a psychologist.

The purpose of this paper is to enable mental health professionals to inspire scoliosis sufferers though, the general principles of adjustment and coping can apply as equally to others, undergoing illness, disability or adversity in life.

What is Scoliosis?

Scoliosis is a lateral or sideways curvature of the spine. There are many different types and causes of scoliosis which can affect children, adolescents and adults. Adolescent idiopathic scoliosis is a type of scoliosis that typically affects adolescent girls- “idiopathic” means cause unknown. AIS is normally detected around the onset of puberty and depending on the degree of curvature may require correction. The Scoliosis Australia website (http://www.scoliosis-australia.org) gives comprehensive information.

Whilst information about scoliosis is now on the increase, the level of community awareness of scoliosis in Australia is not optimal. There are many international research studies on AIS and its psychological ramifications on the sufferer (e.g., Sapountzi-Kreapia, Valavanis, Panteleakis, Zangana, Vlachogiannis & Sapkas, 2001; Ólafsson, Saraste & Ahlgren, 1999; Sapountzi-Kreapia, Psychogiou, Peterson, Zafiri, Lordanopoulou, Michailidou & Christodoulou, 2006; Ugwonali, Lomas, Choe, Hyman, Lee, Vitale & Roye, 2004) but there is limited if any, psychological research studies on scoliosis in Australia. Additionally, a review of research literature indicates that the majority of studies undertaken on AIS have focussed on the psychosocial ramifications of bracing and body image disturbances at this developmental stage in life when adolescents are particularly sensitive to pubertal and other physical changes occurring in the body. There is a scarcity of research on the psychological implications of progressive AIS over the lifespan of the sufferer. Moreover, there is limited to no studies on the impact of scoliosis on parents who are the primary supports or on parental coping styles and its impact on AIS sufferers.

The Spine Society of Australia indicates that: “Whilst 90% of cases that are presented in scoliosis clinics in Australia are girls with AIS, only two to three per thousand require some form of intervention in the growth phase and only one per thousand may require surgery.” (Scoliosis Australia: About Scoliosis, 2011).

Research is suggestive of a genetic component to scoliosis and recommendation is made for a person with treated scoliosis to have siblings and children screened. In some instances however, even with a genetic predisposition scoliosis can skip a generation. The earlier intervention is sought the better the prognosis. In progressive or untreated cases, scoliosis can lead to medical complications and result in a change in the appearance of the spine and body. The most obvious deformities of untreated AIS are uneven hip and shoulder heights, a hump in
the upper back and distortion of the rib and chest cavity area which can lead to significant body image disturbances over the lifespan.

The National Self-Detection Program for Scoliosis (NSDP) was introduced by the Spine Society of Australia with the support from the Royal Australian College of General Practitioners; it is recommended for girls in Years 7 and 9 (11 and 13 years of age) as a preventative health measure to detect Scoliosis (Scoliosis Australia Self Detection Program, 2011). Australian schools can participate in the programme in the abovementioned years to facilitate early detection of AIS. Where test results indicate treatment is necessary, a referral to a spinal specialist would be recommended.

The method of treatment to correct AIS is generally, bracing or spinal fusion. Where bracing is the recommended form of treatment, a brace is required to be worn for a certain number of hours per day and monitored by a physician. Where surgery is the method of treatment, it entails fusion of the spine and possible implant of instrumentation with bone grafts. Recuperation period is generally 4-8 weeks after which rehabilitative activities such as gentle exercise and hydrotherapy may be recommended. Intervention for scoliosis in adolescence can reduce the likelihood of medical complications and also result in significant improvement in body image.

**Emotional Impact on Adolescents**

A diagnosis of AIS can have significant psychological impact at a time when adolescents are coping with the developmental challenges of adolescence. Psychologists are aware of the risk of emerging mental health issues at this developmental stage: school and peer stress; early dating; autonomy and independence issues; sexual identity problems; substance use issues and other mental health problems often, with co-morbidity. Current research on mental health indicates that: 75% of mental illness commences before the age of 25, afflicting one in four young adults under 18 years of age, with only 30% seeking professional assistance (Carr- Gregg, 2011).

In adolescence, identification with and acceptance from peers is significant for a positive and healthy sense of self identity. An adolescents’ desire not to be different from peers can present considerable barriers towards engagement in help seeking behaviours (Carr- Gregg, 2011). Current Australian research indicates that young adults experience mental health problems at an earlier age than previously, with increasingly higher rates than older age, which in most cases, continues into adulthood (Carr- Gregg, 2011). Whilst most adolescents are fairly resilient and will make the necessary adaptations with relative ease, a diagnosis of scoliosis in adolescence can impact mental health adversely, when appropriate adaptations are not made. This can get exacerbated by an adolescent’s poor help seeking behaviours.

When scoliosis requires intervention it can often result in the sufferer and the family to experience range of mixed emotions (e.g., Kurtzer-White & Luterman, 2003; Bowes, Lowes, Warner & Gregory, 2009). The most common symptoms experienced by adolescents can be anxiety, depressed moods and preoccupation of thoughts of the condition- normal responses in the “adjustment phase.” At this developmental stage, adolescents can be struggling with autonomy and independence issues so that some may want to process information without undue parental protectiveness or hyper-vigilance. Adolescents most often are
also coping with parental responses to the diagnosis. That is, parental grief and anxiety, as parents come to terms with the condition and its implications. Studies indicate that this can be a common response exhibited by parents of children diagnosed with any childhood medical illness or disability, which can further compound psychological symptoms of children (Kurtzer-White et al., 2003; Bowes et al., 2009; McCauley, Carlson & Calderon, 1991).

Parental response style and eventual acceptance is an important determinant of adolescents’ ability to cope with the diagnosis. Generally, most adolescents can cope reasonably well due to resilience factors and their natural ability to bounce back—especially if parental anxiety is not communicated either. Guidance combined with gentle question and answer will be all that is necessary for some. As further information is collected, questions answered by the surgeon in combination with interventions underway, the intensity and frequency of emotions will subside. Whilst parents require psycho-education on the normality of the range of differing emotions in the initial stages of diagnosis, they also need knowledge of symptoms that would indicate an adolescent’s inability to cope, which can be both, psychological and somatic in nature (Egger, Costello, Erkanli & Angold, 1999; Ginsburgh, Riddle & Davies, 2006).

Where surgery is the recommended method of treatment for AIS it can predispose adolescents to feel different to peers with associated perceptions of a reduced quality of life. In general, any medical condition that sets adolescents apart from peers can be the cause of significant stress and anxiety at this developmental stage, when adolescents have a keen desire not to be different to peers (Carr-Gregg, 2011). Medical intervention for AIS and its consequent impact such as disruptions to school, upcoming surgery and rehabilitative implications can precipitate significant anxiety for some. Post-surgical restrictions for AIS sufferers may mean an inability to partake as fully as peers in some activities, for instance, gym workouts due to restrictions with bending and twisting motions, heavy lifting, including engagement in contact sports, compounding the feeling of being different. Generally, the first month post treatment involves the large majority of adjustments and hence, is often the most difficult period.

A second method of treatment for AIS is bracing. Whilst a large body of international research indicates that bracing can have an adverse psychological impact on adolescents, other research studies contradict these findings indicating that bracing does not adversely impact AIS sufferers at a psychosocial level (e.g., Ólafsson et al., 1999) nor does it impact quality of life (e.g., Ugwonali et al., 2004).

Studies that indicate significant distress can be experienced in the initial bracing period by both sufferers and parents, enumerate stresses relating to: brace fitting; discomfort; physical and social restrictions with the brace; social isolation from peers and perceptions of negative self image, predisposing to anxiety and depressed moods (e.g., Donnelly, Dolan, Grande, Stuart & Weinstein, 2004; Maclean, Green, Pierre & Ray, 1989). Clothes to wear to disguise the brace are often stressful for both mothers and daughters (Donnelly et al., 2004; Maclean et al., 1989). Anxiety can be a common response of adolescent girls in relation to clothes to wear, evidenced by the involvement of fashion consultants on scoliosis forums both internationally and in Australia (Scoliosis Australia Forum, 2011).
Whilst bracing in general, can precipitate significant body image disturbances in relation to perceived differences to peers, Sapountzi-Krepia et al. (2001) found significant gender differences such that boys with scoliosis had a better body image perception than girls. This finding is consistent with many other research studies that indicate girls can experience significant body image concerns in comparison to boys. Societal acculturation on what is considered an acceptable body image for girls may predispose towards this heightened perception. For instance, a study undertaken in Australia by Bakich (2004) that investigated the correlation of body image disturbances, teasing and eating disorders with a cohort of year eight and year nine girls, found socio-cultural and media attitudes in combination with a history of teasing, to be strong predictors of body image disturbances and eating disorders in adolescent girls.

Adolescents’ perceptions of negative peer appraisals and desire for positive appraisal and acceptance from peers can potentially predispose to the development of psychological problems resulting in compliance problems - a common problem faced by parents. For instance, Sapountzi-Kreppia et al. (2006) found AIS sufferers reporting stress, denial, fear, anger and shame during brace therapy supporting many other research findings which indicate bracing is a stressful experience for AIS sufferers (e.g., Donnelly, et al., 2004; Maclean et al., 1989). The authors asserted the importance of emotional support from healthcare staff, family and peers during the initial bracing period.

Whilst recognising that research findings cannot be generalized due to small samples or other limitations, the results are nonetheless informative. It is reasonable to expect that most braced individuals in the initial adjustment phase will undergo both physical and psychosocial stresses - normal responses to an abnormal situation. Over time however, necessary adaptations will be made by both sufferers and parents. In Maclean et al’s. (1989) study, parents reported that eventual acceptance of the brace was significant in terms of reducing anxiety for both mothers and daughters whilst the development of a brace routine and access to brace specialists for adjustments also contributed to reduced anxiety.

In this study, parents also reported the importance of identification and support from peers and other parents to be a significant factor reducing psychological stress in the initial bracing period (Maclean et al., 1989). These findings are congruent with the author’s own experience albeit, in a body cast. The long period of inpatient convalescence with other AIS sufferers enabled identification and normalisation with peers undergoing the same experience; an important protective factor. Other research findings are consistent with this, indicating that nurturing and supportive social support networks provide a protective factor facilitating good adaptations over time (e.g., Donnelly et al., 2004).

These research findings in line with the authors own experience, confirms the importance of social support networks providing a buffer from mental health problems. There are international and more recently, Australian scoliosis forums that provide a venue for supportive networking with other sufferers and parents. Given adolescents poor help seeking behaviours, online forums for scoliosis sufferers provides an excellent avenue for identification and normalisation of feelings, again buffering from mental health problems. Interestingly, a research study undertaken in Australia on the
increasing use of internet by adolescents indicated that anonymity may play an important part when seeking help online which the author stated, required further investigation (Edwards-Hart & Chester, 2010).

Variables such as: a supportive family atmosphere; family response and coping styles; resilience; acceptance and individual coping mechanisms will all determine adjustments over time. Parents and sufferers both need awareness of counselling and support services available through school counsellors/psychologists and other mental health professionals such as: private psychologists; social workers and the local Community Health Centre.

**Emotional Impact on Parents**

There has been little research on parental response to a diagnosis of scoliosis however, studies conducted on initial parental responses to children’s diagnosis of a medical illness or disability indicate that generally, it is normal for parents to experience emotions similar to a grief response – shock, despair, disillusionment with associated anxiety and depressed moods, as normality is thrown into abnormality (Kubler-Ross & Kessler, 2005; Bowes et al., 2009; Reiss, 2010). Since AIS emerges around early adolescence and often not outwardly obvious, parents can experience a response similar to a grief response, in relation to the diagnosis of a “normal” child identified with a condition. Guilt may also be experienced, especially, if the problem was first identified via an external source such as by the general practitioner and not by the parents.

Often there can be recurrence of grief episodes for parents throughout the treatment and recovery phases, necessitating ongoing adjustments (Bowes et al., 2009). Where multiple corrective surgeries are required such as, in progressive cases, parents can continue to experience grief episodes even during the sufferer’s adult life (Bowes et al., 2009; Kurtzer-White et al., 2003). This grief can often be absorbed by children (Kelly, Gil & Schanberg, 2003).

Adjustment to a medical illness is more often a factor of resilience combined with emotional and social coping rather than the actual medical illness itself (Clarke & Nicholson, 2010). Studies indicate that parents with good coping skills experience less depressive symptoms regardless of the severity of their child’s medical condition (e.g., Churchill, Villareale, Monaghan, Sharp & Kieckhefer, 2010). Over time, it is vital for parents to reach a level of acceptance, maintain a positive attitude and cultivate hope (Seligman & Csikszentmihalyi, 2000). Coping styles of parents will determine coping styles of children (Kelly et al., 2003; Wagner, Chaney, Hommel, Page, Mullins, White & Jarvis, 2003). Accepting support from extended family and friends or a mental health professional will facilitate normalisation of feelings. As necessary adjustments are made most of the initial emotions will subside.

Parents require having an awareness of the adolescents’ general ability to bounce back, depending of course, on factors such as: personality disposition; coping skills; a supportive family and good social support networks. On the practical side, parents should keep communication channels open, provide a stable family environment, help adolescents deal with pain and fatigue issues, whilst also incorporating pleasurable activities for the whole family. After all, there is life after scoliosis! Parents can encourage their child to remain positive, accept their circumstances, have hope, view it as a challenge and help build resilience.
Adolescents identified with AIS need to be reminded that they can still live full creative lives. Reliance on a higher power can prove helpful and is a vital protective factor for some.

**Clinical Considerations**

Since adolescents do not readily seek help due to their desire not to be different from their peers, therapeutic alliance and engagement are deemed to be more critical than the model of counselling utilised (Parry, 2011). Where therapeutic engagement has successfully been established often just ventilation and normalisation of feelings on school issues, friends, exams and how Scoliosis is affecting them may be all that is required. Where necessary adjustments are not made, a diagnosis of scoliosis can precipitate mental health problems. Co-occurrence of other psychological problems can present complicated challenges and needs assessment, for instance, one study indicated co-morbidity of AIS and eating disorders (Alborghetti, Scimeca, Costanzo & Boca, 2008) whilst a further study, indicated that scoliosis places sufferers at increased risk of psychosocial problems such as: alcoholism; suicidal ideation and anxiety (Payne, Ogilvie, Resnick, Kane, Transfeldt & Blum, 1997). Although the study had its limitations the results have implications for mental health professionals.

A bio- psychosocial case formulation is useful requiring sensitive discernment of the issues discussed in this paper. Mental health professionals need to assess not only on AXIS I but AXIS II for temperament and personality characteristics which can perpetuate coping styles. For instance, “anxious worrier” or “avoidant” personality styles can correlate with rejection sensitivity and self-criticism, which will significantly increase levels of distress for scoliosis sufferers with bracing and body image issues. On the other hand, it is imperative for mental health professionals not to draw attention to bracing and body image issues needlessly, since it may not be of consequence for most, after the initial adjustment phase.

When bracing continues to be experienced as stressful after the initial phase, mental health professionals have a role to play in addressing erroneous thinking patterns and attitudes, which can precipitate stressful response patterns and inevitably, lead to low compliance. Distortions in thinking patterns such as generalisations and catastrophic thinking—“everything is difficult with the brace,” or engagement in all or nothing thinking patterns—“If only I did not have the brace I would feel better,” can be common responses when the brace is only temporary.

Hence, whilst it is important to understand adolescent risk factors for the development of depression: biological; psychological; social and environmental stressors, equally as important are cognitions. Factors such as: attributional style; dichotomous thinking patterns; cognitive distortions; negative relational patterns and perceptions of control and responsibility, require to be assessed (Yapko, 1997). Core schemas of “social inferiority”, “defectiveness” and “unrelenting standards,” can determine the experience of not just bracing but overall treatment. This will inevitably interact with personality variables and family response and coping styles, impacting individual adjustment e.g. resilient problem solver versus anxious worrier.

A narrative approach to therapy can be beneficial, “You are not your scoliosis. You have scoliosis which needs to be managed.” This entails externalising the problem with
instruction on emotion regulation skills. Utilisation of cognitive behavioural therapy techniques to engage in constructive thinking patterns, with engagement in structured problem solving can help restructure dysfunctional thinking styles. Reframing of negative attitudes and attributional styles such as, “I have Scoliosis. It is not me. I have to manage it and not let it manage me,” will help prevent depressive thinking patterns. Stories and metaphors as part of therapeutic intervention can also be powerful ways to inspire and motivate young people, enabling them to identify with others, empowering them to face a similar challenge, with tools needed to deal with the journey (Burns, 2001).

Adolescents will benefit from learning the skills of resilience: acceptance; a positive attitude; taking control; problem solving; managing stress; seeking help and keeping things in perspective (Clarke & Nicholson, 2010). Positive psychology principles such as: the promotion of wellbeing; acceptance; hope; courage and determination to face adversity are vital as evidenced by the author’s own experience. A positive outlook, viewing it as a challenge, having hope and identifying strengths to cope are protective factors (Seligman et al., 2000; Seligman, Steen, Park & Peterson, 2005). AIS sufferers need to be reminded to focus on outcomes: a better body image; improved self-confidence and reduced likelihood of medical complications. Facing the challenge in itself will impact personality in many positive ways.

Parents need psycho-education on adolescents’ general lack of help seeking behaviours with the need for gentle encouragement to seek assistance, being cognisant of autonomy and independence issues. Psycho-education on adolescents’ symptom patterns, severity and frequency as indicators for counselling, is a role that mental health professionals and professionals in educational settings need to undertake.

Emotional Impact on Adult Sufferer

Mental health is minimally compromised where a sufferer has good prognosis post treatment and no further intervention is required. A study by Danielsson, Wiklund, Pehrsson & Nachemson (2001) found that 20 years after surgery and bracing treatment, the psychological well-being of patients with AIS was comparable to the general population. In some cases however, even after the initial surgery the curvature of the spine can progress, either with age or in some instances, with pregnancies requiring further corrective surgery. In such instances, there can be an associated psychological impact over the lifespan of the sufferer. Often, the impact is felt not only at an individual level but a familial one. Realignment of family and work role responsibilities may need to occur with acceptance required on the part of the sufferer. Anxiety can be experienced in relation to major lifestyle adjustments, prognosis and rehabilitative requirements - a normal response.

Even with a good prognosis, at milestones in life such as pregnancy; managing a new family; increased career responsibilities and/or other role changes, the associated demands on the fused spine can cause anxiety. Support of significant others such as, spouse/parent and their coping styles will influence and determine how well the sufferer copes. An attitude of acceptance, optimism and hope is vital (Seligman, et al., 2005). The attitude of acceptance promotes tolerance, which can counteract mental unhappiness, dissatisfaction and discontent (Dalai Lama & Cutler, 1998). Reiss (2010) states that, some individuals respond automatically to adversity with grace, optimism and problem-solving strategies, whereas others may experience feelings of helplessness and despair.
solving, whilst others have to work at it and that it is a necessary survival skill to cope successfully in life.

Generally, a sufferer with good coping skills, resilience, hope, a supportive family and good social support networks combined with a positive personality disposition, will make necessary adjustments (Salovey, Detweiler, Steward & Rothman, 2000). Gainful employment and engagement in exercise and fitness activities are additional protective factors. When there is an inability to make necessary adjustments, assessment of predisposing and precipitating factors is necessary.

Conclusion

AIS can have significant psychological impact in adolescence. Whilst most adolescents are fairly resilient and can make good adjustments, intervention for AIS can have an adverse impact on adolescents’ psychosocial wellbeing; some sufferers require emotional support and coping strategies. Sufferers with multiple corrective surgeries or residual pain issues can get psychologically impacted over the lifespan. Mental health professionals need to promote positive psychology principles to facilitate coping: acceptance; hope; courage and determination. Parents need psycho-education on adolescents’ response patterns to the diagnosis, including, an understanding of adolescent’s general lack of help seeking behaviours. Nurturing and supportive social support networks such as scoliosis forums are vital for the identification and normalisation of feelings. Clinical assessment and early intervention is required for those who may be at risk of developing mental health problems.

There is a need for more Australian research studies on the psychosocial impact of AIS on adolescents including the psychological impact of AIS on parents and parental coping styles as determinants of sufferers’ coping styles. Future research may consider longitudinal studies on the psychosocial impact of scoliosis across the lifespan of the sufferer, especially implications for sufferers with multiple corrective surgeries.

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