Long-Term Effects of Untreated Adolescent Idiopathic Scoliosis: A Review of the Literature

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Currently, adolescent idiopathic scoliosis (AIS) is principally regarded as benign, but some researchers have cited serious or extreme effects, including severe pain, cardiopulmonary compromise, social isolation, and even early death. Therefore, exploration of the long-term effects of AIS, the most common type of idiopathic scoliosis, is warranted. The purpose of this review was to examine the long-term studies on the natural history of AIS and/or reviews concerning the long-term effects of untreated AIS. A PubMed search was conducted using the key words idiopathic scoliosis, long-term effects and idiopathic scoliosis, natural history. For further analysis, references cited in those studies were reviewed for additional, related evidence not retrieved in the initial PubMed search. A review of the pertinent bibliography showed that older natural history studies did not distinguish between late-onset scoliosis (referred to in this paper as AIS) and early-onset scoliosis (EOS). The more recent studies offer such important distinction and reach to the general conclusion that untreated AIS does not lead to severe consequences with respect to signs and symptoms of scoliosis. It is possible that earlier studies may have included patient populations with EOS, leading to the perception of untreated scoliosis as having an unusually high morbidity rate. Studies on the long-term effects of AIS that specifically excluded EOS patients conclude that AIS is a benign disorder. This indicates that for research and reporting purposes, it is important to distinguishing between AIS and EOS. This will allow the practitioner and patient and their families to decide on an optimal treatment plan based on the most appropriate prognosis.

Keywords: Scoliosis; Long-term adverse effects; Treatment

Introduction

Scoliosis is a three-dimensional deformity of the spine and trunk; it includes lateral deviation, rotation, and a disturbed sagittal profile [1-4]. Treatment is indicated because scoliosis may lead to reduced quality of life and diverse health issues in some patients [1,5,6].

Scoliosis may be caused by disturbances of the neuromuscular system (neuromuscular scoliosis), alterations of soft tissue (e.g., Marfan's syndrome and Ehlers-Danlos syndrome), alterations of the nervous system (neurofibromatosis), failure of formation/segmentation of vertebrae and ribs (congenital scoliosis), and other causes [7]. The majority of patients with scoliosis have idiopathic scoliosis [8,9].

Adolescent idiopathic scoliosis (AIS) is the most common form of scoliosis (80%–90% of the scoliosis population) [10]. AIS is also sometimes referred to as "late-onset

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scoliosis" when it occurs at the age of 10 or later in adolescence [10]. In contrast, early-onset idiopathic scoliosis (EOS) has a far lower prevalence (11%-15% of all idiopathic scoliosis cases) [10]. EOS can be subdivided into two groups: infantile idiopathic scoliosis, which develops before the age of 3, and juvenile idiopathic scoliosis, which has its onset after the fourth year of life [10]. The deformities may increase during phases of rapid growth [2].

Studies have described the natural history of the disorder during growth [2,4,9,11-14]. They indicate that age, gender, curve size (Cobb angle), menarcheal status, and Risser sign are the most critical factors for predicting curve progression during growth. According to Lonstein and Carlson, the risk of progression can be calculated for curves between 20° and 29° [11]. This calculation is the basis for the current indication guidelines [15,16].

The purpose of this review was to identify and evaluate long-term studies on the natural history of AIS or reviews covering the long-term effects of untreated AIS. Most recent studies on the long-term natural history of scoliosis consider AIS as being benign in principle [1,5,17-19]. However, some practitioners continue to report severe pain, cardiopulmonary compromise, lack of social participation, and early death as negative consequences of AIS [20]; these citations are based on a paper that includes a patient population sample treated between 1911 and 1919 [21].

Occasionally, these long-term indications are used as a basis for the recommendation of surgical intervention [20]. This is applicable to AIS patients with curve magnitudes of ≥40° with a potential for further growth and for those with curve magnitudes of $\geq 50^{\circ}$ at or near skeletal maturity. This is standard practice, although there is a clear absence of high-level evidence for recommendation of spinal fusion surgery [22-26]. Therefore, the indications for surgery need to be reevaluated based on the natural long-term effects of patients with AIS (the most prevalent population).

Materials and Methods

A PubMed search was conducted on October 28, 2015 using the following keywords: (1) idiopathic scoliosis, longterm follow up, natural history; and (2) idiopathic scoliosis, natural history

In addition, the literature referenced in the reviews retrieved during the search was examined to uncover additional studies not displayed in the results of the PubMed search.

Results

The initial search returned fourteen citations, of which four appeared to satisfy our review scope [27-30]. The second search resulted in 174 citations, of which twenty-six were considered relevant to our purposes [2,9,13,14,18,27-47]. Seven reviews addressing the long-term consequences of AIS [1,4,9,12-14,18] were also identified (Table 1). Four studies included data on long-term effects with a followup time of 20 years or more [5,17,19,21].

One early study by Nilsonne and Lundgren [21] was a retrospective chart review. The authors concluded that idiopathic scoliosis may lead to severe pain, cardiopulmonary compromise, lack of social participation, and early death; however, their report did not specify age at diagnosis, and at least ten patients were juveniles at the time of admission into the study.

For scoliosis, an accurate age of onset is not always easily determined. A study from 1978 concluded that scoliosis screening is not necessary before the ages of 12 [45]; this recommendation clearly prevents determining the true age of onset.

The Iowa studies [5,17,19] defined AIS as idiopathic scoliosis that begins between the ages of 10-14 and concluded that AIS does not lead to significant health problems other than non-disabling back pain and cosmetic concerns. We found only few studies related to the longterm consequences of untreated AIS (Table 2) with a follow-up period exceeding 20 years [5,17,19], one of which

Table 1. Search 1 (idiopathic scoliosis, long-term follow up, natural history) revealed 4 papers on long-term results of untreated patients, search 2 revealed 11 papers on long-term results of untreated patients

	All papers	Long-term results
Search 1	14	4
Search 2	174	11

Table 2. Long-term studies on untreated patients with idiopathic scoliosis with a follow-up of 20 years or more

Study, year	Benign	Fatal
Nilsonne and Lundgren [21], 1968	-	+
Collis and Ponseti [17] ^{a)} , 1969	+	-
Weinstein et al. [19] ^{a)} , 1981	+	-
Weinstein et al. [5] ^{a]} , 2003	+	-

^{al}Untreated patients from the lowa series had a benign course, while Nilsonne and Lundgren (1968) [21] have described a fatal course of idiopathic scoliosis.

had a 50-year follow-up [5].

As a result of this review, we can conclude that AIS, when left untreated, does not lead to severe long-term health consequences [1,5,13,17-19,30,48].

Discussion

We determined that studies that include the most specific definition of AIS indicate that AIS, when left untreated, does not have severe long-term consequences [1,5,13,17-19,30,48]. This is in contrast to some early 20th century studies on idiopathic scoliosis, which included patient samples from as early as the 1920s [21,45], that did not differentiate idiopathic EOS from AIS in the sample population. One such study in particular, which concluded that untreated idiopathic scoliosis can have fatal consequences, included patients with EOS [21].

This conclusion is not necessarily valid for patients with AIS. It is now known that age at diagnosis is an important factor and must be taken into consideration because the earlier the onset, the more serious the prognosis [1,49]. This lack of distinction between EOS and AIS could be one significant reason for the disparity between conclusions of older [21] and more recent studies [1,5,13,17-19,30,48].

It should also be acknowledged that at the beginning of the 20th century, people rarely showed themselves uncovered publicly. At that time, clothing did not readily reveal the shape of the body, nor did the people wear swimwear with exposed back and torso, thus offering less opportunity for earlier detection. For this reason, it is possible that scoliosis may not have been detected as commonly and as early as it is nowadays.

During that time period (20th century), in Germany, it was also common for patients seeking scoliosis treatment to exhibit curves already exceeding 90° (Fig. 1) [6,50]. School screening programs implemented in the late 20th

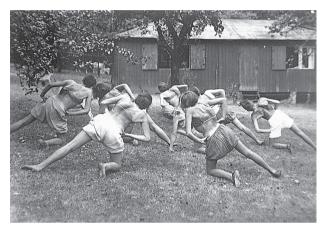


Fig. 1. Patients treated at the Katharina Schroth institute in the 1920s. Most patients presented with curvatures (Cobb angles) exceeding 90° [6]

century improved scoliosis detection. Earlier detection may now allow for a more accurate distinction between EOS and AIS.

AIS, or late-onset idiopathic scoliosis, usually does not exceed 80° after cessation of growth when left untreated [5] and is therefore almost never responsible for increased mortality [51]. This is why practitioners must distinguish between EOS and AIS in patients, as each type has a very different prognosis [1,10].

1. Implications of treatment

There is a growing body of evidence concluding that surgery is rarely necessary for AIS [24-26,52] and that it is usually done for cosmetic and psychological purposes. Based on the current literature, Westrick and Ward [25] concluded that there is no medical necessity for surgery for AIS; this conclusion was recently confirmed by the results of a Cochrane review [26].

Surgery for AIS carries risks and long-term consequences. Low back pain [53,54] and potential disc degeneration [55] may increase over time after spinal fusion surgery [54]. For these reasons, spinal fusion is not proven to prevent low back pain in patients with AIS. In addition, a recent study shows that spinal fusion surgery does not improve the health-related quality of life of patients with AIS [56].

According to the current literature, to provide a balanced view regarding risks and benefits of surgical treatment in patients with AIS, we have to take into account that: (1) no high-quality evidence is available to support the claim that spinal fusion surgery may improve signs and symptoms of AIS [22,24-26,52,57,58] and (2) surgery carries many risks and other, yet unknown long-term consequences [22,53,59-61].

Therefore, considering that there is no evidence that the signs and symptoms of scoliosis can be improved in the long-term, no medical indication for spinal fusion surgery in AIS can be derived [25]. Considering that AIS is at present considered to be a relatively benign condition [1,5,13,17-19,30,48], the adverse long-term consequences of surgery may be more harmful than the adverse effects of the disease itself [22,53,59-61].

For patients with EOS, recent surgical techniques may drastically improve the deformity and enhance the quality of life. Despite this, it should be noted that there are no long-term results available for these procedures, and it is not clear whether the signs and symptoms of scoliosis, i.e., severe pain, cardiopulmonary compromise, lack of social participation, and early death can be prevented in the long-term in EOS cases [57]. One study with a follow-up of up to twenty years after the first double-rod instrumentation showed a significant rate of re-operation [53].

EOS warrants high-quality conservative treatment to reduce the rate of surgery [62-64]. Particularly for brace treatment, the quality is determined by the in-brace correction and comfort, as we know that in-brace correction and the time for which a brace is worn each day determine the outcome [65]. For AIS, the natural history research shows that for patients with curves below 30° who are at Risser 3 or more, observation alone may be justified. At that point, significant consequences for the patient are less likely [15]. However, for adolescents with curves exceeding 30°, i.e., up to Risser 4, conservative measures should be implemented to attempt to reduce the curve so that the chance of progression during adulthood is lessened [1].

Brace overtreatment has been recently criticized [66,67] and should be avoided, according to indication guidelines for AIS [15] determined by the Lonstein and Carlson progression factor [11]. Patient history should contain information about the onset of the deformity to permit appropriate prognostication and treatment plan [15]. This is paramount as AIS has been identified as a benign deformity [1,5], while the rarer EOS condition may instead have severe consequences if left untreated [10,21].

According to the literature referred for this review, there is only one indication for spinal fusion surgery in patients with AIS; it should be considered only in cases with severely decompensated curvatures exceeding 45° and reduced quality of life as a result of social isolation. Thus, when AIS patients avoid swimming or socializing with friends because of the deformity, surgery should be considered. In this case, the patients should be informed that the deformity may return in the long-term and to some extent after surgery [22]. The decision to have surgery, however, has to be made by the patient and not by the surgeon. This evidence-based rationale is employed and promoted by Ward et al. [56].

The materials found in this review present some limitations.

We have speculated that the increased mortality in young patients with idiopathic scoliosis, as reported by Nilsonne and Lundgren [21], is due to the inclusion of EOS. Other confounding factors, such as excessive radiation exposure, have not been considered when explaining early deaths occurring in this patient population sample [21]. Notably, it is possible that some patients reported in the paper by Nilsonne and Lundgren [21] may have died due to conditions unrelated to scoliosis. Finally, the inclusion criteria in the referred study were not clear [21], and thus, congenital scoliosis and syndromic scoliosis may have been included as well.

Although there are several papers addressing the topic [1,5,13,17-19,30,48], only a few studies from the same series (Iowa studies) include AIS follow-up periods exceeding 20 years [5,17,19].

Conclusions

Early studies on the long-term effects of idiopathic scoliosis may be disregarded since they likely contain a percentage of patients with early-onset scoliosis, which causes the results to be skewed with regard to potentially fatal consequences.

More recent studies on the long-term effects of AIS do

not include patients with EOS, thus leading to the conclusion that AIS is a relatively benign disorder.

It is important to distinguish between EOS and AIS to determine an appropriate treatment plan based on a more accurate age of onset and prognosis.

Conflict of Interest

HR Weiss is receiving financial support for attending symposia and receives royalties from Koob GmbH & Co KG. The company is held by the spouse of HR Weiss.

None of the other authors report any competing interest or potential conflict of interest.

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