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FROM ADOLESCENCE TO ADULTHOOD: A PATIENT-CENTERED, LONGITUDINAL REAPPRAISAL OF IDIOPATHIC SCOLIOSIS OUTCOMES THROUGH NATURAL HISTORY, SURGICAL INTERVENTION, AND THE SMALLEST WORTHWHILE EFFECT FRAMEWORK

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ABSTRACT

Adolescent idiopathic scoliosis is traditionally defined as a three-dimensional spinal deformity emerging during growth without a clearly identifiable cause, yet its clinical and social significance extends far beyond adolescence. Over the last four decades, large natural-history cohorts, long-term observational studies, and postoperative follow-ups have demonstrated that idiopathic scoliosis is not a benign childhood condition but a lifelong musculoskeletal disorder with complex consequences for pain, function, self-image, respiratory capacity, and quality of life. Simultaneously, the interpretation of treatment success in adult scoliosis has evolved, driven by patient-reported outcome measures and by a growing recognition that statistical significance alone does not equate to meaningful improvement. The concept of the smallest worthwhile effect, originally developed in physiotherapy and pharmacologic research, has recently emerged as a more patient-centered and ethically grounded alternative to conventional minimal clinically important difference thresholds. This article integrates these two bodies of scholarship to produce a unified, longitudinal and patient-anchored interpretation of adolescent idiopathic scoliosis from its onset through adulthood.

Drawing exclusively on established natural-history studies, contemporary adult follow-ups, and methodological research on smallest worthwhile effect, this work re-examines how progression, symptoms, disability, and treatment benefits should be interpreted. Long-term cohorts have demonstrated that untreated idiopathic scoliosis can remain stable in many individuals yet may also progress, causing increasing pain, cardiopulmonary compromise, and psychosocial distress decades after skeletal maturity (Weinstein et al., 1981; Weinstein et al., 2003; Weinstein, 2019; Erwin et al., 2020). Surgical correction in adolescence can alter curve magnitude and alignment, but adult outcomes show persistent variability in pain and quality of life, indicating that radiographic correction does not guarantee durable symptomatic relief (Helenius et al., 2019; Ansari et al., 2024). These realities expose a fundamental gap in outcome evaluation: clinicians often rely on structural or statistically derived thresholds, whereas patients prioritize whether a change is actually worth the risks, burden, and long-term trade-offs of treatment.

The smallest worthwhile effect framework addresses this gap by explicitly integrating benefit–harm trade-offs into outcome interpretation. Rather than asking whether a score change is statistically or minimally important, the framework asks how much improvement a patient requires before considering an intervention worthwhile given its risks, costs, and inconveniences (Ferreira et al., 2013; Ferreira, 2018; Hansford et al., 2024). Finch (2025) extended this paradigm to adult idiopathic scoliosis, arguing that traditional minimal clinically important difference values underestimate the magnitude of benefit patients demand when faced with surgery, prolonged rehabilitation, or lifelong implants. When applied to scoliosis, this framework reveals that many interventions classified as “effective” may fail to reach the threshold of meaningfulness from the patient’s perspective.

Through a comprehensive synthesis of natural history, adult outcomes, and patient-centered measurement theory, this article argues that adolescent idiopathic scoliosis should be conceptualized as a lifelong risk condition rather than a childhood deformity, and that treatment success should be judged by whether it delivers benefits that exceed the smallest worthwhile effect for the individual. Such a reframing has profound implications for clinical decision-

making, shared decision-making, and health-policy evaluation. It suggests that early intervention, observation, and surgery must all be evaluated not merely by their ability to change curves or scores but by their capacity to produce improvements that patients truly value across decades of life.

KEYWORDS

Adolescent idiopathic scoliosis, adult outcomes, natural history, smallest worthwhile effect, patient-reported outcomes, spinal deformity, quality of life.

1. INTRODUCTION

Adolescent idiopathic scoliosis occupies a paradoxical place in musculoskeletal medicine. It is one of the most intensively studied spinal deformities, yet its long-term implications remain deeply misunderstood by patients, clinicians, and policymakers alike. The condition is defined by the presence of a lateral spinal curvature with vertebral rotation arising during growth, typically in otherwise healthy adolescents, without an identifiable underlying cause (Hresko, 2013; Jada et al., 2017). At first glance, this definition suggests a discrete orthopedic problem that either resolves or is corrected by the time growth ends. However, more than half a century of longitudinal research demonstrates that this assumption is fundamentally flawed. Idiopathic scoliosis does not simply vanish when skeletal maturity is reached; rather, it evolves into an adult disorder with its own pattern of progression, symptoms, and functional consequences (Weinstein et al., 1981; Weinstein et al., 2003; Weinstein, 2019).

Historically, the clinical focus of scoliosis care has been overwhelmingly centered on adolescence. Screening programs, bracing protocols, and surgical indications were designed to prevent curve progression before skeletal maturity, driven by the belief that the adult spine was largely stable once growth ceased (Weinstein and Ponseti, 1983). While growth is indeed the most potent driver of curve progression, long-term follow-up studies have shown that curvature, pain, and disability may continue to evolve for decades after adolescence, particularly in patients with larger curves at maturity (Weinstein et al., 1981; Weinstein et al., 2003). The adult manifestation of adolescent idiopathic scoliosis thus represents not a new disease but the continuation of the same pathological process across the lifespan.

In recent years, this long-term perspective has gained renewed importance. Increasing numbers of individuals treated or observed as adolescents are now entering mid-life and older age, carrying with them the biomechanical and psychosocial consequences of their spinal deformity (Erwin et al., 2020; Ansari et al., 2024). At the same time, the outcomes of surgical and non-surgical interventions are being scrutinized not only in terms of radiographic correction but also in terms of pain, function, and quality of life (Helenius et al., 2019; Ansari et al., 2024). This shift reflects a broader transformation in medicine toward patient-reported outcomes and patient-centered care.

Yet this transformation has exposed a critical methodological and ethical problem: how should improvement be defined in a way that truly reflects what matters to patients? Traditional outcome metrics in scoliosis research, such as Cobb angle reduction or standardized questionnaire scores, are often interpreted through the lens of statistical significance or minimal clinically important difference thresholds. While these metrics are useful for detecting change, they do not necessarily capture whether that change is large enough to justify the risks, burdens, and long-term trade-offs associated with treatment, especially surgical intervention.

This gap has been addressed in parallel fields such as physiotherapy and pain medicine through the development of the smallest worthwhile effect framework. Originally conceptualized to quantify the minimum benefit patients require to consider a treatment worthwhile given its harms and inconveniences, the smallest worthwhile effect has been applied to chronic low back pain, exercise therapy, and pharmacologic interventions (Ferreira et al., 2013; Ferreira, 2018; Hansford et al., 2024). Finch (2025) has recently argued that this framework is particularly well suited to adult idiopathic scoliosis, where treatments often involve substantial risk, prolonged recovery, and irreversible anatomical change.

The literature on scoliosis and the literature on smallest worthwhile effect have developed largely in parallel, rarely intersecting in a systematic way. This separation has limited the ability of clinicians and researchers to interpret long-term scoliosis outcomes in a manner that aligns with patient values. The present article seeks to bridge this divide by synthesizing natural-history studies, adult outcome research, and patient-centered measurement theory into a unified framework for understanding adolescent idiopathic scoliosis across the lifespan.

The central premise of this work is that adolescent idiopathic scoliosis should be understood as a chronic, lifelong condition whose significance cannot be captured by short-term radiographic outcomes alone. Furthermore, the success of any intervention, whether observation, bracing, physiotherapy, or surgery, must ultimately be judged by whether it produces benefits that exceed the

smallest worthwhile effect for the patient, not merely whether it produces statistically detectable change. By reinterpreting the existing literature through this lens, this article aims to provide a more ethically grounded, clinically relevant, and patient-centered understanding of scoliosis management from adolescence into adulthood.

Methodology

This study adopts a narrative-integrative methodology grounded strictly in the peer-reviewed and authoritative references provided. Rather than generating new empirical data, the approach is designed to synthesize, reinterpret, and theoretically elaborate on existing evidence to produce a coherent and patient-centered conceptual framework. Such an approach is particularly appropriate for conditions like adolescent idiopathic scoliosis, where the most meaningful insights emerge not from short-term trials but from decades-long observational cohorts and from evolving theories of outcome measurement.

The first methodological pillar consists of longitudinal natural-history studies of untreated idiopathic scoliosis. Foundational work by Weinstein and colleagues in the early 1980s established the trajectory of curve progression, symptoms, and functional limitations over several decades (Weinstein et al., 1981; Weinstein and Ponseti, 1983). These data were later extended in the landmark fifty-year follow-up published in JAMA, which remains one of the most comprehensive sources of information about untreated scoliosis in adulthood (Weinstein et al., 2003). More recent syntheses have reaffirmed and refined these findings, emphasizing variability in progression and outcomes (Weinstein, 2019).

The second methodological pillar consists of contemporary adult outcome studies that examine individuals with adolescent idiopathic scoliosis many years after either surgical or non-surgical management. These include large-scale analyses of untreated adults (Erwin et al., 2020), systematic reviews and clinical updates on scoliosis in adulthood (Ansari et al., 2024), and focused studies of postoperative quality of life (Helenius et al., 2019). These sources provide insight into how adolescent treatment decisions reverberate through adult life.

The third methodological pillar consists of the smallest worthwhile effect literature, which provides a theoretical and quantitative framework for interpreting patient-reported outcomes. Seminal methodological work by Ferreira and colleagues established how smallest worthwhile effect can be estimated through benefit–harm trade-off methods and how it differs from traditional minimal clinically important difference thresholds (Ferreira et al., 2013; Ferreira, 2018). Recent applications to musculoskeletal pain and exercise therapy further illustrate how this concept can be operationalized in clinical research (Hansford et al., 2024). Finch (2025) extended this framework directly to adult idiopathic scoliosis, providing a conceptual bridge between scoliosis outcomes and patient-centered measurement.

The integration of these three pillars follows a structured but narrative process. First, the natural history of adolescent idiopathic scoliosis is examined in detail to establish the baseline trajectory of the condition across the lifespan. Second, adult outcomes following different management strategies are interpreted in light of this natural history to distinguish treatment effects from disease progression. Third, these outcomes are re-evaluated using the smallest worthwhile effect framework, asking not whether change occurred, but whether the magnitude of change is sufficient to justify the intervention from the patient's perspective.

Throughout this process, every major claim is grounded in the provided references and cited using an author–year format. No extrapolations beyond the scope of these sources are introduced. The goal is not to produce a meta-analysis or statistical synthesis, but to generate a theoretically rigorous and clinically meaningful reinterpretation of existing evidence.

Results

The synthesis of longitudinal scoliosis data and patient-centered outcome theory reveals several interlocking patterns that fundamentally reshape how adolescent idiopathic scoliosis should be understood in adulthood. These patterns emerge most clearly when the natural history of the condition is viewed alongside adult outcomes and the smallest worthwhile effect framework.

One of the most striking findings from long-term natural-history studies is the heterogeneity of scoliosis trajectories. Weinstein et al. (1981) demonstrated that while some curves remain relatively stable after skeletal maturity, others continue to progress, particularly when the curve at maturity exceeds certain thresholds. This observation was further elaborated by Weinstein and Ponseti (1983), who showed that thoracic and double major curves are especially prone to progression, leading to increasing deformity and biomechanical imbalance over time. The fifty-year follow-up study later confirmed that progression, pain, and disability are not rare late sequelae but common experiences among individuals with untreated idiopathic scoliosis (Weinstein et al., 2003).

These long-term data directly contradict the notion that adolescent idiopathic scoliosis is primarily a cosmetic or developmental issue. Instead, they reveal a condition that can exert cumulative mechanical and psychosocial stress over decades. Adults with untreated scoliosis in the JAMA cohort reported higher rates of back pain,

functional limitation, and reduced health status compared with matched controls, even though many had adapted to their condition in remarkable ways (Weinstein et al., 2003). Erwin et al. (2020) reinforced these findings in a modern cohort, showing that unoperated adults with adolescent idiopathic scoliosis experience measurable impacts on physical function and health-related quality of life ten years after initial assessment.

When surgical outcomes are examined against this natural-history backdrop, a more nuanced picture emerges. Surgical correction during adolescence is designed primarily to prevent progression and improve alignment, but adult follow-up studies indicate that structural correction does not always translate into proportional improvements in pain or quality of life. Helenius et al. (2019) reported that five years after surgical treatment, many patients still experienced back pain and limitations, even when radiographic outcomes were favorable. Ansari et al. (2024) further emphasized that adults with a history of adolescent idiopathic scoliosis, whether treated or untreated, often face ongoing symptoms that require lifelong management.

These results highlight a fundamental tension in scoliosis care: interventions can alter anatomy, but the lived experience of the patient is shaped by a far broader set of factors, including muscular adaptation, degenerative change, psychological resilience, and social context. Traditional outcome measures, such as Cobb angle or standardized questionnaire scores, capture only fragments of this complexity.

The smallest worthwhile effect framework provides a way to integrate this complexity into outcome interpretation. Studies of chronic low back pain and exercise therapy have shown that patients require relatively large improvements in pain and function before considering a treatment worthwhile, especially when that treatment carries risks or burdens (Ferreira et al., 2013; Hansford et al., 2024). Ferreira (2018) argued that this threshold reflects a rational balancing of benefit against harm, cost, and inconvenience.

When applied to adult idiopathic scoliosis, this logic becomes even more compelling. Finch (2025) demonstrated that patients contemplating or evaluating scoliosis interventions often demand substantial improvements before judging them worthwhile, given the invasiveness, recovery time, and potential complications associated with surgery. This means that many changes classified as clinically important under traditional minimal clinically important difference criteria may fall below the smallest worthwhile effect threshold and therefore be perceived as insufficient by patients.

The combined evidence therefore indicates that both untreated and treated adolescent idiopathic scoliosis can lead to persistent adult morbidity, and that the evaluation of treatment success must be anchored in patient-defined thresholds of meaningful benefit rather than purely statistical or structural metrics.

Discussion

The convergence of long-term scoliosis research and patient-centered outcome theory compels a fundamental rethinking of how adolescent idiopathic scoliosis is conceptualized, treated, and evaluated. Historically, the field has been dominated by a structural paradigm in which curve magnitude, alignment, and radiographic progression are treated as the primary indicators of disease severity and treatment success. While these indicators are undeniably important, they represent only one dimension of a multifaceted condition that unfolds across a lifetime.

The natural-history studies by Weinstein and colleagues provide the empirical foundation for this rethinking. Their decades-long follow-ups show that scoliosis is not a static deformity frozen at skeletal maturity but a dynamic condition whose effects accumulate over time (Weinstein et al., 1981; Weinstein et al., 2003; Weinstein, 2019). The fact that many individuals adapt and maintain functional lives does not negate the reality that they do so often in the presence of chronic pain, fatigue, and physical limitation. From a patient-centered perspective, adaptation should not be conflated with absence of burden.

Surgical intervention complicates this picture further. By altering spinal alignment and halting progression, surgery can change the biomechanical trajectory of the spine. However, the adult outcomes reported by Helenius et al. (2019) and summarized by Ansari et al. (2024) indicate that surgery does not erase the long-term risks of pain and functional limitation. In some cases, it introduces new trade-offs related to hardware, fusion, and adjacent-segment degeneration. These realities underscore why outcome evaluation must go beyond radiographs.

The smallest worthwhile effect framework provides a principled way to navigate these complexities. Unlike the minimal clinically important difference, which is often derived from statistical distributions or anchor-based methods, the smallest worthwhile effect is grounded in patient preferences and trade-offs (Ferreira et al., 2013; Ferreira, 2018). It asks a simple but profound question: how much improvement does a patient need to make an intervention worth it? In a condition like scoliosis, where interventions can be life-altering, this question is ethically central.

Finch (2025) argued that adult idiopathic scoliosis is an ideal context for the application of this framework because patients face decisions with long-lasting consequences. When a surgical correction yields a small improvement in a quality-of-life score that barely

exceeds the minimal clinically important difference, it may still fall short of the smallest worthwhile effect if the patient endured years of recovery, pain, and risk to achieve it. Conversely, a moderate improvement that clearly surpasses the smallest worthwhile effect may be genuinely transformative, even if it does not meet some arbitrary statistical threshold.

Integrating this framework into scoliosis care has implications for shared decision-making, research design, and health policy. Clinicians must move from telling patients what is statistically effective to engaging them in discussions about what level of benefit would justify the risks they face. Researchers must design trials and observational studies that report not only mean changes but also the proportion of patients who achieve benefits exceeding the smallest worthwhile effect. Policymakers must recognize that interventions with modest average effects may still be valuable if they deliver meaningful benefits to a substantial subset of patients.

There are, of course, limitations to this synthesis. The smallest worthwhile effect literature is still evolving, and its application to scoliosis is in its early stages. Estimating these thresholds requires careful elicitation of patient preferences, which may vary by age, culture, and disease severity. Nevertheless, the conceptual clarity it brings to outcome interpretation represents a major advance over traditional metrics.

Conclusion

Adolescent idiopathic scoliosis is not merely a childhood deformity but a lifelong condition whose consequences unfold across decades of adult life. Long-term natural-history studies have demonstrated persistent risks of progression, pain, and disability, while adult outcome studies reveal that even successful surgical correction does not guarantee freedom from symptoms. In this context, the evaluation of treatment success must move beyond radiographic change and statistical significance to embrace a truly patient-centered standard.

The smallest worthwhile effect framework offers precisely such a standard. By anchoring outcome interpretation in the benefits patients require to justify the burdens of treatment, it aligns clinical decision-making with the lived realities of those affected by scoliosis. When applied to adolescent idiopathic scoliosis in adulthood, this framework reveals that many interventions may fall short of what patients actually consider worthwhile, even when they meet conventional criteria for effectiveness.

Reframing scoliosis care around this patient-centered, longitudinal perspective has the potential to improve not only how outcomes are measured but also how care is delivered. It encourages honest conversations about trade-offs, supports more individualized treatment decisions, and ultimately honors the experiences of people who live with this complex condition throughout their lives.

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