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Case Report

Sharing the Truth of Scoliosis Curve Progression Risk with Patients and Families Using a Colorized Natural History Graph Handout - A Quality Improvement Shared Decision-Making Case Report from a Pediatric and Adult Scoliosis Clinic

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Abstract

An exhaustive literature review was performed on the natural history of adult progression of scoliosis along with any published guidelines with the hope of creating better shared decision-making tools for patients and families. A single page colorized handout based on the best natural history data available was then created and has been used consistently over the last two years with both pediatric and adult patients and their families with very high satisfaction as a way of directly connecting evidence from the literature with patient preferences and values in an effort to improve the quality of evidence-based practice (EBP) that respects patient choice.

Keywords: Families; Natural History; Pediatric; Patients

Introduction

Evidence-based practice (EBP) requires the clinician to combine evidence from the literature with clinical experience, and patient values and preferences using Shared Decision-Making (SDM) [2,3]. We are also required to practice Continuous Quality Improvement (CQI) for hospital and board credentialing [4]. While this may seem feasible on paper, trying to actually implement EBP, SDM and CQI together in the very busy "real world" we practice in can seem to be nearly impossible. The following report documents the CQI journey that our small scoliosis clinic has made during the last few years in response to a need we identified through clinical experience. As part of that journey, we have developed a colorized handout, which we use regularly with our pediatric, adolescent and adult patients and their families who find it to be very helpful in their education and decision-making process. We hope this will be inspiring and helpful for other surgeons and their team members.

Motivation

Back in the 1930's, it was widely believed that scoliosis progressed during childhood and adolescence but did not progress in adulthood. In the following decades there have been a few natural history studies completed that proved this was not true [5-9]. However, practice variation still exists and some practitioners still use "Rules of Thumb" they may have learned during their training years and that may not be supported by actual natural history research. In the lead author's (LAH) twenty-seven years of clinical experience caring for scoliosis patients of all ages, I have seen many adult patients with scoliosis suffer over many years due to their deformity. Many of these patients express significant dissatisfaction and even anger toward pediatric and/or orthopedic caregivers who saw them early in life and who did not screen them properly, or who were told that they did not have to worry about curve progression since their curves were below a critical threshold such as 40 or 50 degrees. Decades after getting this reassurance as a child or young adult, these patients look with disbelief at their current x-rays that show evidence that what they were told many years ago was wrong and that their curve could, and in fact, did progress significantly and now they were paying the price. These patients feel that they missed the early treatment "window of opportunity" choice by not being told the truth or offered treatment choices.

In response to this suffering, it was apparent that further investigation and innovation was needed to develop better tools to help educate our patients and their families about the truths about scoliosis so that they could be equipped with the information needed to make wise choices during each phase of their life.

Our first step was discussing with our patients that 68% of adolescent idiopathic scoliosis (AIS) curves will progress during adulthood [7]. While sharing this basic truth with patients, it did not go far enough to educate the patient and family about the individual patients more specific risk given their curve size and age.

Anatomy and Biology

The reason why scoliosis can progress in children and in the adult is largely due to the complex 17 segment thoracolumbar spine geometry combined with the effect of asymmetric loading on the discs which can cause decreased proteoglycan and collagen production on the concavity of the curve [10]. This decreased production leads to weakening of the cartilage on the concavity, which can lead to further angulation of the disc space and also affect loading and angulation of adjacent disc spaces.

This in turn can lead to further asymmetric loading which can become an ongoing "vicious cycle" that can go on life-long, leading to disc and facet joint degeneration, spondylolisthesis, spinal stenosis, back and leg symptoms, and difficulties with posture and appearance.

Methods

The first step in this process was to complete a comprehensive literature review on the natural history of scoliosis curve progression in adulthood through a comprehensive literature review through PubMed and Google Scholar searches, and also online textbooks and websites, including society websites. A careful search was also made for any formal practice guidelines for scoliosis care. These references were compiled into a RefWorks database, obtaining the original articles when available.

Results and Literature Review

After hundreds of hours of literature review research, it was surprising how few scoliosis natural history studies have been performed, and how small the sample size is for these studies. It was simply very difficult to do a natural history study over decades, especially as new treatments including instrumentation surgery were introduced beginning in the 1950's.

There is no natural history study evidence supporting the opinion that patients with curves less than 40 - 50 degrees as a young adult can be reassured that their curve will not progress during adulthood. However, Weinstein and his colleagues did find that curves under 30 degrees were not likely to progress. The best scoliosis natural history study available to date by Weinstein and his colleagues report on a group of 102 patients with 133 curves [7]. The initial sample of patients were treated for adolescent scoliosis in the 1930's and brought back periodically for follow-up x-rays over an average of 40.5 years. They found 68% of the curves overall progressed during adulthood [7]. The actual graphic data for the 4 different curve patterns (thoracic, combined, thoracolumbar, and lumbar) is given in the article, along with even a case example of a lumbar curve under 30 degrees that progressed significantly over 40 years which had significant rotation early on [7].

After studying the graphic data of cobb angle vs. time for each of the curve types, a one-page handout graphic was created where all five graphs representing all 4 curve types were placed on one slide and normalized to match the cobb angle on the Y-axis.

Given the author's conclusion regarding curves under 30 being unlikely to progress, this less than 30 curve range was colored in green (Figure 1). Since curves over 50 degrees were found to have nearly a 100% rate of adult progression, this section was colored in red. The two zones in between were colorized yellow for 30-40, and orange for 40-50 degrees to help with data visualization. Data from the graphs was also used to help calculate the approximate rate of curve progression for the 30-40-degree range which was 80%, and 76% for the 40-50-degree demographic. These curve progression numbers were printed on the far-left hand side of the graphic. A portion of the 1981 and 1983 abstracts along with titles of the articles was placed on the top of the graphic to be reviewed with the patient and family as well.

After completion of this shared decision-making tool handout, it was printed on a single sheet of paper, and multiple copies were made and placed in each exam room. Over the last two years, this form has been used routinely with pediatric and adult patients. In many cases, the patient and family are given the opportunity to read a portion of the 1983 abstract out loud, where the various terms are explained. Key numbers like the 68% curve progression risk as well as the 30 degree "green zone" conclusions are highlighted. A red pen is then used to put the patient's curve measurement (s) on the correct graphic that matches his/her curve size, even for the pediatric patients. The patient and family can then be asked "what zone are you in now", and also "what zone do you want to finish life in?" For the pediatric/adolescent patient who is in the green zone, under 30 degrees, we have found this form to have proven to be quite motivational to encourage the younger patient to be willing to try and be compliant with conservative measures such as Schroth Physiotherapeutic Scoliosis Specific Exercises (PSSE) and/or bracing.

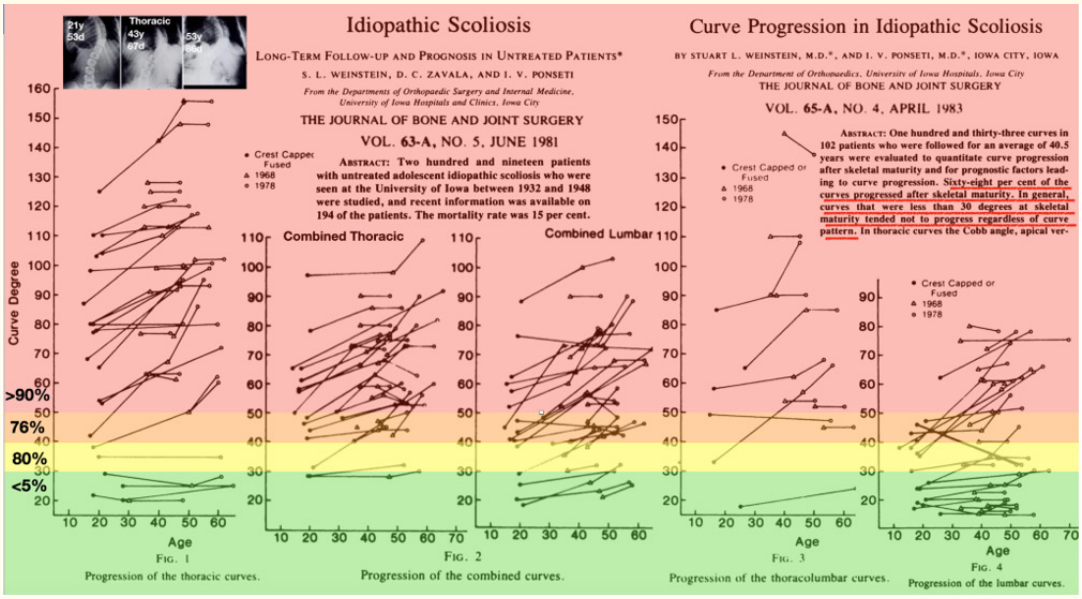

Figure 1: Colorized Patient/Family Education Handout/tool based on Weinstein natural history graphs to share the truth about lifelong scoliosis progression risk based on curve magnitude.

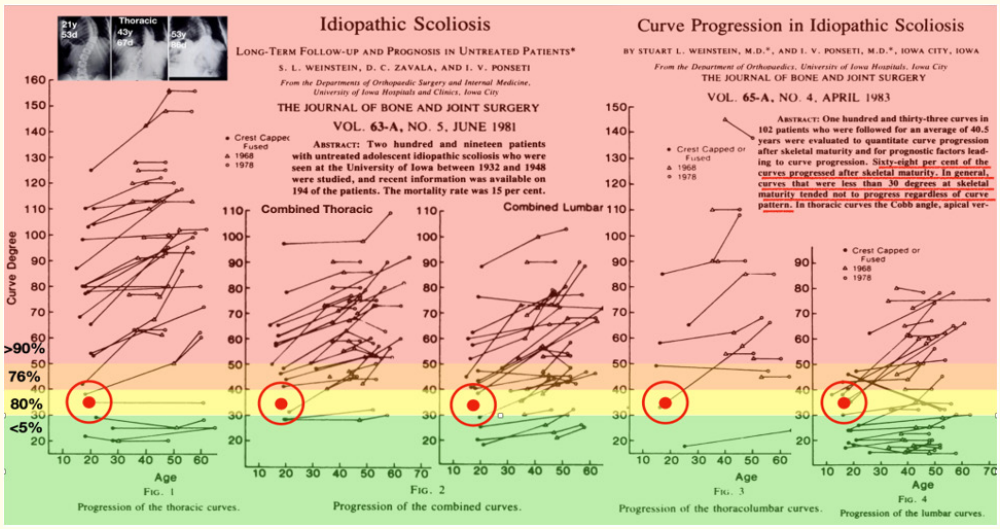

Figure 2: Colorized handout with an individual patient's data drawn onto graphs in red, with a circle to show similar patients who started off with a similar curve.

An effort is made to make each line on the graph "personal" - meaning that we refer to that line as a particular patient who then goes through life on one of several possible paths (Figure 2). Sometimes a red circle is drawn around the patient's datapoint, to capture other data points from the study that are near that patient's data and demonstrate what happens to each of them. This helps them to see the data variation, and actually see how a 60-80% risk plays out.

The data sheet interaction helps to also explain the uncertainty and the sparsity of data in certain areas such as thoracolumbar data in the 30-50-degree range which has only 3 data points. In fact, there are only 2 patients with thoracolumbar curve data.

There is only one datapoint in the 30-49-degree range, which is 33 degrees that progresses to 68 degrees; and one datapoint at

49 degrees that does not progress (Figure 2). Sharing this uncertainty humbly with the patient and their family, and the limitations of natural history data has been very well accepted by them and helps link them as closely as possible to the natural history truth as available in the published literature. Uncertainty with outcomes is one of the key factors that increases the weight of patient and family values and preferences, which is always the foundation of Evidence-Based Practice (EBP). The patient preference trumps everything out of respect for human autonomy in bioethics [11-14]. A retrospective trial is underway to assess the actual clinical benefit of this intervention.

This form can also be used for adult patients as well, potentially graphing multiple data points from their pediatric and adult measures, and once to see how their data is trending relative to this historic dataset. Such data can serve as a motivator for annual or bi-annual follow-up visits for adult patients to have that data over time to allow patients and families to consider earlier less invasive interventions which may be less prone to complications and may prevent later suffering. Overall, the graphic appears to help patients and family members of all ages to consider the life-long effect of scoliosis, and the need for life-long follow-up, and periodic reassessment of treatment choices.

Conclusion

A thorough review of the literature shows there is actually very little natural history information available for scoliosis that includes detailed Cobb measurements, and such studies are no longer possible due to the modern interventions like surgery that are now available. A careful review of the literature does not provide any basis a certain curve measurement below which curve progression will not occur, but curves under 30 degrees are much less likely to progress. The Weinstein Iowa study can be studied in detail to actually determine approximate curve progression rates within different cobb angle segments. The graphs can also be assembled into a colorized handout that has been found to be very helpful for patients and families of all ages. Further Shared Decision-Making (SDM) research is underway to understand this effect, and how this tool may be combined with other tools such as the Mayo AIS Scoliosis Tool [15]. This handout may provide a more direct link from evidence from nature and the literature directly to patients and family preferences and can be also combined with clinician experience to be able to practically perform Evidence-Based Practice (EBP) in the real world. This can allow the patient and family to better understand their risks, choices and consequences, and allow the final decision to rest with the patient and family, rather than the surgeon.

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