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Better follow-up of idiopathic scoliosis

OPINIONS

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Orthopaedists should ensure that patients with idiopathic scoliosis receive better and more tailored care.

Idiopathic scoliosis, defined as increasing sideways curvature of the spine of unknown aetiology, has a prevalence of 2–3 % and is typically diagnosed in childhood and adolescence (1, 2). In cases of moderate to severe deformity, the so-called Cobb angle is 25–45 degrees. The angle is measured from the two most tilted vertebrae in the curved area. A brace is used for patients who are not skeletally mature (1). For a more severe deformity, multilevel spinal fusion surgery with correction of curvature is recommended. The decision to operate is difficult as it results in lifelong loss of spinal mobility (1–3).

Sideways curvature in unoperated, skeletally mature patients puts excessive strain on the vertebrae. Over years and decades, vertebrae can degenerate, which also exacerbates the curvature through degenerative scoliosis (2, 4, 5). When compensatory mechanisms have been exhausted, the patients experience increasing pain in the back muscles and from lumbar spinal stenosis (2, 4, 5). Age-related osteoporosis and osteoporosis caused by low activity levels due to back pain can compromise screw fixation and hinder curvature correction and spinal fusion. Advantages of operating at an early stage are less degenerative scoliosis and functional impairment, as shorter fusion is needed, along with better screw fixation (2, 5, 6).

Poorer prognosis than previously thought

A study published in 2023 by Rigshospitalet in Copenhagen assesses outcomes in patients 40 years after diagnosis with idiopathic scoliosis (7–9). Three groups were observed, with an average age of 54 years. At the last contact with Rigshospitalet in adolescence, the average Cobb angle was 19 degrees in the observation group, 38 degrees in the group treated with a brace and 39 degrees in the group who underwent surgery. Forty years after diagnosis, the average Cobb angle had increased to 25, 55 and 47 degrees, respectively. Back pain was the main reason why 21 % of patients were unable to work full time, compared to 11 % in the corresponding general population. Just over half of those who were unable to work full-time had worn a brace. The scoliosis patients' quality of life was significantly lower than that of the corresponding general population.

A Canadian study published in 2019 compared surgery outcomes in adults and adolescents (5). The average age was 44 and 16 years, respectively. The adults experienced higher levels of pre-surgery pain and disability than the adolescents, but showed more improvement following surgery. However, they needed a significantly longer fusion due to degeneration of vertebrae.

There is now strong evidence that a Cobb angle of more than 30 degrees in unoperated, skeletally mature patients entails a high risk of gradual exacerbation of the deformity over years and decades, due to concurrent idiopathic and degenerative scoliosis (2, 4, 5, 7–9). Pain, disability and loss of quality of life may not occur until several decades later, when compensatory mechanisms have been exhausted (2, 4, 5, 7–9). In my opinion, this patient group should therefore receive regular follow-up to prevent worsening of the prognosis.

Violation of the Patients' Rights Act and Health Personnel Act

There is currently a lack of guidelines on follow-up and information for unoperated, skeletally mature patients. Simple X-ray imaging, for example every five years for unoperated patients with a Cobb angle exceeding 30 degrees, will reveal increasing idiopathic and degenerative scoliosis. Surgery at an earlier stage results in less pain and disability (2, 4, 5, 8, 9).

My impression is that orthopaedists have not informed health authorities and specialists in physical medicine and rehabilitation that the prognosis is worse than previously thought. The result is incorrect information in the guidelines for physical medicine and rehabilitation (10). Under the heading 'Structural neck and back problems', the guidelines state that the indication for surgery is primarily cosmetic, that bracing stops progression and that most patients have the same level of functioning and a comparable quality of life as those of the same age without scoliosis 20–30 years after surgery or bracing. Practically no

light is shed on the problems involved. Consequently, idiopathic scoliosis is not prioritised for specialised rehabilitation, such as group sessions with pool training to reduce back pain when exercising and to improve quality of life.

In my opinion, the orthopaedists are adversely impacting the prognosis for this patient group by violating the patients' right to information and the requirement for propriety, as well as by depriving them of the opportunity for shared decision-making and specialised rehabilitation.

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