




Beyond the curve: the mental health burden of Scheuermann's kyphosis

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Abstract

Purpose To examine the prevalence and association of mental health symptoms, social factors, and healthcare experiences in individuals diagnosed with Scheuermann's disease (SD).

Methods We analyzed self-reported data from the Scheuermann's Disease Fund (SDF) CoRDS registry from September 2021 to March 2025, which included 168 patients. Of these patients, 106 self-reported a Cobb angle. Participants completed a 196-item questionnaire covering demographics, curve severity, mental health domains of anxiety, depression, PTSD, and social isolation, healthcare experiences, and social factors. Statistical analyses, including descriptives and chi-square tests ($\alpha=0.05$), were conducted with IBM SPSS Statistics v30.

Results Patients diagnosed with SD in these specific cohort were between the ages of 11–20 (59.5%), 21–40 (28.0%), and > 41 (12.5%) years, with thoracic kyphosis Cobb angle <60° (15.1%), 61–80° (40.6%) or 81° and above (44.3%). Patients often reported pain (73.2%), with 37.3% reporting severe pain or worse. In total, 46.1% reported anxiety, 45.2% reported depression, 9.6% reported PTSD, and 63.0% reported social isolation. Depression was associated with chronic pain ($r=0.27$, $p<0.001$), and anxiety was correlated with social isolation ($r=0.26$, $p=0.001$). Over 72.0% of the patients felt misunderstood, and 65.1% lacked mental health referrals to receive appropriate counseling. Patients expressed that they did not believe their physician could understand or treat their condition, with 52.6% visiting at least two to four doctors before finding adequate care that met their unique needs.

Conclusions SD imposes substantial mental health burden, with many patients experiencing anxiety, depression, or feelings of social isolation. Many patients reported challenges in finding specialty care. These findings suggest the need for further research to determine whether earlier diagnosis and integrated care could improve outcomes.

Keywords Scheuermann's disease · Scheuermann's kyphosis · Kyphosis · Spinal deformity mental health · Adolescent

Introduction

Scheuermann's disease (SD) is a structural sagittal spinal deformity defined by anterior vertebral body wedging of > 5° in three or more contiguous vertebrae [1–3]. SD most

commonly affects the thoracic spine and is characterized by a rigid curvature that fails to correct with voluntary effort [2]. The prevalence of SD ranges from 0.4% to 8.0% among adolescents in the United States, with a male predominance [4]. European epidemiologic data suggest that roughly 8.0% of individuals over age 50 exhibit similar deformities, indicating that SD may persist into adulthood or be underdiagnosed earlier in life [5].

The clinical presentation of SD includes thoracic hyperkyphosis, compensatory lumbar hyperlordosis, progressive sagittal imbalance, and chronic axial back pain [3, 6, 7]. These physical manifestations often coincide with postural fatigue and aesthetic concerns. In some patients, the deformity may be progressive and accompanied by functional

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limitations that impair participation in physical activity. Bracing remains the standard of care for moderate curves, while physical therapy and Schroth therapy are frequently employed to address compensatory imbalances and improve muscular control [8]. Recent comparative data indicate that children with hyperkyphosis experience greater back-pain disability and worse PROMIS scores than peers with idiopathic scoliosis [9], highlighting the distinct clinical burden of kyphotic deformities.

While bracing is a noninvasive and potentially effective modality for SD, it often imposes a substantial psychosocial burden, particularly during adolescence [10–12]. However, recent evidence suggests bracing may not significantly impact body image in adolescent idiopathic scoliosis [13]. Evidence from populations with adolescent idiopathic scoliosis (AIS) and adult spinal deformity (ASD) has established a consistent link between visible spinal curvature and adverse psychological outcomes [14–16]. These include diminished self-esteem, body dissatisfaction, and social withdrawal, with many patients reporting feelings of embarrassment, shame, or reduced self-worth [17–20]. Physical appearance is the main reason why younger individuals with SD may seek treatment [21].

Despite these well-documented trends in related deformity populations, large-scale studies evaluating the psychosocial burden of SD remain notably under-examined in orthopedic literature. As a result, current treatment paradigms may fail to adequately address the full spectrum of the patient experience, representing a significant unmet need in both clinical care and research. The objective of this study was to characterize the psychological and social burden of SD. We hypothesize that SD patients experience substantial mental and social health-related challenges that exceed those seen in the average spine patient.

Methods

Study design

This was a retrospective analysis of prospectively collected, patient-reported data obtained through a not-for-profit academic registry administered by the Scheuermann's Disease Fund in partnership with the Coordination of Rare Diseases at Sanford (CoRDS; <https://research.sanfordhealth.org/rare-disease-registry>). The CoRDS is an online patient database open internationally to individuals who self-report a physician-diagnosed Scheuermann's disease. No patient recruitment was conducted by the research team. Between September 2021 and March 2025, individuals who self-identified as being diagnosed with SD were invited to complete a comprehensive survey about the impact of their diagnosis on their

health. Participation was voluntary, unsupervised by treating clinicians, and available internationally to any individual who reported a prior medical diagnosis of Scheuermann's disease. Responses were entered directly by patients via a secure web portal. Patient enrollment and data availability are summarized in Fig. 1.

The registry survey comprised of 196 items covering demographics (age at onset, current age, sex), clinical characteristics (Cobb angle category and kyphotic apex location), mental health domains (anxiety, depression, post-traumatic stress disorder [PTSD], social isolation; each coded yes/no and by self-rated severity), healthcare experiences (number of providers seen before adequate care, history of mental health referrals), and psychosocial factors (perceptions of being misunderstood by physicians, experiences of bullying, feelings of social outcasting). Because imaging and diagnostic confirmation were not independently verified, all data reflect self-reported values by the patient. Institutional review board oversight was waived for this de-identified dataset, and electronic informed consent had been obtained by the CoRDS registry at the time of participant enrollment. For participants under 18, parental consent was also required.

Statistical analysis

The complete dataset was obtained from CoRDS. Participant characteristics and mental health disease prevalence was described using frequencies and percentages. General-population prevalence values used for contextual comparison were derived from previously published large-scale epidemiologic studies of anxiety, depression, PTSD, and social isolation [23–25, 40–42]. Associations between each mental health condition and categorical predictors (age group at diagnosis, curve severity, number of providers seen, physician misunderstanding, referral history) were evaluated using chi-square analyses. Relationships among continuous measures (current age, Cobb angle, number of providers) and a composite psychosocial score (sum of “yes” responses for bullying, outcasting, misunderstanding) were assessed using Spearman rank-order correlations. All statistical tests were performed using IBM SPSS Statistics v30, with $p < 0.05$ indicating statistical significance.

Results

Patient characteristics

The final analytic cohort included 168 respondents with a self-reported, physician-diagnosed Scheuermann's disease, which represents one of the largest published patient-reported cohorts to date. Comparable quality-of-life studies have evaluated 100–120 patients each [9, 18, 44–46].

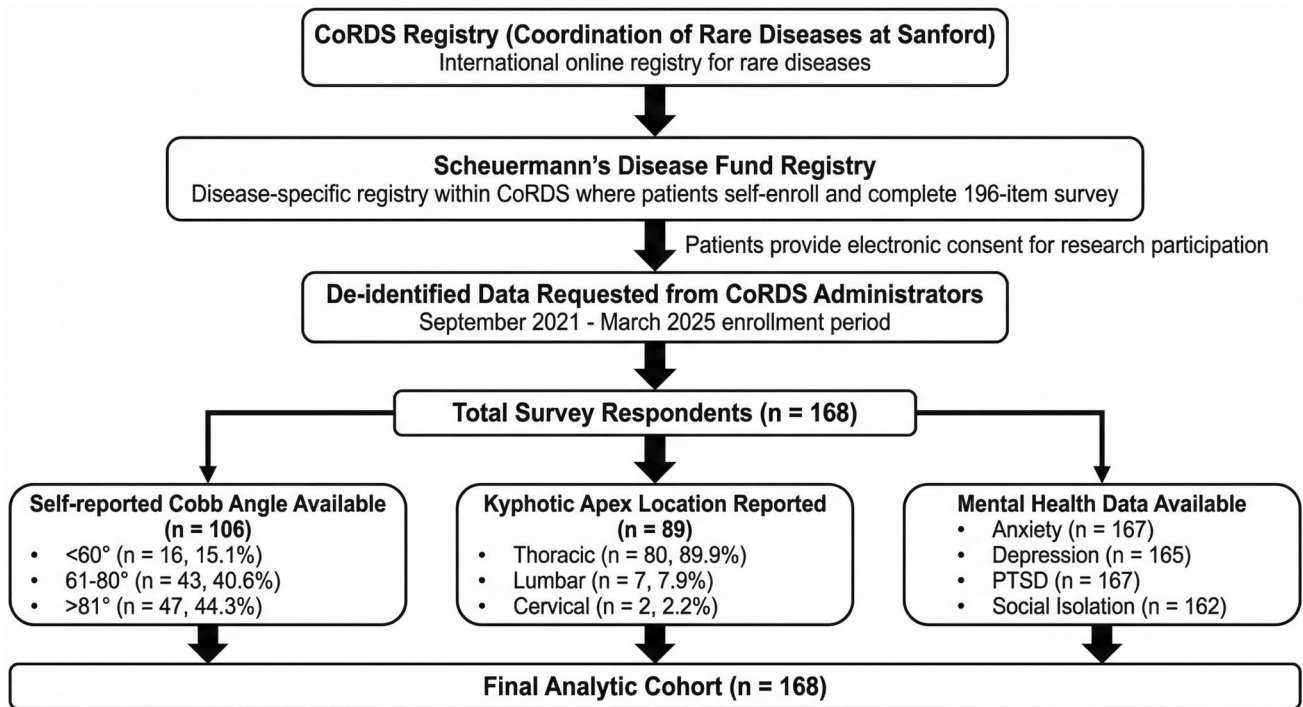


Fig. 1 Patient flow diagram showing enrollment from the Scheuermann's Disease Fund CoRDS Registry and data availability for the analytic cohort

Most participants were diagnosed during adolescence (ages 0–20 years; 59.5%) or early adulthood (ages 21–40 years; 28.0%). Among 106 participants who reported their Cobb angle (self-reported, without centralized radiograph review), 44.3% indicated severe deformities exceeding 81°, 40.6% reported moderate curves between 61°–80°, and 15.1% had curves less than 60°. Although a small subset of respondents were over 50 years old, these individuals self-reported a prior diagnosis of Scheuermann's disease earlier in life and were therefore retained to capture the full spectrum of disease chronicity. Of the 89 participants who reported their kyphotic apex location, the majority (89.9%) identified a thoracic apex, with lumbar (7.9%) and cervical (2.2%) regions reported less frequently (Table 1).

Prevalence of mental health conditions

In comparison to the general population, participants with a history of SD had higher rates of anxiety (46.1% vs 26.9%), depression (45.2% vs 28.0%), and PTSD (9.6% vs 3.9%) (Table 2). Participants with a history of SD also commonly reported social isolation (44.7% vs 27.9%) and bullying (49.1% vs 39.4%) due to their visible deformity. Additionally, 51.1% of respondents described feeling like outcasts, and 36.8% reported difficulty forming friendships.

Table 1 Demographics and radiographic characteristics at time of diagnosis

Age at diagnosis (n = 168)	
0–20 years	100 (59.5%)
21–40 years	47 (28.0%)
> 40 years	21 (12.5%)
Radiographic features	
Cobb Angles (n = 106)	
<math><60^\circ</math>	16 (15.1%)
61–80°	43 (40.6%)
> 81°	47 (44.3%)
Kyphotic apex location (n = 89)	
Cervical (C1–C7)	2 (2.2%)
Thoracic (T1–T12)	80 (89.9%)
Lumbar (L1–L5)	7 (7.9%)

Mental health and psychological wellness

Depression was associated with chronic pain lasting more than one year ($r = 0.27$, $p < 0.001$). Anxiety was associated with difficulty forming friendships ($r = 0.25$, $p = 0.001$) and social isolation ($r = 0.26$, $p = 0.001$). Anxiety and depression were also strongly correlated ($r = 0.64$, $p < 0.001$), suggesting a high degree of psychological comorbidity among SD patients.

Table 2 Prevalence of psychological and social symptoms in the Scheuermann's disease cohort compared to general population estimates

Variable	Scheuermann's cohort N(%)	General population N(%)
Anxiety	77 (46.1) ^a	107,269 (26.9)[40]
Depression	75 (45.2) ^b	111,490 (28.0)[40]
PTSD	16 (9.6) ^c	2,772 (3.9)[41]
Social Isolation (PROMs)	72 (44.7) ^d	7,109 (27.9)[42]
Bullied	80 (49.1) ^e	75,344 (39.4)[43]

^aCohort n = 167, ^bCohort n = 165, ^cCohort n = 167, ^dCohort n = 162, ^eCohort n = 163

General-population values are for contextual comparison only; no direct statistical testing was performed [40–43]

PTSD Post Traumatic Stress Disorder, PROMs Patient Reported Outcome Measures.

Healthcare experience

Participants reported challenges in their healthcare experiences. Of the 168 respondents, 72.0% felt that their physician did not understand or effectively treat SD. Additionally, 52.6% (n = 114) reported seeing between two and four providers before receiving a diagnosis or treatment plan that adequately addressed their condition. Despite the high burden of psychological symptoms, 65.1% (n = 166) reported that they had never been referred to a mental health professional for evaluation or counseling (See Appendix Table 3).

Discussion

Scheuermann's disease is associated with a significant and under-recognized burden of psychological and social morbidity. In this international cohort, patients diagnosed with SD reported high rates of anxiety, depression, PTSD, and social isolation. These conditions were further compounded by negative healthcare experiences, with over 70% of respondents feeling misunderstood by their physicians. Social stigma, bullying, and a persistent sense of social disconnection emerged as dominant themes, highlighting a pattern of psychosocial vulnerability that is not routinely addressed in standard SD care [22, 23]. Additionally, recent biomechanical analyses reveal measurable functional limitations in spinal motion among SD patients compared to controls, likely further contributing to the psychological burden [9]. These findings underscore the need for a biopsychosocial framework that integrates mental health and patient-centered support in the clinical management of SD.

Mental health symptoms were reported at strikingly elevated rates in this cohort. Nearly half of all participants endorsed symptoms of anxiety and depression, while a tenth

of them acknowledged PTSD. These rates significantly exceed population-based estimates [23–25] and mirror trends observed in adolescent idiopathic scoliosis, where spinal deformity has been strongly linked to poor self-image, emotional distress, and impaired psychosocial functioning [16, 26–28]. These findings suggest that SD patients may grapple with heightened self-consciousness about their visible deformity, which is intensified by pain. Together, these factors may explain the increased rates of depression and anxiety seen within this population. Despite this significant burden, only 35% of respondents reported having ever been referred to a mental health provider. The absence of referral in the majority of cases represents a critical gap in care and a missed opportunity for early psychological intervention. Prior studies suggest that surgical or rehabilitative intervention can improve self-esteem and quality of life in patients with spinal deformity [29], and consensus guidelines have outlined indications for spinal fusion in Scheuermann kyphosis [44]. Comparable long-term improvements in health-related quality of life following pediatric spinal deformity correction have also been documented [45].

Social adversity emerged as a central component of the SD experience, with a substantial proportion of participants reporting peer rejection, diminished self-worth, and isolation. Bullying and feeling like a social outcast due to visible deformity were reported by approximately half of the respondents. Difficulty forming friendships and chronic social isolation were also commonly endorsed by SD patients. These findings align with previous research on AIS, which has shown that visible curvature and bracing, commonly indicated for patients with moderate, flexible curves and ongoing growth potential, negatively impact body image, social engagement, and treatment compliance [33–36]. The elevated symptom burden among younger patients, particularly those diagnosed during adolescence, may reflect heightened vulnerability to appearance-based stigma during critical phases of identity formation [37–39]. While the present cohort may overrepresent more severely affected individuals, the consistency and severity of reported psychosocial hardship provide compelling evidence for the long-term, non-structural burden of SD. Given the high prevalence of anxiety and depression identified in this cohort, routine screening for mental-health symptoms should be incorporated into standard care, with referral to appropriate support services when indicated.

Participants reported challenges in their healthcare experiences, with many indicating that their physician did not understand or effectively treat their condition. Over half consulted up to four providers before receiving an accurate diagnosis or a meaningful treatment plan. These diagnostic delays not only contribute to prolonged physical and functional limitations but may also contribute to long-term psychological harm by reinforcing feelings of invalidation and neglect. A lack of familiarity with SD among general practitioners [30] and the absence of standardized diagnostic pathways [31, 32] likely contribute

to this fragmentation in care. The finding that 65.1% of respondents did not receive mental health referrals suggests psychosocial concerns may not be routinely addressed in clinical encounters. These perceptions must also be interpreted in light of the registry's self-selected, online nature, which may attract participants who have experienced more unsatisfactory care. Consequently, the views captured here may disproportionately reflect those with higher symptom burden or dissatisfaction with prior healthcare encounters.

The present study has several potential limitations inherent to its design. First, all data were patient-entered through an online registry without independent clinical or radiographic verification, thereby introducing recall bias or misclassification. Specifically, severity was assessed subjectively rather than using standardized radiographic measures, limiting the definitive conclusions that can be drawn from these data. Moreover, patients with greater symptom severity or dissatisfaction with care may have been more motivated to participate, potentially creating over-representation from individuals experiencing persistent symptoms or psychological distress. Self-selection into the registry may introduce response bias, as individuals with more severe symptoms or negative healthcare experiences may be more likely to participate. Because the registry relied on self-report rather than clinician recruitment, the true prevalence of each mental-health condition among all patients with Scheuermann's disease cannot be definitively determined from these data. Finally, information regarding prior surgery or disability status was not captured in the registry and therefore could not be analyzed.

Despite these limitations, this study provides novel and clinically relevant insight into the lived experience of individuals with SD. To our knowledge, it represents one of the largest investigations into the psychosocial burden of SD, offering a unique patient-centered perspective on an under-explored domain [22].

Conclusion

Scheuermann's disease imposes a multifaceted burden that extends beyond its structural manifestations. Patients reported high rates of anxiety, depression, PTSD, and social isolation. Many patients reported challenges in finding specialty care, and 65.1% did not receive mental health referrals. These findings suggest the need for further research to determine whether mental health screening, earlier diagnosis, and multidisciplinary care pathways could improve outcomes for this population. Recognizing SD as a biomechanical and psychosocial condition will allow clinicians to more effectively address the full scope of patient needs and deliver care that benefits the patients.

Appendix

Table 3 Select questions from the Scheuermann's disease fund CoRDs survey

General/descriptives

- Q1: At what age was the participant diagnosed?
- Q2: What is the degree of the patient's Cobb Angle for accentuated curvature, if known?
- Q3: What is the apex of the accentuated curvature, if known?
- Q4: Would the participant consider the pain to be severe chronic pain?

Mental health conditions

- Q5: Has the participant ever been diagnosed with or experienced anxiety as a result of Scheuermann's?
- Q6: Has the participant ever been diagnosed with or experienced depression as a result of Scheuermann's?
- Q7: Has the participant ever been diagnosed with or experienced PTSD as a result of Scheuermann's?

Psychosocial conditions

- Q8: Has the participant felt socially isolated due to their physical looks from Scheuermann's?
- Q9: Has the participant been bullied as a result of a spinal deformity?
- Q10: Has the participant found it difficult to make friends as a result of the participant's Scheuermann's?
- Q11: Has the participant ever felt like an outcast as a result of the participant's physical looks from Scheuermann's?

Healthcare experiences

- Q12: Does the participant feel that most spine specialists do not understand how to treat Scheuermann's and its patients?
- Q13: How many specialists has the participant seen before the participant found one who "understands how to treat Scheuermann's and the people who suffer from the disease?"
- Q14: Has the participant ever sought or been referred to counseling as a result of Scheuermann's?

To facilitate standardized responses, each question was presented with predefined multiple-choice options from which participants selected the most applicable answer.

Author contributions MJF, AHM, and DK contributed to the methodology, formal analysis, manuscript writing, critical feedback, and revision. MS and CBH were involved in manuscript writing, critical feedback, and revision. JEN contributed to manuscript writing, critical feedback, and methodology. DS was responsible for data collection, critical review, approval of the final version of the manuscript, and supervision. EOK, BGD, and AHD provided critical review, approved the final version of the manuscript, and supervised the project. The Scheuermann's Disease Fund Study Group contributed to data collection and critical review. All authors have reviewed and approved the final version of the manuscript and agree to be accountable for all aspects of the work.

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Data availability Data analyzed in this study are hosted within the Coordination of Rare Diseases at Sanford (CoRDS), an international-rare disease registry at Sanford Research. The Scheuermann Disease Fund collaborated with Sanford CoRDS to curate and host the dataset. Data are available to qualified investigators upon reasonable request and approval in accordance with CoRDS data governance policies.

Declarations

Conflict of interest MJF, AHM, DK, MS, JEN, and CBH have nothing to declare. DS reports the following: founder of The Scheuermann's Disease Fund. EOK reports the following: receives consulting fees from Seaspine and Spineart and grant from Scoliosis Research Society. BGD reports the following: receives consulting fees from Medtronic and Spineart; CEO and shareholder at Spinal Alignment Solutions. AHD discloses the following, receives royalties from Spineart and Stryker, consulting fees from Medtronic, research support from Alphatec, Medtronic, and Orthofix, and Fellowship support from Medtronic.

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