

Lived Experiences of Vertebral Body Tethering: A Qualitative Study of the Patient Journey

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Purpose: Adolescent idiopathic scoliosis (AIS) is the most common spinal deformity in children. While posterior spinal fusion is the standard treatment for curves $\geq 45^\circ$, anterior vertebral body tethering (VBT) has emerged as an alternative for some patients. This study explores the experiences of patients who underwent VBT, focusing on decision-making, recovery, and long-term concerns.

Patients and Methods: Semi-structured interviews were conducted with twenty patients diagnosed with progressive AIS and a spinal deformity less than 60° at the time of surgery. All participants underwent VBT, completed three years of follow-up, and had reached skeletal maturity. Recruited from a single orthopaedic institute and treated by the same physician, participants averaged 18 years of age, 85% were women. Interview transcripts were analyzed using collaborative content analysis.

Results: Key decision-making factors included pain, worsening condition, brace use, and concerns about appearance. VBT was preferred over fusion due to perceived benefits such as preserved flexibility, less invasiveness, shorter recovery, and lower risk of infection. Decisions were also influenced by family, physicians, and experiences of others. Recovery experiences were mixed. Some participants described difficult early recovery but felt positive overall; others recalled prolonged pain and physical limitations. Most reported reduced anxiety post-surgery, though concerns about long-term effects and future surgeries remained.

Conclusion: This study offers insight into the lived experience of individuals who underwent VBT and underscores the importance of patient-centered care in surgical decision-making and recovery. Findings highlight opportunities to support patients considering VBT versus fusion and the need for comparative effectiveness studies focused on long-term outcomes and quality of life.

Keywords: adolescent idiopathic scoliosis, vertebral body tethering, qualitative research, lived experience

Introduction

Adolescent idiopathic scoliosis (AIS) is the most common spinal deformity affecting the pediatric population, typically manifesting during the growth spurt around puberty. For patients with curves greater than 45 degrees, surgical intervention is recommended.¹ Spinal fusion, the traditional surgical treatment, involves connecting adjacent vertebrae to form a single rigid structure that is no longer curved using rods, screws, hooks, and/or wires. While safe and effective, spinal fusion can lead to substantial loss of spinal mobility, persistent pain, and adjacent level disc disease.²⁻⁴

Anterior vertebral body tethering (VBT) is an alternative to spinal fusion for some patients. VBT utilizes the Hueter-Volkman principle, leveraging the patients' spinal growth to correct the deformity.⁵ The procedure involves attaching screws to the outside of the curve and connecting a flexible cord, called a tether, that is tensioned to guide correction. Approved by the US Food and Drug Administration (FDA) in 2019, VBT has shown to be a safe and effective treatment for skeletally immature patients with growth remaining.⁶⁻¹⁰ Although spinal fusion provides better correction with fewer complications and reoperations, VBT offers benefits that are often not available with a fusion, such as a faster recovery, preserved spinal mobility, smaller incisions, and return to sports.¹¹⁻¹⁴

However, VBT is not suitable for all patients with AIS, and the decision to pursue this treatment should be individualized, considering factors such as curvature severity and flexibility, location, skeletal maturity, and patient preferences and goals.^{5,15} Current VBT research predominantly features quantitative studies, focusing on biomedical and

expert perspectives. The personal perspective, exploring the lived experiences of patients who underwent VBT, is notably absent. Understanding these experiences is crucial for effective shared decision-making, a key component of patient-centered care, which involves clinicians and patients collaboratively making treatment decisions based on evidence and patient preferences and values.¹⁶

Existing studies explore the psychosocial experiences of patients with AIS before surgery, as well as the experiences of those undergoing fusion surgery.^{17–19} A previous study using data from the same VBT participants as the present study explored patients’ perceptions of success and satisfaction after VBT and fusion.²⁰ However, these studies do not reflect the VBT experience or provide comprehensive analysis of the patient journey. Therefore, this study aims to provide detailed descriptions of patients’ lived experiences across different phases of the VBT journey. Specifically, it seeks to deepen our understanding of how patients deliberated and decided to have VBT surgery, their recovery experiences, and their post-surgery worries and concerns. By elucidating these experiences, this study offers valuable insights for improvements in patient care, support services, and decision-making processes surrounding VBT surgery.

Methods

Study Design and Setting

This qualitative study was informed by concepts from phenomenology to facilitate a thorough explanation of patients’ lived experiences and perspectives.²¹ It was conducted at the University of Missouri Health Care’s orthopaedic clinic, a prominent tertiary hospital in the Midwest United States. The study complies with the Declaration of Helsinki and was approved by the University of Missouri Institutional Review Board (#2064983). The study consisted of semi-structured interviews with patients who had undergone VBT surgery performed by the same orthopaedic surgeon.

Recruitment of Participants

Patients were identified through retrospective screening of an established registry and selected for recruitment if they met the following criteria: (1) diagnosed with progressive AIS with a deformity less than 60° at the time of surgery, (2) underwent VBT with three or more years of postoperative follow-up, and (3) reached full skeletal maturity, defined by a Sanders Score of 7 or 8 or a Risser Stage of 4 or 5. Patients were excluded from recruitment if they had (1) insufficient hearing to communicate with an interviewer or (2) inability to complete the session within the allowable time. Forty-seven patients met inclusion criteria and were approached via phone or e-mail and invited to participate in the study. The recruitment process was continuous until a total of 20 patients consented to participate. Of the 47 patients, 20 did not respond, 4 agreed but did not schedule an interview, 2 lacked contact information, and 1 declined. The sample size was informed by review of four relevant studies that incorporated individual, semi-structured interviews with sample sizes ranging from 6 to 40 participants.^{18,19,22,23} Our decision to include 20 patients in this study was guided by the goal of achieving saturation, which is a crucial criterion for determining the adequacy and completeness of the data collected that signifies the point at which no new themes, insights, or patterns emerge from additional data collection and analysis.²⁴ Saturation was reached during analysis of transcript 12 and was further confirmed through analysis of an additional 8 transcripts with no new coding categories identified. Informed consent was collected from participants aged 18 and older or their guardians if younger than 18 years old. See Table 1 for participant characteristics. The participants in this study were among the earliest to undergo this procedure, with surgery dates ranging from April 2014 to November 2018. As

Table 1 Participant Characteristics

Participant	Age at Surgery	Age at Interview	Gender	Pre-Surgery Lenke Type	Pre-Surgery Curve Angles			Levels Instrumented
					Proximal Thoracic	Main Thoracic	Thoraco-Lumbar	
P1	13	19	F	1A	32°	46°	28°	T6-L1
P2	14	17	F	1A	21°	45°	25°	T6-L1

(Continued)

Table 1 (Continued).

Participant	Age at Surgery	Age at Interview	Gender	Pre-Surgery Lenke Type	Pre-Surgery Curve Angles			Levels Instrumented
					Proximal Thoracic	Main Thoracic	Thoraco-Lumbar	
P3	16	21	M	5C	10°	35°	49°	T11-L3
P4	16	22	M	1A	25°	49°	39°	T6-T12
P5	11	19	F	2A	45°	40°	21°	T6-L1
P6	15	18	F	1A	27°	48°	21°	T6-L1
P7	12	18	F	1B	31°	46°	32°	T6-T12
P8	11	16	F	1C	19°	43°	38°	T5-T11; T11-L3
P9	13	17	F	1AR	35°	50°	20°	T6-L3
P10	14	19	F	1A	33°	61°	28°	T6-L1
P11	16	19	F	5C	10°	33°	45°	T11-L4
P12	14	19	F	1A	16°	56°	38°	T5-L1
P13	12	18	F	1A	29°	40°	26°	T6-T12
P14	14	17	M	1B	31°	50°	38°	T7-L1
P15	15	18	F	1AR	26°	56°	32°	T6-L3
P16	13	16	F	1A	36°	55°	28°	T5-L1
P17	13	19	F	5C	3°	26°	45°	T10-L3
P18	15	18	F	5C	14°	30°	40°	T11-L3
P19	12	16	F	6C	14°	43°	60°	T5-T11; T11-L3
P20	13	18	F	1C	28°	46°	39°	T5-T11; T11-L3

noted, VBT was approved by the FDA in 2019; therefore, these patients received the surgery while it was still considered experimental, using an off-label device that differs from current surgical techniques. While indications for VBT have since evolved, the insights from these early patients provide invaluable perspectives on their surgical journeys.

Data Collection

Individual, semi-structured interviews were conducted using an interview guide developed collaboratively by a pediatric spine surgeon, a pediatric spine researcher, and two qualitative researchers (see [Appendix 1](#)). It included fixed as well as follow-up and probing questions for clarification and expansion. To refine the interview guide, a pilot interview was conducted with one individual who had undergone VBT but was not included in the main study. The pilot participant provided valuable feedback on the clarity of instructions, interview questions, and flow of the interview. Based on the feedback, improvements were made to the wording and order of the questions. All interviews were conducted by the same researcher (LAR), a female with PhD-level training and extensive experience in qualitative research who had no prior professional or personal connections with the participants. Ten Zoom and ten phone interviews were conducted, lasting 52 minutes on average. Interviews were audio-recorded, transcribed verbatim using a professional transcription service (Rev.com) and cross-checked against the audio recordings. To ensure trustworthiness and credibility, transcripts were shared with participants for their input, allowing them to add any additional reflections before analysis.

Data Analysis

Data analysis of all transcripts was conducted using QDA Miner 5 coding software (Version 5.0.34) by two experienced qualitative researchers. Each researcher independently identified unique content ideas within participants' statements and assigned categories and codes. Individual coded files were merged to address discrepancies through consensus.²⁵ After coding, the research team identified relationships among categories and codes, comparing findings across transcripts. This comparative analysis yielded the final themes and study results.

Member Checks

To enhance dependability and confirmability of the final themes, member checks with two interviewees were conducted. Each interviewee was tasked to review distinct study results by reading sections of the results, answering questions to verify themes encompassed varied responses, and checking if their views were reflected. They gave feedback on the clarity of themes and related quotes, and both interviewees confirmed that their perceptions were aptly represented in the results.

Results

Deliberations and Decision-Making

There were many factors that influenced patients' and their families' decisions to have surgery and to decide on the VBT procedure. Themes are organized into physical factors that influenced their decision to have surgery, physical factors that influenced their decision to have VBT vs fusion, interpersonal influences, and VBT newness factors (Figure 1).

Physical Factors That Influenced Decision to Have Surgery

Patients described several physical characteristics that influenced their decision to undergo surgery. Among them were experiencing pain and discomfort, a deteriorating condition in which the curve in their spine was progressively getting worse, and the need to wear a back brace.

Most patients described experiencing severe pain and discomfort in their backs, which was a deciding factor in their decision to undergo surgery. Several described having to sit out of activities because the pain was unbearable. While most described pain in their backs, two participants mentioned experiencing shoulder pains, and one described pain in their ribs and side.

I was in severe pain constantly. It was all the time. My back would just feel so uncomfortable and I could never get comfy and the more I would do stuff like be in PE or cheerleading, my back would hurt, my ribs would hurt. (Participant 12)

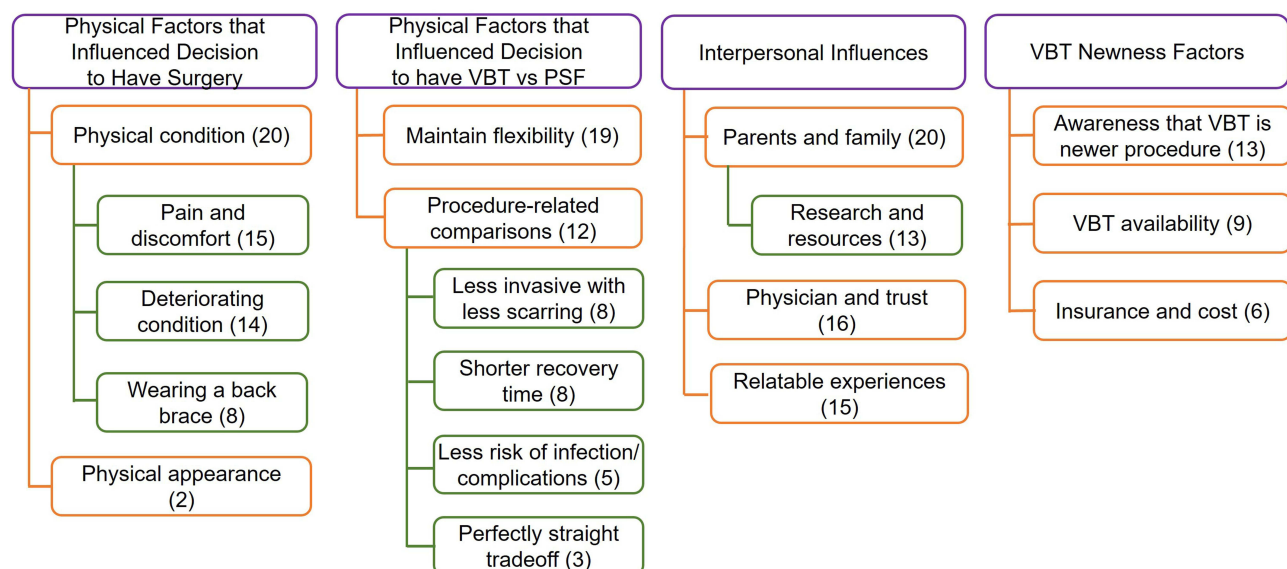


Figure 1 Factors influencing deliberation and decision-making (numbers represent the number of participants who discussed each factor).

For many patients, the main reason for deciding to undergo surgery was because the curve in their spine was progressively getting worse. Many described their curve progressively worsening despite wearing a back brace or trying other treatment methods like going to a chiropractor and the Schroth method. Some noticed their deteriorating condition and described it as a change in their posture, a change in the appearance of their back, and inability to catch their breath because their ribs were compromising their lung.

I was just wearing braces and they weren't doing anything for me. It wasn't working because I think I was getting worse anyway. (Participant 3)

Another factor that influenced patients to have surgery was having to wear a back brace. Patients described being sick of wearing their back brace because it was uncomfortable and hard to sleep in. The brace prevented them from participating in activities with their friends and made them feel self-conscious because they looked different with the brace on. Some patients described reluctance to comply with the brace treatment because the brace was uncomfortable and they wanted to move around like a normal kid.

I was in a back brace 23 hours a day...I definitely wanted the surgery just because I was very unhappy in my back brace and not being able to do all the things that my friends were doing...my back brace was really hard on me. (Participant 2)

They gave me a brace. I chose not to wear it because it felt uncomfortable. It was hard to sleep in, I couldn't do it. That brace made me itch everywhere. (Participant 18)

For some patients, their physical appearance was a deciding factor to have surgery. Patients described not wanting to look crooked or hunched over.

This isn't really a symptom, but I was very self-conscious of my back because I had a hump, and I would wear really loose shirts because I was so scared that people would notice, and that really kind of decreased my self-esteem. It made me really self-conscious. (Participant 9)

Physical Factors That Influenced Decision to Have VBT vs Fusion

When deciding between VBT and fusion, patients wanted to maintain their flexibility as much as possible. Many described participating in sports and activities that required bending and flexing like swimming, dancing, basketball, cheerleading, gymnastics, and track. They believed that the VBT procedure would allow them to continue to participate in the activities they enjoyed while the fusion would not. Many also described wanting to have the ability to be flexible later in life and retain as close to normal functioning and mobility as possible.

Our biggest thing was my cheer and my tumbling. I still wanted to be able to do that. And my mom still wanted me to be able to do that because she knew how important it was to me, so if I have VBT surgery, I will still continue to be able to do what I love to do. We also didn't want me to be confined and being stiff my whole life. (Participant 9)

I was super involved on the swim team at the time, so I was constantly moving around and doing flips and turning my back and all of that stuff. The main part of it was the fact that I was swimming, and I wanted to swim for a while. I wasn't going to be able to if I had a giant rod in my back. (Participant 20)

In addition to maintaining flexibility, participants' main criteria for choosing VBT over a fusion involved perceived differences between the two procedures. Compared with the fusion procedure, patients felt the VBT procedure was less invasive with less scarring, had a shorter recovery time, and had less risk of infection.

Some patients perceived the VBT procedure as less invasive than the fusion procedure. One described the fusion surgery as violent and wanted to avoid cutting their back muscles. To some, it was important to have a less visible scar on their side after the VBT surgery rather than a scar down the spine after the fusion surgery.

It's not as invasive either. That was another thing, because I looked into how they actually do a fusion and they made it sound really violent. I mean, this is a Google search, but they cut the back muscles open, it's just straight on, you're entering into the

spine versus the VBT which goes through the side...I achieved the desired outcome and even though it's not perfect, it's still better than a fusion. (Participant 11)

Many patients chose the VBT procedure because it involved a shorter and easier recovery time than the fusion procedure that enabled a quicker return to school and activities.

We really didn't want to go with spinal fusion because it was going to be a much longer recovery. It's much more invasive...I think I was out of school for almost two months which I think I would have been out for three or more if I had a fusion and my restrictions would have been worse. (Participant 2)

Some patients felt the VBT procedure had less risk of infection and future complications than the fusion procedure. A couple of participants factored in the ability to have a future surgery into their decision-making. They described being able to get a fusion in the future if the VBT procedure failed but that option not being available with a fusion.

Any risk in surgery, an infection or problems with the spine, we had seen that it was a low percent chance of complications. (Participant 3)

If I needed to do fusion in the future, I could, but I couldn't go back. It was like, okay, if it gets worse, I have the option to get fused if it got horrible. (Participant 19)

When comparing the fusion procedure with VBT, participants knew that a fusion surgery would result in a straighter spine but were willing to make the tradeoff for the perceived advantages of VBT.

The difference between VBT and fusion, where the outcome is maybe not a perfectly straight spine but where I was able to maintain my flexibility still. (Participant 3)

Interpersonal Influences

Patients' decision to undergo surgery and choose VBT over fusion was influenced by their parents and family, their physician, as well as relatable experiences of people they knew. At the time of surgery, if patients were under the age of 18, the decision to have surgery and which type of surgery was legally up to the patient's parents or guardians. However, all but one patient indicated that their guardians involved them in the decision, and many described the ultimate decision being left up to them. Many explained that their parents or guardians did a lot of research about the two surgical options and explained to them details about the procedures. Several indicated that their parent had a strong preference that they have the VBT procedure.

Both of my parents made a pretty substantial effort to make sure that my opinion was definitely included because it is ultimately my body and I'd have to live with that decision for the rest of my life. (Participant 1)

While deciding on the best surgical option, some patients and their families conducted research to better understand the details of the surgery and its risks and benefits. It was mainly the parents who did the research but in some instances, it was the patients themselves. Among the resources were various online sources, Facebook groups, and blogs.

She [mom] would look on the internet and then she found Facebook groups of people that had kids or had gone through with the VBT and learned about it on a VBT Facebook group. (Participant 15)

Physicians were another major influence on patient and family decision-making to have surgery and their deliberation between VBT and fusion procedures. In many instances, a physician insisted that it was time to have surgery resulting from the worsening curvature of the patient's spine. For six patients, the physician they were initially seeing did not recommend the VBT procedure and rather insisted they receive the fusion surgery. In these cases, the patient and their family conducted their own research to find a doctor who was open to the VBT procedure. Patients indicated that the physician who performed both surgeries explained the benefits and risks of each procedure which helped with their decision-making. Several patients explained that one reason they decided to have the VBT procedure was because they trusted their doctor and the health care team.

Honestly, the main thing is we just trust doctors because we know that they're smarter than we are. We trusted that they knew what they were doing and that I needed it. (Participant 13)

More than half of participants knew a family member or a friend who had the fusion surgery and this influenced their decision to have VBT. They observed a "brutal recovery" and heard about complications from the fusion procedure like infections, things breaking, inability to return to activities, and limited flexibility. Some participants knew a family member or friend who had the VBT procedure and described their outcome as successful. This increased confidence in their decision to have VBT. Two participants explained that their parent had scoliosis and never had surgery to fix it. They watched them complain and struggle with their back and this influenced their decision to go ahead with the surgery.

I actually have a friend that went through the fusion, and I got to see that recovery experience, and it was pretty brutal. (Participant 1)

I had a younger sister and she also has scoliosis, and she had VBT performed...and it was successful for her at the time. (Participant 4)

VBT Newness Factors

More than half of the patients described being aware that VBT was not an FDA approved procedure at the time of their decision. However, these patients had trust in their doctor and health care providers, were explained the details and previous outcomes and results of the procedure and willing to take a risk.

It was scary only because it had only been done so many times in the United States. But, also just being a part of that small percentage of people who have had it was also very intriguing. (Participant 8)

Some patients did not have the option of VBT surgery where they resided. They described having to spend time searching for doctors who performed the procedure and then deciding among several states where to have their surgery. Several chose the University of Missouri Health Care because it was closest to them. Hospital proximity allowed them and their families to drive home post-surgery and avoid air travel.

I remember we went to my main doctor here and he pushed the fusion on me, not VBT. He was against it because at the time it wasn't FDA approved or whatever. And then that's whenever we went to go get a second opinion from another doctor in our state. And he said that VBT was new and it was risky, but it was a good option. That's when we flew out to Missouri to meet with Dr. H. (Participant 6)

Patients described insurance coverage and the cost of the procedure playing a role in their decision to undergo VBT. Several explained it took a long time to get their insurance company to approve the procedure because it was not FDA approved. This involved appeals that delayed their surgery. One patient described difficulty finding a doctor who took their insurance, and this limited their surgeon options. Another patient indicated that their insurance would not cover it but they still did it.

We had to fight with insurance for a good nine months to get coverage for it because it wasn't an FDA approved at the time. (Participant 11)

Recovery

Recovery Experience at the Hospital

Overall, many reported not remembering much about their hospital stay. Seven patients reported a positive hospital stay and described it as a good, wonderful, and pleasant experience despite feeling some pain. Eight patients described negative aspects of their hospital stay and remembered it being rough, painful and uncomfortable, passing out or throwing up when getting up, and feeling scared about the chest tube and enema. Three patients reported having an extended hospital stay of more than a week resulting from complications such as reactions to medication or chest tube issues. Six patients reported having bad reactions to medications. Overall, during their hospital stay, most patients

recalled being able to walk within one to four days after surgery. They also slept a lot, did therapy (eg, music, pet, physical), played Wii, and watched TV. Four patients reported experiencing issues with decreased appetite as a reaction to the medicine. Two patients reported wanting to leave and go home as soon as possible. Visitors and social interactions with friends and family was a pleasant experience.

But I think my biggest issues was the first couple of days. My stay was extended because I was very weak and every time I got up I would almost pass out, throw up, or something. I would just completely turn pale. I couldn't get up. So that kept happening for several days and they couldn't figure out why. They took me off medicine, morphine, just thinking it may be a bad reaction to that. And then they did a couple of blood transfusions but it ended up just being that I needed to take the pain patch off my arm...I couldn't really eat so I think that just made me super tired and kind of dreary and very low energy. I don't remember being super happy while I was there. (Participant 2)

My hospital stay, I don't remember a lot of, I don't really remember any pain the entire time I was in the hospital. And like I said, I was only there for three days, but the hospital stay was pretty nice. I was up and walking a day and a half after surgery. (Participant 7)

Recovery Experience at Home

Patients described missing their friends and social activities due to surgery and the lengthy recovery process. Six patients reported that they wanted to speed up recovery and get back to the life they had before surgery. Activities at home during recovery included watching movies and TV, playing video and board games, reading books, and coloring. In addition, social interactions with family and friends who visited were described as positive and supportive.

I know I was like sad some parts because I would just get mad that I wasn't healing as quickly as I wanted to. But then, I would just try to not be so sad and try to just distract myself and try to make it seem like everything's normal and fine, even if it wasn't... I will say, my family, they were so great. They made it a whole lot better than it could have been because they would still try to include me as much as they could, even though I was basically just stuck on the couch all day, every day. But they would still try to do things that I could do like playing board games. And they would always make sure that I was comfortable or as comfortable as I could be. I think that the biggest thing that helped me was my family. (Participant 13)

Emotions During Recovery

When asked how patients felt emotionally during recovery, many described experiencing a variety of positive and negative emotions at the hospital and at home. Negative emotions included feeling antsy; scared that the procedure would not work or there would be complications; aggravated; bored; frustrated and mad with their healing progress and physical limitations during recovery; lonely and sad from lack of social interactions; tired; upset; miserable; and bummed. One patient described developing social anxiety and depression after the surgery.

Mentally, there were times when I was a little frustrated with my progress in the fact that I was getting restless with the limitations imposed on me...I think like six months was the timeframe before you were fully released. I remember in four months, I felt like I was ready to rock and roll, and I was still being limited by these restrictions. I couldn't dive off the blocks. I couldn't do things that were necessary to be competitive in the pool, so I felt frustrated in that I was being limited. (Participant 4)

Among the positive emotions, patients described experiencing good mood, felt happy and relieved and sometimes even excited at the hospital and at home. Patients felt personal achievement as they progressed through recovery and were able to walk up and down the room. Others described positive emotions related to taking a break from school, being motivated to recover to be able to continue with their favorite sports, and keeping up with school so they did not get behind.

After I came down off some medication that I was on, because I was on some pretty strong pain pills because it was such a big surgery, but after I came down off it I was in a really good mood because I had known everything just got fixed and I was going to be good to go. And the doctor said the surgery went well. (Participant 10)

Need for Assistance

Post-surgery at the hospital and at home, most patients described needing a lot of help and assistance from their nurses and family. Several described needing help to sit up, roll over, walk, shower, and put on their back brace.

I needed to rely on other people to help me through things because I didn't have the strength to do it. (Participant 7)

For the first week I had my mom help me take showers because I couldn't take them on my own. (Participant 15)

Pain and Discomfort During Recovery and Physical Accommodations to Cope

Patients described experiencing pain and discomfort during recovery and sought out physical accommodations to cope. Post-surgery the discomfort and pain were mostly associated with sleeping, finding a comfortable position, lying down, sitting up, or turning. Some patients experienced pain with the chest tube in the hospital, when putting on a brace, or when walking. They described taking painkillers regularly to keep the pain manageable but some patients did not like taking them because they made them feel tired.

I was frustrated, and I was in pain, so I wasn't super happy the entire time. (Participant 1)

And honestly being at the house, it really wasn't bad. I really had very minimal pain after surgery. So, the healing process at my house wasn't bad at all. (Participant 10)

Patients described making physical accommodations and adjustments mostly to help them sleep. It was difficult for patients to sleep in certain positions, so they made modifications and arrangements like sleeping in a recliner, using a foam block, propping their back with pillows, and adjusting their usual sleep positioning. Other physical accommodations and adjustments included wearing a brace, sitting out of physical education class during recovery, and learning new ways to bend over, lie down, and sit up.

The only annoying part was the fact that I couldn't bend or twist or sleep on my stomach or my back or on my side. (Participant 17)

Complications and Reactions to Medications

Some patients experienced complications after the surgery. The most common complication was a bad reaction to pain medications. For example, a pain patch caused a severe negative reaction in which the patient could not get up without turning pale and throwing up. In addition, patients reported having gastrointestinal issues and feeling out of it, confused, disoriented, and nauseous when taking strong drugs. This made some of them feel very tired and unwilling to move while this made others move more than necessary because they could not feel any pain. Other instances of complications at the hospital included a nicked artery during the surgery, getting a C diff infection, and lung issues. Post-surgery, at home complications included developing crepitus, collapsed lung, infected stitches, developing anxiety and depression, and breaking a tether.

Well, actually the morphine didn't work on me. I think it made my pain worse, so they just did, I think they did fentanyl for a little bit and then some other narcotic every two hours. (Participant 11)

After surgery, my tether had broken in four places and they think that it was just from the accident itself and then cheerleading after it and just pretty much just doing what I wanted to do. And they think the main cause was probably the ATV accident since it was only six months after surgery. (Participant 15)

Worries and Concerns

Most patients reported feeling less worried after their surgery, expressing relief from the constant concern about what might happen next, whether their back would worsen, or whether they would continue to experience pain. As one participant shared, "I'm very satisfied mostly, because I don't really have to worry about back pain as much as I used to"

(Participant 17). However, some patients noted an increase in their worries, particularly regarding scoliosis, which they had been less aware of before surgery due to their young age. One patient reflected,

I guess when taking into account how naïve or not understanding the wider, future scope, probably more worried now than I was back then, I should have been more worried than I am now. (Participant 3)

Specific concerns that emerged included the fear of breaking a tether, with one participant stating,

There's still just like that little seed of doubt...I don't want to snap a tether or anything. (Participant 1)

Additionally, some patients expressed worry about needing another surgical procedure, fearing that their condition might worsen and lead to fusion surgery:

I think a lot of times I worry about it reverting even worse and having to have another surgery. I don't know if that would mean having to have a fusion surgery. (Participant 16)

More than half of patients also voiced concerns about the long-term effects of scoliosis, such as potential pregnancy complications or the possibility of their condition deteriorating with age, with one patient saying,

I just want to know what it's going to look like when I'm 10 years out and 15 years out, that kind of thing. (Participant 8)

Discussion

The aim of this study was to describe patients' lived experiences across different phases of the VBT journey, with a focus on decision-making, recovery, and post-surgery worries and concerns. The insights gained from this study offer valuable contributions to patient care, support services, and decision-making processes surrounding VBT surgery.

Decision-Making Process

While there is some documented evidence regarding the surgical decision-making process, particularly concerning the timing and type of scoliosis surgery,²⁶ this study uniquely contributes to the literature by focusing on how and why adolescents and their caregivers decide to pursue VBT surgery, an area previously underexplored. We found that in addition to physical pain, discomfort, and dissatisfaction with physical appearance, factors such as VBT availability and insurance coverage significantly influenced the decision to opt for this procedure. These findings suggest that delays in access to VBT could lead to significant curve progression, potentially resulting in loss of eligibility for the surgery and necessitating more invasive interventions.²⁷

A primary finding from our study was that patients experienced chronic pain and this was a driving factor to have surgery. This aligns with findings from Chan et al,²⁸ in which patients and families highlighted pain as a significant preoperative concern, although surgeons place less emphasis on it. While some studies have evaluated pain outcomes for VBT and fusion individually,^{14,29,30} no prospective studies, to our knowledge, directly compare pain outcomes between the two procedures.

Our findings also indicate that parents and family members play a major role in helping patients decide on VBT, particularly because patients were minors at the time of surgery. This underscores the importance of involving patients in treatment planning, as adolescent patients often seek independence and agency in decisions affecting their bodies.³¹ Given the role of parents in the care of their children affected by AIS, exploration of parental experiences throughout the whole process is another worthy direction for future research.

Interestingly, while many patients and their families conducted extensive research online, including social media groups and blogs, they should be cautious of the varying quality of information available.³² With an increasing amount of peer-reviewed evidence now available, these sources should be prioritized for factual information. Blogs and social media groups provide valuable personal perspectives but often lack accurate data on critical factors such as tether breakage and revision rates. Online resources and peer support groups play a crucial role in decision-making, offering both information and emotional support, which are pivotal during this process.³³ The influence of others' experiences, whether positive or negative, also strongly shaped patient decisions, underscoring the importance of relatable narratives in patient education.^{34–37}

Recovery

Recovery experiences varied among patients, with the majority requiring significant physical assistance both in the hospital and at home. This finding suggests that caregivers need to be well-prepared to provide support, as the demands of caregiving can be substantial and may impact the caregivers' own physical and mental health. Thus, educating and preparing caregivers before surgery is crucial for the well-being of both patients and their caregivers.^{38,39}

Positive interactions with healthcare providers were frequently mentioned, highlighting the importance of compassionate and attentive care during recovery. Social support, whether from family, friends, or online communities, played a significant role in patients' emotional well-being during recovery.

Future Worries and Concerns

The findings related to patient worries and concerns after surgery provide insights to identify key topics in patient-centered comparative effectiveness studies comparing VBT and fusion surgeries. Although most participants described reduced anxiety following surgery, particularly relief from concerns about worsening curvature and pain, some reported increased worry over time. This increase often reflected a growing awareness of scoliosis and its long-term implications that many participants acknowledged they had not fully understood at the time of surgery.

Importantly, these worries must be interpreted in the context of VBT's early adoption. Participants in this study underwent surgery when VBT was not yet FDA approved and long-term outcomes were largely unknown. While patients were aware of the experimental nature of the procedure, decision-making was often guided by trust in surgeons rather than a clear understanding of what outcomes might look like 10, 15, or more years postoperatively. This uncertainty was further compounded by surgeons' limited ability at the time to counsel families about long-term durability, revision risk, or downstream consequences, contributing to ongoing concern among some patients after surgery.

Specific worries related to the novelty of the procedure were emotionally salient, particularly fears of tether breakage, curve progression, or the need for additional surgery, including conversion to fusion. These concerns reflect a broader psychological burden associated with living with an implanted device from a newly introduced technique. Patients also expressed uncertainty about longer-term life impacts, such as pregnancy, aging, and functional decline, emphasizing the enduring nature of these concerns even among those satisfied with their surgical outcomes.

Together, these findings highlight the importance of incorporating both clinical outcomes and patient-reported experiences into future comparative effectiveness research. Studies that directly compare VBT and fusion should explicitly address long-term uncertainty, complication-related anxiety, and evolving patient understanding over time. Doing so will better support informed, patient-centered decision-making and align research priorities with the questions that matter most to patients navigating treatment choices for AIS.

Limitations

Our study has limitations. Although we achieved saturation within our single-center, single-surgeon study, saturation in qualitative research is inherently context dependent. The themes identified reflect the experiences of patients treated by one pediatric orthopaedic surgeon in a specific geographic and cultural setting. Different themes may emerge in other regions or healthcare systems, where patients may have unique expectations and challenges. This highlights a limitation in the transferability of qualitative findings, which are context sensitive. However, as the first study to capture VBT patients' perceptions of their journey, our findings offer valuable insights that all surgeons can consider when discussing surgical options for scoliosis. These insights, while specific to our patient population, provide important perspectives that can guide discussions of patient expectations and outcomes. Self-selection bias is also a potential limitation, as participation was voluntary and may reflect those most or least satisfied with their care. We approached all eligible patients, regardless of their experiences, to mitigate this bias. Despite this, qualitative research enables a deep exploration of patients' experiences, capturing subjective evaluations that are essential to understanding patients' decision-making, recovery experiences, and long-term concerns. Retrospective interviews conducted years after surgery may introduce recall bias, with recollections possibly influenced by time, clinician interactions, and social influences. Additionally, interviews were conducted using different formats (10 audio-visual via Zoom and 10 audio-only via telephone), a factor

that may have shaped participants' comfort, engagement, or responses; although the interviewer did not observe differences in interview length or depth by format, the mode of data collection may nonetheless have influenced how experiences were shared. Finally, our sample included more women and girls than men and boys, consistent with the typical gender distribution in AIS. Because of our focus on individual experiences and the small sample size, we did not analyze gender trends, and findings may not fully represent both genders. This aligns with qualitative methodology, which emphasizes individual perspectives over subgroup analysis.

Conclusion

This study provides novel insights into the lived experiences of individuals undergoing VBT surgery, emphasizing the importance of patient-centered care in surgical decision-making and recovery processes. By highlighting the unique challenges and concerns faced by these patients, this research contributes to a deeper understanding of how to better support individuals choosing and undergoing VBT. Future research should continue to explore these areas, particularly through comparative effectiveness studies that focus on long-term outcomes and patient-reported quality of life after VBT versus fusion.

Ethics Approval and Consent to Participate

This study was approved by the University of Missouri Institutional Review Board (#2064983). Informed consent with waiver of documentation was collected from participants aged 18 and older or their guardians if younger than 18 years old. Before each interview, participants were provided with a consent form that was also read aloud. The form stated: "We may present the results of this study in public talks or written scientific articles, but we will not use information that can identify you."

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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