



Parent-to-Parent Advice on Considering Spinal Fusion in Children with Neuromuscular Scoliosis

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Objectives To convey advice from families whose children recently underwent spinal fusion to families whose children are under consideration for initial spinal fusion for neuromuscular scoliosis and to providers who counsel families on this decision.

Study design We interviewed 18 families of children who underwent spinal fusion between August 2017 and January 2019 at a freestanding children's hospital. We conducted phone interviews a median of 65 (IQR 51-77) days after surgery. We audio recorded, transcribed, and coded (line-by-line) interviews using grounded theory by 2 independent reviewers, and discussed among investigators to induce themes associated with surgical decision making and preparation.

Results Six themes emerged about decision making and preparation for spinal fusion: (1) simplify risks and benefits; it is easy to get lost in the details; (2) families prolonging the decision whether or not to pursue spinal fusion surgery may not benefit the child; (3) anticipate anxiety and fear when making a decision about spinal fusion; (4) realize that your child might experience a large amount of pain; (5) anticipate a long recovery and healing process after spinal fusion; and (6) be engaged and advocate for your child throughout the perioperative spinal fusion process.

Conclusions Parents of children who had recently undergone spinal fusion had strong perceptions about what information to convey to families considering surgery, which may improve communication between future parents and physicians. Further investigation is needed to assess how best to incorporate the wisdom and experiences of parent peers into shared decision making and preparation for spinal fusion in children with neuromuscular scoliosis. (*J Pediatr* 2019;213:149-54).

Parent and family engagement is increasingly promoted as a valuable approach for improving clinical processes. Families whose children undergo major medical treatments can be valuable resources and potential catalysts in empowering prospective patients and families to be active partners in shared decision making with their healthcare providers.^{1,2} Spinal fusion for children who live with neuromuscular scoliosis is one procedure for which advice from families may be especially valuable.³⁻⁵

Spinal fusion is performed to mitigate the curvature of the spine caused by altered neuromuscular tone from a disorder such as cerebral palsy, muscular dystrophy, or spina bifida. Goals of spinal fusion include improved positioning (eg, sitting and standing), reduced pain, and preserved or improved ability to breathe. Many families report improvement in their child's functioning and quality of life as a result of spinal fusion.^{6,7} Despite its benefits, spinal fusion is an invasive surgery that is associated with substantial blood loss, high rates of complications, and protracted health recovery.⁶⁻¹⁰ There is a paucity of existing data to project which children with neuromuscular scoliosis will truly benefit from spinal fusion. To help with decision making, many families considering spinal fusion seek out information about the experiences of families whose children underwent the operation.

Contemplating the decision to have a child undergo major surgery, such as spinal fusion, can be a daunting process. Families whose child has undergone the procedure have a unique, shared perspective with those contemplating the decision, and they note the importance of being fully informed and having support.^{11,12} Parent peers who have previously made this difficult decision, decided to proceed, and experienced the spinal surgery journey are uniquely positioned to convey experiential knowledge of the surgical procedure and recovery their child endured as well as their families' emotional, social, and cognitive experiences throughout the process.

The objectives of this study were to understand parent experiences of perioperative care for their child's spinal fusion and to obtain parent-to-parent advice for future patients and families from those who have been through the perioperative spinal fusion process. Children, families, and perioperative providers may

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find this form of patient and family engagement useful as they strive to support families making a decision about and preparing for spinal fusion and similar clinical processes.

Methods

This is a qualitative study of semistructured interviews conducted by phone from August 2017 to January 2019 with parents of children who recently (at least 3 weeks prior) underwent spinal fusion surgery at Boston Children's Hospital. Topics explored in the interviews for this qualitative study were informed by the parent partner on our research team, discussions with parents of spinal fusion patients, prior literature reviews of patient and family experiences, and the Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey.¹³ Approval for this research was obtained (IRB15-2971) by the Boston Children's Hospital Institutional Review Board.

Postoperative Interview Procedures

Eligible participants were identified from a prospective database used to monitor spinal fusion patients for quality improvement purposes. A study team member initially approached the parent(s) for study participation in person during their child's postoperative stay during surgery or by phone prior to surgery. Informed consent was obtained then. A study team member then called the parent(s) by phone approximately 3-6 weeks after surgery to participate in a postoperative interview. Of families approached for participation, none declined to participate. The main questions asked were, "I would like you to think back to before your spinal fusion process began. What do you know now that you wish you had known then? What advice would you give to other families about the spinal fusion process?" If parents expanded on other aspects of perioperative care, we also included that advice for analysis. Interviewers did not have a clinical relationship with the patients or parents. Interviews were audio recorded and transcribed verbatim. Participant enrollment continued until thematic saturation occurred.

Qualitative Analysis

We created a codebook through iterative steps. Initially, 2 members of the team reviewed transcripts and independently created codes, using line-by-line coding to generate concepts rapidly without introducing coder bias.¹⁴ Then, the 2 initial coders reviewed codes together, discussed them among the entire team, and agreed upon a common set of codes. The same coders conducted a second round of coding, reviewed codes, and determined a final set of 6 themes with multiple codes and subcodes, using grounded theory to group related concepts.¹⁴ The coders applied these final codes to all transcripts using Dedoose¹⁵ and Microsoft Word. Occasionally, coders modified initial codes to reflect insights derived from further coding. For example, an initial code was "manage the pain," which was later revised to "short and long-term pain management."

Data verification techniques including concurrently collecting and analyzing data and idea reconfirmation were performed to confirm the reliability of the data generated.¹⁶ In addition, fact checks were completed by 2 parents on our team who have children who previously underwent spinal fusion surgery. Our parent team members corroborated the parent experiences reported in this study. Participant enrollment was discontinued once theme saturation was observed. Theme saturation was determined by completing data analysis on 18 parent interviews. Data were then analyzed from 2 additional parents, and no new themes were found.

Results

Eighteen postoperative interviews were conducted with families at a median of 66 days (IQR 50-77 days) after surgery (Table I). Children of families interviewed had a median age of 15 years (IQR 13-19 years), 44% were female, and 83% were non-Hispanic white race/ethnicity. The median number of vertebrae fused was 15 (IQR 14-16). Median length of hospital stay after spinal fusion was 8 days (IQR 5-14) days. Approximately 72% of patients had at least 1 complication after surgery, and 39% of patients required a second procedure either for a fusion revision, extension, or a surgical complication ahead of the interview. Complications included pneumothorax, pneumonia, hypertension, dural tears, and wound infections. The median duration in minutes of the semistructured postoperative interviews was 31 minutes (IQR 20-42 minutes). The number of total words transcribed across interviews was 56 206 (Table I).

Among the interviews, 6 themes emerged for new families to consider when deciding about spinal fusion for children with neuromuscular scoliosis: (1) simplify the risks and benefits presented to you by your child's healthcare providers; it is easy to get lost in the details; (2) understand that prolonging the decision on whether or not you want your child to undergo spinal fusion surgery may not benefit your child; (3) anticipate anxiety and fear when making a decision about spinal fusion for your child; (4) realize that your child might

Table I. Characteristics of the study population

	Measure
Patient characteristics (N = 18)	
Age in y (median, IQR)	14.5 (13.25-18.75)
Female (%)	44.4%
Non-Hispanic white	83.3%
Median number of vertebrae fused	15 (14-16)
Median number of organ systems (out of 26) affected by coexisting conditions	11 (7-13)
Median hospital length of stay (d)	8 (5.1-13.6)
Complication rate	72.2%
Interview characteristics	
Days interviewed after surgery (IQR)	26.5 (19.7-42.1)
Median length of interview (min)	30.7 (19.7-42.1)
Total h of interviews	9.38
Total words transcribed	56 206

Table II. Illustrative quotes on risks and benefits as well as prolonging the decision for surgery from parents of children who underwent spinal fusion for neuromuscular scoliosis

Themes	Quotes
Simplify the risks and benefits presented to you by your child's healthcare providers; it's easy to get lost in the details	<p>"I knew what was at stake, and the benefits definitely outweigh the risks in this case. My child was one of the worst cases the doctor had seen, and he came out splendidly. The whole process went very well."</p> <p>"The experience of two other parents that I met by coincidence at Children's I kept in mind because their outcome was so amazing and so beneficial to their child's health; that [is something that I] definitely had to keep in mind."</p>
Understand that prolonging the decision on whether or not you want your child to undergo spinal fusion surgery may not benefit your child.	<p>"What I know now, we talked about the surgery a couple years prior, and we kept pushing it off because obviously you don't want to go through such a big surgery."</p> <p>"I wish we did it sooner because the outcome of surgery has been great so I'd tell families, especially families that, they're scared, concerned, that from where he is now from where he was prior to surgery is like night and day just for us, for his happiness, his comfort level, for his quality of life."</p> <p>"They did offer us an earlier surgical date... At the time, that was only a week ahead of us, and my child was still in school... so for various reasons, we decided to wait. We kind of wished that we hadn't given up that date. After that, her pain just didn't stop."</p>

experience a large amount of pain; (5) anticipate that your child may have a long recovery and healing process after spinal fusion; and (6) be engaged and advocate for your child throughout the entire perioperative spinal fusion process. Each theme is defined with illustrative quotes in **Tables II-IV** and also explained in detail below.

Simplify the Risks and Benefits Presented to You by Your Child's Healthcare Providers; It is Easy to Get Lost in the Details

Parents acknowledged that the decision to pursue spinal fusion was "heavy" and should not be taken lightly (**Table II**). They recognized the desire for a deep understanding of the nuanced risks and benefits of spinal fusion for their child. However, regarding benefits, parents felt it was easier to anchor their decision on one attribute (eg, visualizing a severely "crooked spine" on a plain radiograph, or recognizing that their child's co-existing conditions were worsening because of scoliosis). Parents also considered how spinal fusion might improve their child's co-existing conditions (eg, constipation and respiratory difficulties). When making a firm decision,

parents described arriving at a feeling of clarity that the chance of benefit outweighed the risk of harm (**Table II**).

"If the end goal is that your child is going to be better, if you don't consider the possible negatives and the possible complications, if you could just jump to that stage where my child is today, you know three months after surgery, I think that it's something that you should really consider doing."

Understand that Prolonging the Decision on whether or Not You Want Your Child to Undergo Spinal Fusion Surgery May Not Benefit Your Child

Parents admitted that the decision to put a child through spinal fusion surgery was difficult, and that it could take weeks, months, or longer to decide (**Table II**). Some parents felt that their apprehension about the surgery led to a delay in making a decision to pursue it; and many parents wished that they had overcome their apprehension more expeditiously and pursued surgery sooner. Some parents reported that having surgery earlier would have reduced the "torture" of watching their children experience discomfort when wearing spine/trunk bracing. Parents noted that delaying surgery negatively affected their child's quality of life and happiness in the year preceding surgery (**Table II**).

"I think that now I would have maybe done it sooner so that the muscles and curvature didn't get as bad as it did, and I wish now that I wouldn't have held off as long as we did and hadn't put her through all the torture of wearing the brace and everything and had done it sooner and had not been so afraid of doing it because it really has changed her life for the better."

Anticipate Anxiety and Fear when Making a Decision About Spinal Fusion for Your Child

Parents reported feeling anxiety and fear throughout the entire process of anticipating, choosing, and preparing for spinal fusion (**Table III**). Fear began well before surgery, with parents admitting that they dreaded the day when the physician would say, "It's time for surgery." Difficulty sleeping and second guessing the decision to have surgery were also common among parents. Some parents reported that the anxiety improved after they made the decision, and others continually tried not to overthink their decision after deciding to proceed with surgery (**Table III**).

"You have to go through the emotional trauma of putting your child through such an invasive, unbelievable surgery... You can't tell a parent, 'Go ahead and do it,' but if it's something that's going to benefit your child, you kind of have to process... what you're going to put your child through."

Appreciate the Large Amount of Pain that Your Child Might Experience

Parents reported wishing they knew better what to expect with regard to pain and pain management prior to surgery (**Table III**). They suggested that "anticipating what the pain will look like" and talking through pain management options in advance of surgery could better prepare parents

Table III. Illustrative quotes on fear and anxiety as well as postoperative pain from parents of children who underwent spinal fusion for neuromuscular scoliosis

Themes	Quotes
Anticipate anxiety and fear when making a decision about spinal fusion for your child	<p>“It’s a very difficult decision to make because it’s such an involved surgery, and to think of what your child is going to go through in that operating room is... I mean, the entire week before she had the surgery, I could barely sleep.”</p> <p>“For me, as a mom, it’s sort of this anxiety that I know it’s going to happen. So once we knew, okay it’s going to happen this year or next year, it was actually a little bit of a relief to know okay, we’re going to finally move forward... because I’ve been dreading it.”</p>
Appreciate the large amount of pain that your child might experience	<p>“I always left room for myself to bolt out of it, but I’m glad I didn’t. It was really for the best.”</p> <p>“He was uncomfortable every now and again, but he was not really uncomfortable. And he was really able to spend a lot of time out of the room and do a lot of things and enjoy himself.”</p> <p>“We knew he was going to be on a Morphine pump when he came out. We knew we were going to want to get him off that, but I did not ask, and I don’t remember the conversation, ok what’s the first one, two, three months going to look like, and how are we going to manage his pain?... That should be the focal point... I guess looking back that should have been part of the discharge.”</p>

Table IV. Illustrative quotes on postoperative recovery as well as patient advocacy from parents of children who underwent spinal fusion for neuromuscular scoliosis

Themes	Quotes
Anticipate that your child may have a long recovery and healing process after spinal fusion	<p>“Just the fact that she was healing for 5 months afterwards was very trying, and some people heal faster, but my child didn’t. And that good relationship with the doctor is just critical, that they stay engaged and interested and caring, not only in the recovery in the hospital but also afterwards and be available by email or phone, whatever the way is but that contact is very important.”</p> <p>“I think healing really doesn’t happen in the hospital. It really happens at home, but the hospital portion was critical and getting that right balance in the transition... that was really important.”</p> <p>“Be prepared for a marathon. As a parent, you got to take your down time and sleep when you can, and stay positive... We don’t anticipate these complications, but... when you’re super complicated like my child is, you never know what tomorrow might bring. And that’s a pretty devastating thing to realize, but also, it gives you something to work with. So you can deal with the devastation and then build some tools. So I guess my advice is geared towards people [who have] little bumps in the road on the way, as there always are with us, and that is keep your faith in tomorrow coming.”</p>
Be engaged and advocate for your child throughout the entire perioperative spinal fusion process	<p>“We all heal at different rates and get injured at different rates so be patient.”</p> <p>“When my child went down for an MRI, he told me his scariest moment of the whole hospitalization was the MRI because he said he felt like I needed suction, but I couldn’t tell anybody... I was like of course, you couldn’t speak for yourself very well. You didn’t have a way to communicate. Now I know his oxygen sat was probably monitored the whole time so I know he wasn’t desatting, but he felt like he needed suction and he couldn’t tell anybody and that bothered him.”</p> <p>“The child will always try to communicate and you have to be the bridge to let everyone else know what they’re saying or trying to tell you, and you know your child best so don’t ever doubt that. And it’s ok to step in.”</p> <p>“I did step in one time at 3 a.m. on Sunday morning when doctors said that my child’s heart rate dipped and he had a horrible headache ... And I just said, ‘Can we just get him some fluids?’ In ICU, it seems like they resist flooding people with water. And I get that, but I really felt like he needed water so I said can we please give him some fluids and that helped him right away. So in other words, parents need to step up and speak to the doctor and say ‘I think this is what he needs,’ even though they’re the ones with all the degrees and everything, but as a parent, you just know what they need.”</p> <p>“If you have any questions, no matter how stupid they may be, ask them. Even if you open them up and let them know, ask.”</p>

and children and enable them to cope with expected postoperative pain. Although some parents reported their children were in pain for longer than anticipated, others reported that recovery and pain management went more smoothly than they had anticipated. Many felt that pain management was the center of the recovery process, and “if you can manage pain, then you can do everything else.” (Table III).

“I would like them to understand beforehand that their child WILL HURT, but it will get better, faster than they realize.”

Anticipate that Your Child May Have a Long Recovery and Healing Process after Spinal Fusion

Parents reported knowing in advance that recovery was going to be a long and arduous process but felt that this point should be emphasized more (Table IV). Some parents also wished that they were given more information before the surgery about what to expect postoperatively in terms of caregiving needs and timeline. They noted that healing takes time and really does not begin until the child is discharged from the hospital. Communicating with physicians during recovery, staying positive, and being

“prepared for a marathon” were noted to be important aspects of helping to prepare for the long recovery process after spinal fusion. Parents also noted the need to be patient through the recovery process, as its duration is highly variable and dependent on the individual patient (Table IV).

“I recommend that families engaging in this sort of surgery be advised of the possibility, as we were, the possibility of a long healing process.”

Be Engaged and Advocate for Your Child throughout the Entire Perioperative Spinal Fusion Process

Parents noted that knowing what is at stake and knowing your child’s needs were incredibly important throughout the surgical process (Table IV). Parents felt that there were times when they had to be their child’s voice because parents know their children better than do the hospital staff. “Just being involved” and advocating for the child throughout the perioperative process, especially during hospitalization, was the underlying message of many parents to families considering spinal fusion surgery for their child. Parents also noted the importance of asking questions before surgery. Being engaged and advocating for their child required that parents understood the process (Table IV).

“As a parent, you still need to be front and center keeping an eye on flow of things, keeping an eye on your child, letting everybody know that your child has a voice and is going to tell you one way or another what they think... just know that sometimes staff miss what your child is trying to say and you have to be the bridge. That’s it, 24/7, you’re the bridge.”

Discussion

Findings from the current study support the growing body of literature demonstrating the value and importance of families learning from each other when making major medical decisions about their children’s care.¹⁷⁻²⁰ Relating families’ experiences to families of prospective patients enables, encourages, and supports parents to make informed decisions about their child’s healthcare.¹⁶ Parent-to-parent peer support may also reduce isolation, shame, blame, and other undesirable feelings that families may encounter when navigating the healthcare system.²¹ Parent perspectives can also help clinicians improve communication with families and help families prepare for unique experiences in the healthcare system.²² In the current study, we find that parent-to-parent advice is particularly valuable because it conveys perspectives and experiences about decision-making for spinal fusion that healthcare providers may not typically prioritize when offering advice and counseling families about the surgery.

One theme that emerged from the parent-to-parent advice that we found to be particularly striking was the recommendation to simplify the risks and benefits and not get lost in the details of the surgery. This advice counters typical clinical practice, in which providers are expected to discuss and

expand upon a lengthy list of risks and benefits for spinal fusion with the nuances of each child’s co-existing conditions, medical fragility, quality of life, and other important attributes in mind. Contrasting this clinical approach, many parents in our study found it effective to simplify the clinical information provided by focusing predominately on the one outcome that was the most important to them: a straightened spine for their child. In that context, parents wished that, in retrospect, they would not have delayed surgery because of the fear and anxiety that emerged when considering all the risks. Despite recommending that other families not delay surgery, parents still reported significant fear and emotional trauma leading up to the procedure. Knowing that this fear and anxiety is normal and should be expected can help parents better prepare for the process. Parents “never felt good” about the decision to have their child undergo spinal fusion, but knowing that this feeling is common among parents may be a helpful coping strategy.

A second noteworthy theme identified through parent-to-parent advice was the child’s experience of pain following spinal fusion surgery and the long duration of recovery. Some parents felt like their children experienced less pain after surgery than expected, and many others felt inadequately prepared for persistent, severe pain. Parent-to-parent advice on this topic highlights the need for families to discuss pain management options. As a result, parents may ask more questions about recovery and about what to expect after surgery in advance of spinal fusion. This may lead to conversations not currently occurring pre-operatively between physicians and parents about pain management. In addition, parents noted the importance of “keeping the faith” while realizing how long and bumpy the recovery process may be. Given the complexity of children with neuromuscular scoliosis, frequent difficult patches in the recovery process are common; knowing that other families had similar experiences, eventually got through them, and felt like the process was worth it, may be reassuring.

This study highlights potential benefits of engaging families as parent-to-parent advisors in order to enhance shared decision making in the perioperative spinal fusion process. For this to happen, clinicians need to accept and act in a way that acknowledges that parents know their children best. Parent-to-parent advice has been successful in many domains and through multiple modalities.¹⁸ Similarly, disseminating advice to parents with children considering or undergoing spinal fusion could take many forms. Previous studies, for example, have shown that parent-to-parent advisory groups have both increased advocacy by parents for their children while also raising clinician awareness of prevalent family concerns and needs.¹⁷⁻¹⁹ Parent-to-parent advice has also been disseminated through platforms including documents, websites, videos, and mentorship models. One parent in our study noted the Courageous Parents Network as being a helpful resource to learn about parent experiences with spinal fusion.²³ Many other parents and caregivers reported reaching out to parents at their child’s school or other programs, such as disease specific organizations. Knowing other

parents had been through a similar process provided reassurance and confidence, enabling parents to act in a situation where action can be very difficult. This is critically important, given parents' advice for parents to be engaged and advocate when their child undergoes spinal fusion. Future research should evaluate when and where physicians should have conversations about resources for parent-to-parent advice.

There are a few notable limitations to this study. First, there may be important parent perspectives that we were unable to capture because we interviewed only parents of patients who decided to proceed with spinal fusion surgery. Parents who decided against having surgery may also have important advice for families of prospective patients. Additionally, parent perspectives may change several months or years after surgery and we interviewed parents a few months after surgery. Finally, this was a qualitative study; as such, we cannot conclude that parent-to-parent advice benefits patients or families. Notably, the majority of parents' comments seem to be positive in nature and many recommended proceeding with surgery, despite the 72% complication rate among the patients whose parents we interviewed. Future studies are needed to evaluate the feasibility and the effects of parent-to-parent discussions, parent advisory groups, and/or mentorship programs, among families undergoing spinal fusion surgery.

Although every child is different, parents whose children have undergone spinal fusion surgery are a valuable resource for those contemplating the procedure. Advice drawn from personal experiences represents information that may otherwise not be effectively communicated that could reduce fear and anxiety typically associated with major medical decisions. Engaging families as parent-to-parent advisors can generate insights to guide perioperative providers about what they can anticipate may be the prominent issues families are most concerned about and struggle with when making spinal fusion decisions. This study highlights the value for clinical process improvement of clinicians connecting families of prospective patients with families whose loved ones have already undergone spinal fusion surgery and enabling them to share of their invaluable insights and experiences. ■

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Data Statement

Data sharing statement available at www.jpeds.com.

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