



# Parent Perspectives on Short-Term Recovery After Spinal Fusion Surgery in Children With Neuromuscular Scoliosis

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## Abstract

Family perspectives on short-term recovery after spinal fusion for neuromuscular scoliosis are essential for improving patient outcomes. Semistructured interviews were conducted with 18 families of children within 3 months after spinal fusion performed August 2017 to January 2019 at a children's hospital. Interviews were recorded, transcribed, and coded line-by-line by 2 independent reviewers using grounded theory to identify themes. Five themes emerged among families when reflecting back on the postoperative recovery: (1) communicating and making shared decisions regarding postoperative care in a patient- and family-centered manner, (2) setting hospital discharge goals and being ready for discharge, (3) planning for transportation from hospital to home, (4) acquiring supports for caregiving at home after discharge, and (5) anticipating a long recovery at home. Important family perceptions were elicited about the recovery of children from spinal fusion for neuromuscular scoliosis that will inform better perioperative planning for clinicians, future patients, and their families.

## Keywords

spinal fusion, neuromuscular scoliosis, short-term recovery

## Introduction

Recovery after major surgery in children is often more difficult than patients or families initially anticipate (1). Preoperative discussions about recovery from major surgery, when conducted, focus mostly on the anticipated hospital experience, including risk of complications (2–5). Recovery beyond hospitalization is critical to discuss because it can impact a child and family's life in several areas, including physical and emotional health as well as education, employment, and finances. Improved understanding of the comprehensive patient and family experience about recovery—from hospital to home—could enhance the ability of clinicians to optimally prepare children and their families for major surgery. Discussing anticipated long-term outcomes is also important for understanding patient and family goals and expectations upfront, in order to help better align patient and provider expectations for the surgery and recovery.

Spinal fusion—along with other major elective surgeries and procedures—accounts for a large proportion of hospital care experienced by children with medical complexity (6–8).

Recovery from spinal fusion can be arduous and unpredictable. Spinal fusion for neuromuscular scoliosis in children, in particular, is associated with major physiologic stress, prolonged recovery, and high complication rates (9–11). After spinal fusion, children are at risk for wound infections

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**Table 1.** Characteristics of the Study Population and Family Interviews.

Patient characteristics (N = 18)	Finding
Age in years (median, IQR)	15 (13–19)
Female (%)	44%
Non-Hispanic white	83%
Median number of vertebrae fused (IQR)	15 (14–16)
Median number of organ systems affected by coexisting conditions	11 (7–13)
Median hospital length of stay (days)	8.0 (5.1–13.6)
Interview characteristics	
Median days interviewed after surgery (IQR)	27 (20–42)
Median length of interview (minutes)	31 (20–42)
Total hours of interviews	9.4

Abbreviation: IQR, interquartile range.

as well as functional impairment of the gastrointestinal, pulmonary, urinary, and other organ systems (12–16). Parents of children with neuromuscular scoliosis undergoing spinal fusion report that they, in retrospect, wished that they had been better prepared for the recovery experience (17). Parents, who have observed their child's experience with spinal fusion, can provide unique perspectives on their child's recovery, including the postoperative inpatient phase, hospital discharge, and recovery at home. Prior studies have examined patient and parent experiences, including stressors and coping strategies with spinal fusion for idiopathic scoliosis in otherwise healthy children (18). The current study advances knowledge by assessing the postoperative experiences of children with neuromuscular scoliosis and their families to provide a roadmap for a more comprehensive conversation about recovery and to better prepare future parents and patients considering spinal fusion.

## Methods

### Study Design, Setting, and Participants

We conducted a qualitative study using semistructured phone interviews from August 2017 to January 2019 with parents of children with neuromuscular scoliosis who recently underwent spinal fusion surgery at a freestanding children's hospital. Operation procedures remained unchanged during the study. The interview guide was developed with input from the parent partner on our research team, discussions with others parents of spinal fusion patients, literature review of patient and family experiences with spine surgery, and the Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey (19). Approval for this research was obtained (IRB15-2971) by the institutional review board of Boston Children's Hospital.

### Postoperative Interview Procedures

Participants were identified from a prospective list of children with neuromuscular scoliosis scheduled for spinal fusion maintained for quality improvement purposes. A study team member approached parents for study participation by phone or in person during their child's postoperative stay. Informed written consent was obtained from parents at that time. Phone interviews were scheduled 3 to 6 weeks after surgery. Of families successfully contacted for postoperative interviews, none declined to participate.

The interview focused on in-hospital recovery, transition home from the hospital, and recovery at home. Example questions that followed the course of the postoperative period included, "How did your child's recovery compare to what you expected?," "Can you tell me about your child's experience leaving the hospital?," and "How has your child's recovery progressed?" Interviewers did not have a clinical relationship with the patients or parents. Interviews were audio recorded and transcribed verbatim and were continued until thematic saturation occurred.

### Qualitative Analysis

Two study team members independently reviewed each interview transcript using line-by-line coding to generate themes about recovery without introducing coder bias (19). Then, those 2 team members reviewed the themes and related codes with the full study team to harmonize findings and set the final nomenclature for the themes. To assess reliability of findings, data were concurrently collected and analyzed, thereby confirming recurrent ideas generated (20). Two parent study team members (L.B. and E.W.), whose children previously underwent spinal fusion, corroborated the parent experiences. Interviews were discontinued once theme saturation was achieved.

## Results

### Characteristics of the Study Population

Results draw on 18 semistructured postoperative interviews lasting a median 31 minutes (interquartile range [IQR] 20–42 minutes) that were conducted a median of 66 days (IQR: 50–77 days) after surgery (Table 1). For families interviewed, the children had a median age of 15 years, and the median number of vertebrae fused was 15. After surgery and prior to the interview, approximately 72% of patients had at least one complication, and 39% of patients required a second procedure due to a surgical complication (eg, wound infection, pneumothorax). Perceptions of families did not differ between children with versus without a complication. After surgery, the median length of hospital stay was 8 days (IQR: 5–14 days).

**Table 2.** Family Perceptions of Their Child's In-Hospital Recovery.

Theme	Illustrative quotes
Engaging in patient and family-centered postoperative care planning	<p>I would say that there's room for some improvements with communication between doctors and parents. I know they probably felt like they were doing things the way they usually do, but sometimes I would find out things later and kind of go, "Wait what? What do you mean?"</p> <p>I was under the impression that the breathing tube was going to stay in for the night. And when I got there, they were taking it out. And nobody had talked to me about that and I felt like all of a sudden my participation on the team sort of flew out the window. Nobody communicated to me why. And what I thought as his mother, what was most important for him was to have a good night's rest. And I wasn't consulted and the breathing tube was taken out, and sure enough, there were issues with him and the BiPAP. If they had read the behavior plan, they should've seen that that BiPAP was going to be tricky with him.</p> <p>I appreciated a couple of the docs and surgeons in rounds who were willing to talk to me clearly about what they were seeing in regular terms and about how pleased they were with what they were watching for. I really appreciated that.</p> <p>I think it would have helped to have somebody sit down with us each day, maybe a head nurse, maybe a doctor or intern, and really get out our concerns and questions at a table with just 1 or 2 people. That might have made us feel better.</p> <p>Seeing a team of providers come together and listen to that behavior plan and really do what was right for [my child], it was a beautiful thing. It really was. It was like the A team. When you put a plan in place, and you see it work, it's beautiful. It really is. To see individuals work together for the sake of a child with such complex issues is a beautiful thing. So that was the best thing.</p>

### Themes on Recovery Following Spinal Fusion

Over the course of the postoperative period, 5 themes about short-term recovery emerged: (1) engaging in patient- and family-centered postoperative care planning, (2) setting hospital discharge goals and being ready for discharge, (3) planning for transportation from hospital to home, (4) securing caregiving help at home after discharge, and (5) anticipating long recovery at home. The results for each theme are presented below.

**Theme 1: Engaging in patient- and family-centered postoperative care planning.** Some parents highlighted the importance of strong, direct communication regarding the plan of care with their child's postoperative providers. They expressed frustration when medical decisions (eg, when to extubate the breathing tube after surgery) were made without their input. Some parents were unclear on "the best person to have a good pow-wow with" about their child's recovery and postoperative plan of care, because there were so many providers (eg, nurses, residents, fellows, and attending physicians) involved in their child's postoperative care. Some parents conveyed that they were unsure which provider was "in charge" of the postoperative plan. For example (also see Table 2):

Going in, they needed to do a better job of telling me what they were doing. Because their plan was different than what the plan was when he left from surgery. They needed to do a better job of communicating to me that that plan had changed and why.

**Theme 2: Setting hospital discharge goals and being ready for discharge.** Many parents reported having different opinions with the hospital staff about the timing of discharge. Some

parents wanted to leave before the clinical team felt like the child was recovered enough to go home. Other parents felt that their children recover best at home; they wanted to leave as soon as their children were medically stable and the clinicians felt comfortable with them leaving the hospital. Other parents felt like their child needed a few more days in the hospital, despite clinicians saying their child was ready to go home. A few parents reported asking the perioperative team if they could stay in the hospital an extra day or 2 because they did not feel prepared to take their child home. For example:

The only thing that made him stay longer was I didn't want to have to bring him back here. [The orthopedic team] asked me if we could send him home . . . and I said no. To me, it was too early.

All parents noted the importance of reviewing and discussing discharge paperwork with perioperative clinicians, most frequently an inpatient nurse, and having the opportunity to ask any questions they may have prior to leaving the hospital. Some parents felt it was important to do this with a provider that they trusted. For example:

And it just worked out that the same nurse who had checked my child into the floor when we arrived was the woman who discharged him. We knew her, we were comfortable with her, [and] she was comfortable with us so the process . . . felt really comfortable.

Additionally, some parents felt that the hospital providers entrusted them too much to be the "link" of information and care between the inpatient and outpatient settings. Parents felt that inpatient clinicians assumed that parents would

**Table 3.** Family Perceptions of Their Child's Hospital Discharge.

Theme	Illustrative quotes
Setting hospital discharge goals and being ready for discharge	<p>When [the hospital providers] brought up hospital discharge, we were like, "What are you talking about?" He was doing really well I would say, better than we had even hoped so although they might have even released him the day before, but I wasn't quite ready.</p> <p>One of [my child's] needs is that she doesn't do well in a hospital environment. After a week, I said I don't see why we would stay any longer, and her surgeon felt that my child was well enough to go home. The person in charge of the floor didn't necessarily[agree], but [our surgeon] conveyed to her my child's situation and trusted me to take care of my child and bring my child home.</p> <p>We were so anxious to leave, and we did get out fairly quickly, but I think it might have been beneficial had we had time to sit down with someone before we left, just have a good sit down conversation, and maybe one time to go over the discharge papers carefully and think about questions we might have an so on. Probably would have been better.</p> <p>Because we got transferred to a different nurse who . . . wasn't familiar with [my child], I wasn't familiar with her, she wasn't even familiar with our meds, it was just kind of this rushed procedure to hurry up and get the process done and get us out of there. And frankly, part of that was my fault too, because all I wanted was to get the hell out, because I had been there a week and a half. I was tired. I could barely see straight, [and] all I wanted to do was get into my bed.</p>
Planning for transportation from hospital to home	<p>We were planning on probably an ambulance ride home, although part of me was like, "I don't know why we really have to do that." Then, when it came down to Monday morning, the nurse made a call to the ambulance to see if they could take my child home today and they said, "No." We literally checked out of the inn, packed, got him dressed, everything, and then the ambulance was saying, "No we can't do that trip on so short of notice. We can do it tomorrow." And we're all just standing there going "NO!?!?" So at this point, I just felt we could get him home safely ourselves, and the doctor in charge of the ICU was ok with that so we did.</p> <p>We actually had him ride backward so that his head would lean back, and his chair can recline and tilt so he could be as comfortable as he chose in his own chair on the ride home, which I think made more sense than an ambulance personally.</p> <p>If the transportation is being provided, it needs to be vetted more thoroughly, [including] exactly what type of van is coming . . . That was probably the sourest point of the whole process.</p>

accurately relay the information to the child's outpatient clinicians. This responsibility was prominent when parents did not have a comprehensive understanding of the discharge plan (Tables 3 and 4).

**Theme 3: Planning for transportation from hospital to home.** Many parents reported significant stress and difficulty coordinating transportation home from the hospital. Many parents had to decide between a car, plane, transport van, and/or ambulance while considering the comfort and well-being of their child as well as the feasibility and cost of the transportation. For example:

We were back and forth between airplane being the best way or car ride, and in the end, we decided car ride because we could lay her down, as opposed to an airplane where we would have to lay her up on her back and you can't really rest that area. So it worked out. I feel that the doctors really leaned forward trying to get us discharged, which I appreciate.

Some parents reported challenges with insurance approval for, as well as the timing of, arrival for ambulances and transport vans in relation to their child's hospital discharge. In retrospect, parents who used those transportation options wished that they had elected to drive their own vehicle home to optimize convenience and their child's comfort. Some parents felt like they did not receive sufficient help from their child's inpatient providers with transportation

home. Parents were often unsure which provider was in-charge of transportation (eg, nurse, social worker, or case manager).

Parent comments underscored the need to provide comprehensive and coordinated care for all aspects of discharge—including transportation, equipment, medication changes, home nursing or care needs, and therapeutic interventions and for team roles to clearly define who will follow through with these action items.

**Theme 4: Securing caregiving help at home after discharge.** Many parents noted that caregiving at home after discharge was particularly challenging, especially with insufficient sleep and rest while in the hospital and with feelings of stress about their child's recovery. Some parents noted the importance of self-care (ie, care for themselves) in order to provide the best care for their child. Many parents perceived that greater help from home nurses would have been beneficial. Many parents expressed the desire for increased hours of home nursing after their child's surgery. Many parents confessed that they did not seriously consider asking for home nursing until it was too late (eg, they were already home) and retrospectively wished they had asked for more help at home. For example:

I'm kicking myself because I realized I should've asked for help. I didn't realize what that would look like when I got home.

**Table 4.** Family Perceptions of Their Child at Home After Hospital Discharge.

Theme	Illustrative quotes
Securing caregiving help at home after discharge	<p>If things had gone a different way, I would have liked to have nursing assistance at home, that's what in my mind I had been prepared to request, but it didn't happen.</p> <p>We didn't have a visiting nurse with my oldest daughter (had spinal fusion 8 years ago), and my wife really felt that we should have a visiting nurse and they've been really, really good . . . They're absolutely fantastic. They took time to explain to my wife exactly what she was seeing and why.</p> <p>They told me that because he's nonverbal and he has a lot of special needs, they thought that he would recuperate better at home with family because those are familiar surroundings, but all that did was delay everything because home physical therapy care is like nothing.</p> <p>He should've been referred to [rehabilitation]. We weren't in any position to take care of him [at home]—he was dead weight, we couldn't lift him, he couldn't stand, he couldn't do anything at all. And that's when he just went downhill . . . Now, in order for [my child] to come home, I have to renovate my bathroom to make it wheelchair/shower chair accessible, I have to find a car that I can put a wheelchair in, I have to get all sorts of equipment, Hoyer lift, a custom wheelchair. I mean all sorts of stuff that I would have never even thought I would have to do.</p> <p>Well, it was just getting used to holding my child, and transferring, and sitting my child. It was awkward because my child went from being almost in half, folded over to being very straight and stiff too. My child has loosened up since the surgery. My child is much more flexible now than my child was then, but it was a little bit difficult on the transfer because my child was kind of pushed against you, and I mean it wasn't easy, and I decided to take care of her myself for the next 2 weeks because I didn't trust the personal care attendant to take care of my child. So it was on the family for the next 2 weeks after that.</p> <p>We pictured the surgery, we pictured what might happen but I didn't remember that he's going to be laid up for a long time, and you're going to come out of the hospital having been in the hospital for 2 weeks without any sleep, you're going to need help. I didn't think about me, and that's always the case. I didn't think about me. And I'm his caregiver, and I need to think about me.</p>
Anticipating long recovery at home	<p>We see signs that things are better and will be better, but [my child has] weaknesses there that aren't there before. But also this is fully expected.</p> <p>Before any of this happened, [I would have thought] his recovery has been amazing, way better than it might have been. Given the knowledge I acquired closer to surgery, I still think his recovery is kind of amazing, but then you get sort of surprised by things because he's walking around and he's sitting up, and he's doing things for himself but then something will happen, and you go, "oh, he's still pretty weak."</p> <p>There's nothing to compare [recovery] to, but consistently early on, it was more obvious. You sort of see, wow he looks better today than he did 2 days ago. So it's less obvious now to say if [recovery is] easier or better, but I would say its consistent progress. It's slower lately, but still happening.</p> <p>So then you start to sort of understand that there's the immediate recovery, but that doesn't even touch what the actual recovery is.</p> <p>There are some of the things about recovery that I didn't learn until close to surgery time, and they make good sense once you've heard them, but sort of the length it will take to recover. It's long.</p> <p>I was not prepared for many things that happened [after] the surgery, like the 2 times I had to end up in the emergency room, I was not prepared for that, so [families] have to prepare themselves. That's the only thing I didn't know.</p>

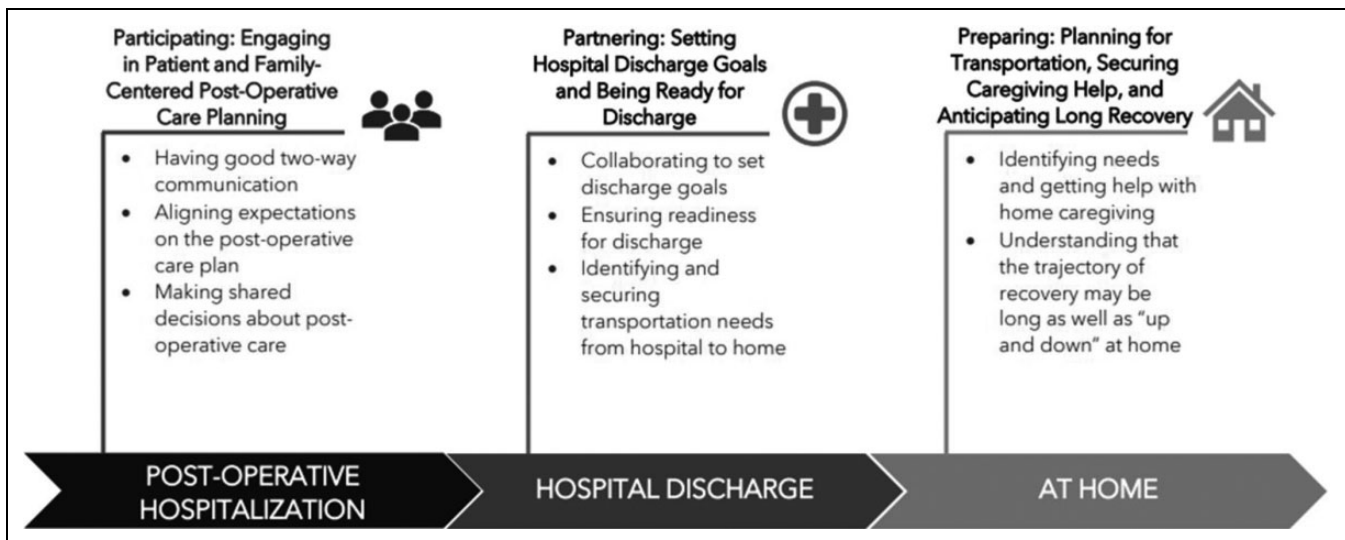
**Theme 5: Anticipating long recovery at home.** In general, most parents reported that their child's hospital recovery was smoother than they anticipated but that long-term recovery following discharge was slow and nonlinear. Most parents were very pleased with their children's ability to sit upright after spine surgery. However, as one parent noted, "The immediate recovery doesn't even touch what the actual recovery is." Some parents reported that their children experienced prolonged weakness and fatigue and that—even a few months after surgery—recovery was still ongoing and sometimes frustrating. Although most parents noted home physical therapy helped to some degree, the therapy exercises were difficult to conduct when their child was recovering and in pain. Overall, most parents reported improved quality of life after surgery which they attributed to decreased back pain, as well as improved respiratory health

and reduced constipation. However, some parents reported that their child continued to experience significant pain and stiffness several months after surgery. For example:

At first, his recovery was stellar. I was like oh my God! This is too good to be true. And in true [child] fashion, the swelling reared its ugly head and that put us back.

## Discussion

Parents whose children underwent spinal fusion for neuromuscular scoliosis conveyed unique and important perspectives about short-term recovery in hospital, the hospital discharge experience, and on-going recovery at home. In particular, parents highlighted (1) engaging in patient- and family-centered postoperative care planning, (2) setting



**Figure 1.** Pathway of short-term recovery after spinal fusion.

hospital discharge goals and being ready for discharge, (3) planning for transportation from hospital to home, (4) securing caregiving help at home after discharge, and (5) anticipating long recovery at home. Embedded throughout all of these areas were critical family and social aspects of patient recovery that ranged from seemingly simple constructs (eg, transportation home from the hospital) to more complicated matters (eg, ability and comfort level of parents taking care of their child at home with significant postoperative impairments; Figure 1). All of the themes raised by parents suggest that perioperative care may benefit the most from a more patient and family-centered approach that focuses on clear communication about plans and anticipatory guidance.

The challenges with patient and family-centered postoperative care conveyed by parents in the current study merits further attention. Prior studies underscore the value of fully partnering with parents in making decisions about their child's postoperative care plans (21,22). Care is more likely optimized when families are empowered to “speak up” about their needs and concerns, especially when clinicians are not sufficiently involving and informing them (23). Across patients, there are routine aspects to postoperative care management that could serve as touch points to ensure high-quality patient and family-centered care. These include, for example, decisions about extubation from ventilatory support following surgery, initiation of enteral diet after the use of IV nutrition, and weaning patients from postoperative pain medications. These are anticipated decision points in postsurgical care that could be first reviewed and discussed in perioperative clinical discussions with the family. Family-centered rounds during hospitalization—particularly with these postoperative aspects of care in mind—might be beneficial to ensure that patient and family perceptions and preferences are explicitly sought, conveyed, and used in medical decision-making. Family-centered rounds have an

established impact on improving patient communication, education, safety, and satisfaction (24–27).

Of the themes conveyed by families, setting discharge goals and deriving discharge plans carried particular weight among the families who were interviewed; these themes may represent the most critical components of postoperative spinal fusion care to optimize. Establishing discharge goals, including the achievement of a stable postoperative physiologic state, is a foundational step to pediatric hospital discharge care (3). Clearly, many parents in the current study expressed concerns about discordant family provider views of the optimal timing of hospital discharge. Disagreement about discharge readiness among physicians, nurses, and pediatric patients and families is not uncommon (28–30). Prior studies report higher rates of unplanned, hospital readmission when children and families are discharged before they feel ready to leave the hospital (31). High rates of readmission are reported among children with neuromuscular scoliosis undergoing spinal fusion (14,32,33). Considerations for discharge goals after spinal fusion routinely include sufficient postoperative pain control, cardiopulmonary stability, nutrition/hydration, and bowel and bladder functioning. Perhaps these and related clinical issues could be better addressed through discussion early in the admission—or even ahead of surgery altogether—to best educate and prepare patients and families to anticipate the process and planning for hospital discharge (28).

Once home, many parents noted that they underestimated the amount of time and effort needed to care for their child. Prior studies of children undergoing other high-risk operations (eg, solid organ transplant) report high rates of familial struggles coping with children's health, well-being, and cares after discharge (34). Multiple parents in the current study mentioned the need for home health care assistance. Setting up home health care for children expeditiously—especially for children and families using it for the first

time—can be a challenging task. The supply of pediatric home health care providers often does not match the demand for them (35). Perhaps, with further inquiry on the specific aspects of home health for which families need the most help (eg, lifting and transitioning their children, adjustments needed with, and new acquisition of medical equipment), other clinical personnel options (eg, personal care attendant) could be explored preoperatively. In particular, post-discharge home visits for hospitalized children with medical complexity conducted by hospital providers have been valuable to help families work through challenges in caregiving that they are experiencing at home (36).

There are several limitations to our study. Parent perceptions of recovery were measured within a few months of surgery. Longer term perspectives may reveal new important themes about recovery. The current study involved a single freestanding children's hospital. Additional investigation of parent experiences in other hospitals is needed to assess the generalizability of the study findings. The qualitative approach to the current study is not positioned to assess correlations or causality between the themes and the perioperative health outcomes experienced by the children. Perceptions of recovery from the viewpoint of clinicians (eg, nurses, physicians, and adjunct staff) were not obtained in the current study. Relatedly, the viewpoint of the child was not elicited in the current study. Future studies should assess and compare these perceptions with those conveyed by families.

The current study elucidates several opportunities to optimize in-hospital recovery, hospital discharge, and at home recovery from spinal fusion for neuromuscular scoliosis in children, especially regarding (1) patient and family-centered postoperative care, (2) discharge goal setting, (3) planning for transportation home, (4) caregiver support after discharge home, and (5) home recovery trajectories. These important constructs may be used to derive the clinical structure and content of perioperative care plans (eg, through a template) for use by families and providers. Certainly, such a structure may help standardize the derivation of high-quality care plans. Articulating families' needs throughout the recovery process and sharing them with clinicians and future families considering spinal fusion may heighten attention to the recovery process after spinal fusion surgery. Future studies are needed to evaluate the feasibility and impact of integrating families' perspectives and experiences outlined in this study in the care of future families whose children will undergo spinal fusion for neuromuscular scoliosis. Efforts to evaluate the impact of parent-to-parent advice, in particular, are needed; it is possible that such advice may help shape and augment perioperative care planning discussions and decision-making.

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## Author Biographies

**Brigid M Garrity** is a medical student interested in pediatric health services research. Ms. Garrity completed her BS at Providence College and her MS and MPH at Boston University. She hopes to continue child health advocacy and public policy research as a pediatric physician.

**Sara J Singer** is a professor of Medicine at the Stanford University School of Medicine and Professor by courtesy at the Stanford Graduate School of Business and Freeman Spogli Institute for International Studies. Her research in the field of health care management and policy focuses on how organizational leadership and culture impact efforts to implement health delivery innovations, integrate patient care, and improve safety and reliability of health care organizations.

**Erin Ward** holds a master's degree in Education and a Certificate of Advanced Study in Counseling and is committed to combining her personal experiences as a mother of a child with complex



medical needs with her professional skills to work towards improving parent-professional relationships and the quality of healthcare for children.

**Lucia Bastianelli** is a pediatric nurse practitioner at Boston Children's Hospital in the Cerebral Palsy and Spasticity Center. Lucia has also combined her experiences as a parent of children with complex medical needs to improve quality of pediatric healthcare.

**Jay G Berry** is a general pediatrician and hospitalist who specializes in the care of children with medical complexity. Dr Berry's current NIH and foundation-funded research on children with medical complexity includes the development and use of contingency plans, the use of machine learning methods to assess the impact of co-morbid conditions on health and utilization, and the development and use of standards of hospital discharge care.

**Charis Crofton** is a medical student with several years of experience in health services research. After receiving her BS from the University of Chicago, she conducted four years of research at Boston Children's Hospital and is currently studying medicine at Rush University.

**Laurie Glader** is the medical director of the Cerebral Palsy Program at Nationwide Children's Hospital. She was previously an associate in Medicine at Boston Children's Hospital and assistant professor of Pediatrics at Harvard Medical School. Dr Glader's work is comprised of clinical care, teaching, advocacy and research on topics related to the care of children with medical complexity (CMC), particularly those with cerebral palsy.

**Elizabeth L Casto** is a clinical research specialist within the Complex Care Service at Boston Children's Hospital. She received her BA from Bowling Green State University and her MPH from Boston University. The EHRLI Working Group is a multi-disciplinary team of engineers at Northeastern University and clinicians at Boston Children's Hospital working to redesign pediatric clinical care processes.

**Joanne E Cox** is the associate chief of the Division of General Pediatrics and the director of Boston Children's Primary Care Program. Dr Cox's research and quality improvement work involves the optimization and effectiveness of primary care for children.