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Patient and family experiences with peri-operative care for spinal fusion surgery

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Thesis

**PATIENT AND FAMILY EXPERIENCES WITH PERI-OPERATIVE CARE FOR
SPINAL FUSION SURGERY**

By

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ABSTRACT

Children with medical complexity (CMC) require increased number and length of hospitalizations, and increased need for care coordination.¹⁻³ Many complex children with neuromuscular diseases have scoliosis, or a deformity of the spine. Often, scoliosis in these patients affects multiple organ systems and requires spinal fusion surgery to repair the deformity and decrease the likelihood of further organ damage.^{4,5} While it is well-known that spinal fusion surgery is costly and a high-risk procedure, little research has evaluated the perioperative process of spinal fusion patients. Furthermore, few care pathways exist for medically complex patients undergoing spinal fusions.⁶ This study examines the pre-, peri-, and post-operative experiences of families of patients undergoing spinal fusion surgery at Boston Children's Hospital. Providers, organization, leadership and teamwork, and overall outcomes are assessed by this qualitative study. Initial data suggest that a pathway improving coordination and communication, especially among interactions with the surgical coordinator, should be implemented to improve scheduling of surgery and appointments throughout the perioperative process.

TABLE OF CONTENTS

TITLE.....	i
COPYRIGHT PAGE.....	ii
READER APPROVAL PAGE.....	iii
ACKNOWLEDGMENTS	iiiv
ABSTRACT.....	v
TABLE OF CONTENTS.....	vi
LIST OF TABLES	viii
LIST OF FIGURES	ix
LIST OF ABBREVIATIONS.....	x
INTRODUCTION	1
Co-management of hospitalized patients may improve outcomes	2
CMC are hospitalized more frequently than children without medical complexity.....	3
The perioperative surgical home is a patient-centered model that may improve care for CMC.....	4
Scoliosis occurs more frequently in CMC.....	5
Spinal fusion surgery is the primary scoliosis treatments for CMC	6
Limited data exist regarding the family experiences of CMC undergoing	

spinal fusion surgery	10
AIMS	13
METHODS	14
RESULTS	26
DISCUSSION	43
CONCLUSION	47
APPENDIX.....	50
APPENDIX I	50
APPENDIX II	53
REFERENCES	56
CURRICULUM VITAE.....	62

LIST OF TABLES

Table	Title	Page
1	Initial pre-operative interview questions	16
2	Pre-operative interview provider-specific questions	17
3	Other pre-operative interview questions	19
4	Post-operative interview guide questions regarding the day of surgery	20
5	Post-operative interview questions addressing the patient's hospital stay	20
6	Post-operative interview questions addressing spinal fusion recovery post-hospitalization	21
7	Post-operative interview questions on recovery progress	22
8	Concluding questions from the post-operative interview guide	23
9	Themes and sub-themes of the pre- and post-operative interviews	26
10	Summary of Pre-Operative Interviews	38
11	Provider-Specific Interactions	41

LIST OF FIGURES

Figure	Title	Page
1	Radiographic images of a pediatric patient with scoliosis before (left) and after (right) spinal fusion surgery.	8
2	The pathway for CMC undergoing spinal fusion surgery at Children's Hospital Colorado.	12

LIST OF ABBREVIATIONS

BCH	Boston Children’s Hospital
CAPHS	Consumer assessment of healthcare providers and systems
CAPSS	Care pathway for spinal surgery
CCS	Complex care services
CMC	Children with medical complexity
CP	Cerebral palsy
DMD	Duchene muscular dystrophy
ICU	Intensive care unit
LOS	Length of stay
NMS	Neuromuscular scoliosis
SCI	Spinal cord injuries
SMA	Spinal muscular atrophy

INTRODUCTION

The Maternal and Child Health Bureau defines children with special medical needs as those who either have, or are at high risk for chronic physical, developmental, behavioral, or emotional conditions, and require more health-related services than children generally require.^{2,8} Over the past several years there has been an increase in the number of patients with special needs and complex medical conditions due to increased survival rates of premature babies and children with multiple medical conditions. The increased survival rates of these patients result in increased medical resources use and medical-related costs, including intensive hospital or community services, polypharmacy, and homecare required to maintain quality of life for CMC.^{1,9} Additionally, medically complex children require increased hospitalizations, increased length of stay (LOS), and increased need for care coordination.^{1, 10-12}

Given the lack of consistent definitions of CMC, Cohen et al. proposed a framework based on needs, functional limitations, chronic conditions, and health care utilization.⁹ CMC make up less than 1% of the population of children in the United States, but they account for a very high percentage of hospital utilization, including 80% of hospital admissions.¹³ Notably, CMC have extensive medical needs that are frequently not met by many standard healthcare models.^{9, 13}

Despite Cohen's framework, hospitalizations and inpatient management of CMC are frequently not uniform, adding additional complexities to the care process. Management of CMC during hospitalizations often falls upon a wide range of specialists as well as general pediatricians which can increase costs and LOS. Thus, the increase in CMC has

led to an increased demand for more coordinated, cost effective hospital services for these patients which have been lacking in the past.^{12, 13}

Co-management of hospitalized patients may improve outcomes.

Co-management of adults has become a common form of care coordination, designed to reduce hospital-related costs, LOS, and healthcare use in general. Co-management has become more widespread especially among surgeons and hospitalists who are taking care of surgical patients. Co-management provides multiple benefits over multiple specialists making uncoordinated consultations, as one medical provider can take leadership of the team and act as the liaison. That provider can write orders and order consults from other specialists which streamlines the process and allows for all physicians to confer together in a coordinated fashion.¹⁶

Not only does co-management increase care coordination, but several studies have shown that patients who are co-managed have decreased post-surgical complications, decreased LOS, and increased satisfaction of surgeons.^{16, 17} While there have been fewer studies on pediatric co-management, a study among children undergoing spinal fusions showed both decreased LOS and decreased variability in LOS for those who were co-managed.¹⁸ The decreased LOS in this population may be due to pre-operative prevention of medical problems, early post-operative identification of complications and subsequent interventions, increased coordination of care, and consistency of post-operative medical care. This study also found that the greatest decrease in LOS occurred in children with underlying neurologic and neuromuscular diseases which suggests that co-management may be particularly useful for CMC.¹⁸ Co-management studies have been shown to be

effective in decreasing LOS, and given that CMC have much higher and longer hospitalizations than general children, co-management strategies used for adults may be successful in improving care in pediatric patients as well. While care-coordination is an essential feature of all hospitalizations, there are several other aspects of hospitalizations that must also be considered when assessing management of CMC such as severity of disease and increased risk of complications.

CMC are hospitalized more frequently than children without medical complexity.

Rates of hospital admissions for CMC compared to general children are significantly greater. One way to improve healthcare utilization and decrease associated costs and LOS is to decrease overall admissions of CMC. It is well-known that one of the easiest ways to decrease hospital admissions is to decrease the number of preventable hospitalizations.¹³ If preventable hospitalizations are elucidated, these areas could be targeted to decrease hospitalizations and associated costs.^{3, 8, 13}

One major cause of preventable hospitalizations among CMC are associated with problems immediately following discharge to home and post-hospitalization facilities. Discharge of CMC from hospitals often results in family stress, inadequate technology use, and insufficient follow-up, all of which contribute to a high number of preventable hospitalizations.^{1,13} One possible solution is increasing caregiver activation, which includes providing caregivers the skills and knowledge to provide care to CMC once discharged, or having visiting nurses.¹³ Other possibilities are increasing the use of post-acute facilities if caregivers are unequipped to take care of children at home. Care coordination pre-operatively and during hospitalizations may also be helpful in

preventing these hospitalizations, as patients feel like they have a point-person to contact if they have any questions or complications after discharge.¹⁶⁻¹⁸

While caregivers of CMC often receive care coordination plans and get home nursing and therapy after discharge, some hospitalizations and post-acute facilities admissions may not be preventable. It is well-known that recovery periods for CMC are greater than for children generally.^{13, 15, 19} This, unfortunately, puts an increased burden on families and caregivers, with caregivers often providing similar care as one would get in a hospital setting. This results in direct and indirect costs (including lost wages of caregivers who must take time off from work) and increased risk of post-surgical complications. A recent study showed that most CMC are not discharged to home health care earlier because of these increased risks.¹⁹ While care coordination plans and increased instruction for caregivers are essential to improving outcomes for CMC after hospitalizations, another potential solution is the perioperative surgical home.

The perioperative surgical home is a patient-centered model that may improve care for CMC.

Perioperative surgical home care involves taking care of patients from the time they decide to have surgery through recovery.²⁰ Perioperative surgical homes are simpler, less expensive, and provide the same care as general hospitalizations for surgical procedures. Care coordination in these homes leads to decreased emergency department visits, decreases costs, and decreased negative effects on school.²⁰ While the impacts are clearly beneficial, perioperative surgical homes can be expensive, hence a recent study has aimed to improve patient satisfaction of pediatric surgical patients while improving

quality of care and decreasing associated costs.²¹ This study found that better coordination of providers throughout the entire surgical process improved both pre- and post-operative care.²¹ Pre-operatively, pediatricians along with some specialists conducted comprehensive health assessments. The number of pre-operative primary care visits was positively correlated with a decrease in both, LOS and Medicaid spending for pediatric surgical patients, although primary care spending accounted for a negligible amount of total spending.²¹ Data also suggested a correlation between increased perioperative care general pediatrician visits and using fewer hospital resources. The authors hypothesize that general pediatrician and primary care visits elude to increased attention to the comorbidities of CMC which decreases overall morbidity of these patients undergoing surgery.²¹ Post-operative co-management by surgeons or hospitalists was also found to decrease LOS by one day.²¹ Overall, these findings suggest that a common model for all CMC undergoing surgery may be helpful in reducing costs, decreasing LOS, and improving overall quality of life.^{20, 21}

Scoliosis occurs more frequently in CMC.

Hospitalizations are increased among CMC due to a wide variety of medical conditions and comorbidities, including neuromuscular, gastrointestinal, and cardiopulmonary disorders. A common condition that affects many CMC regardless of their primary underlying condition is scoliosis. Scoliosis is a deformity of the spine that can be caused by neuromuscular diseases, tumors, congenital malformation, or by unknown reasons (idiopathic scoliosis).⁵

Idiopathic scoliosis is the most common form of pediatric scoliosis and is

typically milder than scoliosis caused by neuromuscular diseases. In all forms of scoliosis, the location and severity of the deformation determines the extent of impairment. Upper thoracic scoliosis may affect the cervical spine and the shoulder region. Severe thoracic scoliosis can damage the thorax, resulting in decreased chest cavity volume and lung disease. Lumbar scoliosis can affect the pelvis and lower extremities which can result in gait and posture impairments. These impairments are often made worse by neuromuscular diseases and in severe cases, deformities can be so severe that patients cannot ambulate or sit in certain positions.^{5,6} In addition to these limitations, pain caused by scoliosis deformities can also limit overall mobility and decrease quality of life.^{5,6}

When diagnosing scoliosis, it is essential to determine not only the location of the deformity but also any underlying conditions, such as neuromuscular diseases or tumors, as these may increase the risk of complications for patients with scoliosis. Neuromuscular and congenital scoliosis typically occur at an earlier age than idiopathic scoliosis and therefore are diagnosed sooner. Diagnosis is also essential for determining the functional implications of the curvature. Initial diagnosis can be made with a forward bend test or a scoliosis meter. X-rays should be ordered shrewdly on children but can also be used to diagnosis and determine severity of the curvature.^{6, 22}

Children with neuromuscular diseases have increased rates of scoliosis compared to the general pediatric population. This is attributable to multiple factors including asymmetrical paraplegia, decreased muscle tone, congenital abnormalities, and spastic and flaccid conditions.^{6,27} Therefore, neuromuscular scoliosis (NMS) has many

functional implications, including respiratory disease, multi-organ dysfunction, and nutritional deficits.^{6,23,24} NMS is present in children with both upper and lower motor neuron diseases. Patients with cerebral palsy (CP) frequently have spinal deformities, with 30% of quadriplegics with CP having scoliosis.²⁵ Children with Duchene muscular dystrophy (DMD) also have between 48-93% incidence of scoliosis.²⁶ NMS in patients with DMD can result in cardiopulmonary disease, decreased mobility, and moderate-to-severe functional limitations.^{25,27} Children with spinal cord injuries (SCI), spinal muscular atrophy (SMA), and spinal bifida also have increased prevalence of NMS.^{27,28}

Spinal fusion surgery is the primary scoliosis treatments for CMC.

In certain cases, scoliosis can be treated conservatively with braces, exercises, pain management therapies, and seating modifications.²⁹⁻³¹ Braces are used while children are growing to provide stability and to delay spinal fusion surgery.³² In addition to braces, modifications such as seating supports may be made to wheelchairs to both increase patient comfort and to improve function.³¹ Notably, braces are meant to both increase comfort and to delay surgery, but typically, they are not a preventative measure against surgery in the long-term.³²



Figure 1: Radiographic images of a pediatric patient with scoliosis before (left) and after (right) spinal fusion surgery.⁴³

If NMS is severe and begins to cause organ damage or causes decreased quality of life, surgery is often required.^{24,25,32} Spinal fusion surgery has proven beneficial in reducing pain, increasing lung function, increasing mobility, and improving self-image.^{7,}
³³ Recent studies have also shown spinal fusion surgery is associated with low mortality rates (0.15%) and a morbidity rate of 8.4%. However, the rates of morbidity and complication significantly increase for CMC compared to the general pediatric population, with a 13.09% morbidity rate and a 17.9% complication rate.³³

To prevent such complications, the overall health of all patients, but particularly CMC, should be assessed prior to surgery. For patients with NMS, other systems, including cardiopulmonary function, nutritional status, and neurologic status, should be assessed several weeks in advance of surgery.^{23,42} In most cases, data suggests that lung function tests should be completed pre-operatively, and surgery should only be considered if pulmonary function is high enough for patients to undergo anesthesia.²⁶ Nutrition must also be assessed pre-operatively, particularly for low-weight patients with neuromuscular diseases. Feeding tubes may be placed to increase nutritional status throughout the surgical process if necessary.^{23,34,41}

Given the wide variety of patients and conditions requiring scoliosis repair, there are two widely used techniques for spinal fusion surgery: posterior and anterior fusions. Posterior fusions are performed from the upper thoracic region down to the pelvis and are designed to improve posture and balance while sitting. Anterior fusions and combined anterior-posterior fusions are performed if there is a large curve requiring anterior release and fusion or if there are no posterior elements involved. However, the anterior-posterior

fusion is associated with increased risks due to the complexity of the procedure.³⁵ More recently, minimally invasive surgery (MIS) has been done to correct scoliosis, but this is more frequently seen in patients with idiopathic scoliosis, not NMS.³⁶

Growing rods and a vertical expandable titanium rib have also recently been implemented as non-fusion options that allow for increased chest cavity growth in patients with early and frequently less severe scoliosis.³⁵ In all surgeries on patients with NMS, the rate of complication is increased compared to patients with idiopathic scoliosis. Common complications include respiratory problems, excessive blood loss, blood clots, and brainstem damage. Additionally, patients with NMS undergoing spinal fusion surgery have increased LOS and increased mortality during hospitalizations post-operatively.⁷

Limited data exist regarding the family experiences of CMC undergoing spinal fusion surgery.

Given the relatively recent increase in the number of CMC, specifically those suffering from NMS and other forms of scoliosis, pediatric spinal fusion surgery has become an area of interest for medical research. While the overall number of spinal fusions performed yearly may not be as high as other procedures, spinal fusion surgery is an invasive surgery with numerous risks, long recovery periods, and potentially devastating complications, including paralysis and bladder malfunction.³⁷ Bernard et al. 2013 conducted a study on pediatric spinal fusion patients and their transition to home care.³⁸ As previously mentioned, CMC have increased risk for complications during surgery, given both the severity of the scoliosis and the multiple other comorbidities these

patients frequently have. Bernard et al. created a program to improve the medical problems of patients prior to surgery called the Care Pathway for Spinal Surgery (CAPSS). This program requires a pre-operative medical evaluation, which includes discussions of inpatient management of the patient prior to surgery. Caregivers are also trained on post-operative medications, physical therapy, wound care, bathing, and transferring children to and from wheelchairs. These trainings target care that CMC require after discharge from the hospital. Caregivers are equipped with this discharge training well in advance of discharge so that all questions and concerns may be answered. Additionally, the CAPSS program arranges pre-operative consultations with specialists, including pulmonologists, cardiologists, and nutritionists three to six weeks prior to surgery. The CAPSS program also incorporates a social work evaluation during which patients and caregivers are provided education. Family social and economic needs are also assessed during this visit. The CAPSS pathway for pre-operative assessment of candidates for spinal fusion surgery is seen in Figure 1. Bernard et al. found that participation in the CAPSS program decreased LOS, decreased the number of days patients spent in the intensive care unit (ICU), and decreased intra- and post-operative complications.³⁸

While the incidence of NMS is increasing, there has been limited research following patients and families throughout the operative process, from pre-operative care through post-operative care. There are few organized pathways for determining how to best handle spinal fusion surgeries and subsequent admissions for CMC with NMS.

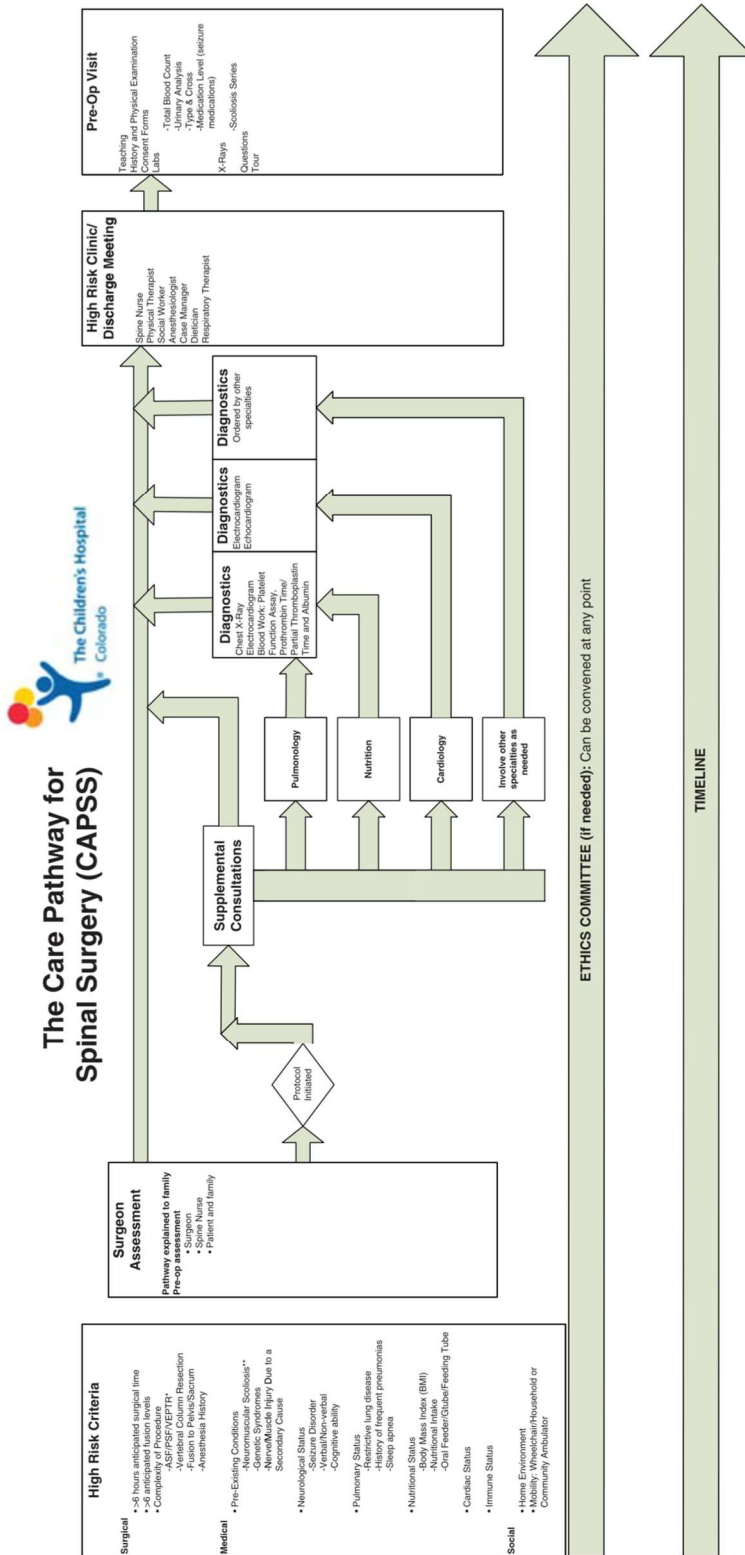


Figure 2: The pathway for CMC undergoing spinal fusion surgery at Children's Hospital Colorado.

SPECIFIC AIMS

1. To understand parent experiences of perioperative care for their child's spinal fusion
2. To learn how to optimize the patient and family experience of undergoing spinal fusion for children with medical complexity

METHODS

Patient Demographics

Caregivers of 10 spinal fusion patients were interviewed. All patients had severe scoliosis and were undergoing a spinal fusion at Boston Children's Hospital in Boston, Massachusetts. The patients were ages 10-15 years old and had between 4-10 chronic conditions, including CP, down syndrome, spina bifida, DMD, epilepsy, chronic respiratory insufficiency, constipation, urogenic bladder, osteopenia, and congenital heart disease. Given the number of chronic conditions, patients had between 4-16 specialists throughout the surgical process. Over the course of the study, there were 17 eligible patients and families. Two international families were excluded. The remaining families were unreachable, refused, or did not meet criteria for this study.

Interview Guides

A qualitative study was conducted, and data was collected via semi-structured interviews. Semi-structured interview guides were created by the research teams based on methods from Fowler and Mangone, the consumer assessment of healthcare providers and systems (CAHPS) surgical care survey, and a qualitative framework analysis.^{33, 39-41} Semi-structured interviews are the best way to elucidate medical experience and evaluate areas where minimal prior research has been conducted.³⁹⁻⁴¹ Information obtained in the first two unstructured interviews prior to the study were used to design subsequent interview guides, along with the CAHPS survey and relevant literature.³⁹⁻⁴¹

Questions were designed similarly to those in the CAHPS surgical care survey from the United States Department of Health and Human Services.⁴² Approximately half

of the pre-operative interview questions focused on the overall surgical process, teamwork and leadership, and administrative topics. The remaining pre-operative interview questions focused on specific providers, including the surgeon, surgical coordinator, anesthesiology, complex care, primary care and pediatricians, and any other providers seen pre- or post-operatively. Questions were similar in nature to the CAPHS questions but were tailored to a qualitative interview setting and therefore were open-ended. A numerical scale was thought to provide less information than open-ended questions and was therefore not used. Post-operative interview questions focused on experiences during the surgery, immediately following the surgery, and several weeks to months after the surgery. Areas of discussion included hospitalizations, discharge, and complications. Post-operative questions also addressed the overall spinal fusion process. Interview topics included overall patient and family experiences pre-, intra- and post-operatively during the spinal fusion process.⁴²

Pre-operative interview guide

Pre-operative questions can be grouped into three categories: overall pre-operative preparation and organization, provider-specific questions, and leadership and teamwork on the part of the providers. Questions regarding the overall pre-operative can be found in table 1.

Table 1: Initial pre-operative interview questions

Question theme	Interview question
Surgery preparation	First, can you tell me your thoughts on how the surgery preparation went and about your experiences during the preparation process?
Surgery preparation	Do you feel that all your child’s health issues were addressed prior to surgery?
Surgery preparation	What about the preparation process leading up to surgery went well? <ul style="list-style-type: none"> a. What aspects were organized? b. What about the preparation process leading up to surgery has been difficult for you or your child? c. What did not go well? d. Other probes: Tell me more about that. Why do you think that happened?
Surgery preparation; teamwork	Tell me about how your child’s providers worked together to get him/her ready for surgery? <ul style="list-style-type: none"> a. How did they interact and communicate? b. How did that make you feel?

These questions were designed to assess how prepared caregivers and patients felt prior to surgery, if all health concerns were addressed pre-operatively, if the pre-operative process felt organized, and if there was a provider in charge of pre-operative care. The questions above were asked but occasionally other probes were asked, depending on responses.

The next several questions addressed specific providers and how they impacted the pre-operative process. Providers included the surgical coordinator, the surgeon,

anesthesiology, CCS, and the pediatrician or primary care provider. Another question addressed any other providers who may have been involved in pre-operative care, including pulmonologists, cardiologists, and neurologists. These providers were specific to patients with certain pre-existing conditions and were not seen by all patients. Examples of provider-specific questions can be found in table 2.

Table 2: Pre-operative interview provider-specific questions

Question theme	Interview question
Provider: Surgical coordinator	<p>First, let’s talk about the <u>surgical coordinator</u>. This was the person who talked with you and the surgeon to help choose and arrange a date for surgery. Do you remember someone serving that role? Please tell me more about your interactions with the coordinator.</p> <ul style="list-style-type: none"> a. In what ways were your interactions with the surgical coordinator helpful for planning for your child’s spinal fusion? b. What could have gone better?
Provider: Surgeon	<p>Now could you tell me about your interactions with the <u>surgeon</u>?</p> <ul style="list-style-type: none"> a. In what ways were your interactions with the surgeon helpful for planning for your child’s spinal fusion? b. What could have gone better?
Provider: Complex care services	<p>[Only ask if child had CCS care] Now I would like you to tell us about your interactions with the <u>complex care service (CCS)</u> providers who conducted your child’s general health assessment.</p> <ul style="list-style-type: none"> a. In what ways were your interactions with CCS helpful for planning for your child’s spinal fusion? b. What could have gone better?

Provider: Anesthesiology	<p>Now let's talk about your interactions with the <u>anesthesiologist</u>.</p> <ol style="list-style-type: none"> a. In what ways was your visit with anesthesia (where they reviewed your child's health assessment and explained the surgical procedure) helpful for planning for your child's spinal fusion? b. What could have gone better?
Provider: Primary care physician/pediatrician	<p>Finally, please tell me about your interactions with your <u>primary care provider</u>.</p> <ol style="list-style-type: none"> a. In what ways was your primary care provider helpful for planning for your child's spinal fusion? b. What could have gone better?
Provider: Other	<p>Did any other providers help you prepare for the surgery?</p> <ol style="list-style-type: none"> a. What was their involvement? b. How did their involvement positively or negatively affect the preparation process?

All provider-specific questions were designed to evaluate the role the provider played in the pre-operative process for patients. Specifically, questions evaluated whether providers were helpful in preparing for the surgery, and if there were any areas in which providers could have been more helpful during the pre-operative process.

The remaining questions on the pre-operative interview guide addressed teamwork, leadership, and possibly improvements to the current surgical preparation process as shown in table 3.

Table 3: Other pre-operative interview questions

Question theme	Interview question
Teamwork/leadership	Did you feel that there was a provider in charge of your child's pre-op care? a. Who was it? What did they do to make you feel that way? b. How well did this person take charge of the process?
Teamwork	Was your sense that this group of providers was acting like a team on your and your child's behalf?
Surgery preparation	If your child had to undergo surgery again, what would you change while preparing for the surgery?
Surgery preparation	What are your thoughts on how we could improve the process for preparing children for spinal fusion surgery?

These questions were designed to evaluate the leadership and teamwork of the pre-operative process. Specifically, questions targeted leadership, communication, and areas that went well or did not go well during the pre-operative phase.

Post-operative interview guide

Post-operative questions assessed experiences during the surgical procedure, experiences during the hospitalization, transition out of the hospital, and overall thoughts on the entire spinal fusion process.

Initial post-operative questions assessed what information was discussed with parents prior to surgery and their experiences during surgery, including receiving updates during the surgery and contact with the surgical team throughout the procedure, given the length of the procedure. These interview questions can be seen in table 4.

Table 4: Post-operative interview guide questions regarding the day of surgery

Question theme	Interview question
Day of surgery; preparation	To begin, I would like you to think about your experience during your child's surgery. a. What information was reviewed with you before the surgery?
Day of surgery; updates	Did you get updates about your child's progress during the surgery? Who kept you informed? a. Did you have enough contact with this person during the surgery?

Subsequent post-operative interview questions were designed to assess the experiences during post-surgical hospitalization, as seen in table 5.

Table 5: Post-operative interview questions addressing the patient's hospital stay

Question theme	Interview question
Intensive care unit	Was your child taken to the ICU after the surgery? Can you tell me about that experience?
Intensive care unit; transition	Did you transition from the ICU to the regular medical floor? How did this process go?
Recovery; hospital stay	How did your child's recovery compare to what you expected? a. Did your child have any health problems after surgery that made him/her stay in the hospital longer than anticipated? b. Was your hospital stay longer or shorter than you expected?

Provider-specific interactions	Did you interact with the surgeon, anesthesiologist, surgical coordinator, PCP, CCS?
Hospital stay	What part of the hospital experience went well? What could have gone better?

These questions were developed to evaluate the time patients spent in different hospital units post-surgery and their experiences. Questions also assessed interactions with the same providers mentioned in pre-operative interviews. Parents were also asked generally what went well and what did not during the hospitalization.

The transition out of the hospital to home care or a post-acute facility was also addressed in the post-operative interview as shown in table 6.

Table 6: Post-operative interview questions addressing spinal fusion recovery post-hospitalization

Question theme	Interview question
Transition	Can you tell me about your experience leaving the hospital? How do you think your child's transition from the hospital went?
Transition	Where did your child go after you left the hospital?
Transition; preparedness for discharge	[PAC – skip if child went directly home] a. Did you feel like the facility was prepared to care for your child after leaving the hospital? b. Did you have clear rehabilitation goals in place?

Preparedness for discharge	[If child discharged directly home:] c. When your child transitioned home, did you feel prepared to take care of your child at home? i. Did you have a clear discharge plan in place? ii. Did you have follow-up appointments in place? iii. Did you have the adequate medications and supplies available?
Home recovery	What were your experiences caring for your child at home after the surgery?
Provider interactions – primary care/pediatrician (and complex care services if involved)	How was your primary care physician involved in the transition out of the hospital? d. How well did your PCP work with the rest of the providers after your child had been discharged? (repeat question for Complex Care Service physician – if the child and family were involved in CCS)

These questions assessed discharge and the transition out of the hospital. Other discharge questions assessed the involvement of providers during this transition.

Recovery and assessments of function were also addressed during the post-operative interview as shown in table 7.

Table 7: Post-operative interview questions on recovery progress

Question theme	Interview question
Recovery progress	How has your child’s recovery progressed? a. Did your child experience any complications after you left the hospital?

Quality of life; recovery	What is your child's functioning and quality of life now after the spinal fusion compared to before the surgery? a. How does this compare to what you expected?
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Finally, parents and caregivers were asked about any changes they would make at any point in the surgical process and any advice they would give other parents considering spinal fusion surgery for their children as shown in table 8.

Table 8: Concluding questions from the post-operative interview guide

Question theme	Interview question
Transition; improvements	If you had to do this again, what would you change about your transition home/to a facility?
Overall process; improvements	Considering the entire process from pre-op to post-op, what went well? What improvements could the team make?
Overall process; advice	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?

Data Collection

Semi-structured qualitative interviews were conducted with parents and caregivers of children who underwent spinal fusions in 2017-2018. The children being operated on had neurologic impairments, anxiety disorders, and other physical and mental limitations as noted in the patient demographics section in the methods.

Therefore, interviews were conducted with parents and caregivers. Caregivers were called approximately one week prior to patients' appointments or one week prior to the surgery to obtain initial consent. Upon interviewing parents in-person during the pre-operative interview, parents of all patients signed an informed consent form. Pre-operative interviews were conducted at pre-operative visits or on the day of surgery in a private conference room. Post-operative interviews were conducted at the post-operative visit or by phone. Interviews lasted 15-60 minutes, depending on caregivers' responses. IRB approval was obtained (IRB15-2971).

Interviews were recorded with a voice recorder and were subsequently transcribed and de-identified.

Qualitative Analysis

Inductive and deductive analytic themes based on interview questions and answers and relevant literature were used to code all interviews.³⁹ Two of the 11 interviews were conducted prior to development of the interview guides and therefore were not coded and analyzed with the same method as the other interviews. The seven pre-operative interviews were coded by provider [surgeon, surgical coordinator, anesthesia, complex care services (CCS), pediatrician, and other], teamwork and leadership, communication, and scheduling and administrative concerns. Codes for post-operative interviews are still being developed, as post-operative interviews did not occur for at least six weeks after surgery. Initial post-operative themes include surgical complications, physician interaction in the ICU and on the floor, support after discharge, transition to home, recovery, and advice for other caregivers. Codes and themes were

determined based on answers to interview questions and literature on co-management and framework analysis.^{16-18, 39}

Some quantitative measures of patients whose families were interviewed were also measured, including LOS, the number of other medical conditions and diseases, and the number of vertebra fused.

RESULTS

A total of 14 pre- and post-operative interviews were conducted with ten families. Ten pre-operative and four post-operative interviews have been conducted to date.

Themes and subthemes

A total of nine recurrent themes were found in pre- and post-operative interviews, including surgery preparation, teamwork and leadership, provider-specific interactions, administrative issues, day of surgery interactions, post-operative hospitalization, at-home recovery, surgical complications, and assessment of the overall surgical process. Several subthemes were derived from these themes and can be seen in table 9.

Table 9: Themes and sub-themes of the pre- and post-operative interviews

Themes	Sub-themes
Surgery preparation	Organization, preparedness
Teamwork and leadership	Teamwork at BCH <ul style="list-style-type: none"> - Yes - No – problems scheduling, problems obtaining records Teamwork between BCH and outside facility <ul style="list-style-type: none"> - Yes - No – problems obtaining records
Provider-specific interactions	Surgical coordinator, surgeon, CCS, anesthesia, PCP/pediatrician, other (behavioral specialist, child life specialist)
Administrative issues	Scheduling surgery, scheduling appointments, surgery cancellations for administrative reasons
Day of surgery interactions	Updates, provider-specific interactions

Post-operative hospitalization	Experiences in ICU, transition from ICU to medical floor, recovery process in the hospital, preparedness for discharge
Surgical complications	Complications during hospitalization, complications after discharge
At-home recovery	Quality of life, recovery progress
Overall process	Improvements/changes, advice

Cancellations and Scheduling Issues

The issue most frequently brought up by families in their pre-operative interview was surgery cancellations and rescheduling. Families recounted several reasons for cancellations, including acute illness, administrative cancellations, and cancellations due to other factors, including inappropriate nutrition, neurologic care, or lack of consultation with certain specialists.

Cancellation due to other medical conditions

Three surgeries were cancelled due to medical issues. Two were cancelled due to acute infection, and one was cancelled due to low baseline hormone levels that were deemed inadequate for surgery. Parents were generally able to clearly articulate the reasons for cancellations due to medical causes.

“They cancelled it because her thyroid level was too low and it was too risky to have her have the surgery.”

Multiple Cancellations for One Patient

One child with surgery cancelled due to infection had a total of four cancellations throughout the entire process. Other than the infection, the surgery was cancelled due to

administrative issues. The surgery was also rescheduled once without consent of the parents and once three days prior to the initially scheduled surgery date. While the parent was clearly able to articulate the cause of the medically-related cancellation, other reasons for cancellations seemed less clear to the caregivers. Both the fact that there were multiple cancellations, and the fact that the reason for cancellations was not fully clear was reported to be a cause of frustration.

“[My child’s] initial date to come in was moved several times so that was stressful because you prepare for that, and we’d move all [my child’s] stuff out of his school or tell [my child’s] whole nursing staff that we’re going in on such and such date, and they’d take on other clients, and then the date got moved 3 or 4 times and reschedules to this November because that was stressful because then [my child] wouldn’t have any home care and [my child’s] stuff would already be moved out of school... [My child] was supposed to come in on a Monday, it was rescheduled at 5pm on the Friday night before because they said they hadn’t gotten insurance approval yet, which is ridiculous to me because you had months to get approval. They had rescheduled it one time from the 7th to the 2nd, and no one told me. I just saw it on one of his printouts and I had called scheduling and she’s like ‘Oh I figured someone on the team would have told you, I should have told you, my bad.’ So that was really aggravating because we’re supposed to come in a week earlier than we knew. So I think the most frustrating out of all those things was scheduling, scheduling not calling me back 3 or 4 times.”

As evidenced by this quote, the multiple cancellations affected multiple aspects of this family’s life. First, the child’s school schedule muddled by the cancellations, meaning that because of a scheduling issue, a child was unable to attend school. Secondly, the scheduling and cancellations led to problems with home nursing staff. Since the parent was told surgery would be on a certain date, the parent had to tell home nursing staff they would not be needed for that date and subsequent days as the child would be recovering in the hospital. Since one of the surgery dates was moved so close to the initial date, the parent had difficulty finding home nursing care for the child. Finally, the parent notes the

stress associated with surgery and the preparation required, all of which occurred multiple times due to the multiple cancellations and rescheduling of this surgery. This data suggests how problematic cancellations and scheduling issues are for patients, families, and caregivers involved.

Cancellation due to miscommunication

Another child had surgery rescheduled due to miscommunication between an outside specialist and the surgical team at Boston Children's Hospital (BCH). Notes from the outside neurologist did not get passed to the appropriate team at BCH, which led to cancellation of the surgery.

“There was miscommunication about [my child's] neurology. My child's neurologist is not currently at Children's, she's at UMass so they did receive the notes from her. In those notes, she expressed that my child should have a specialist at Children's in neurology but it hadn't happened yet so that led to [my child's] surgery being cancelled because complex care didn't say, 'You should have gone to neurology, like could you go on a cancellation.' That was not mentioned to me. Then all of a sudden, I think it was a week or two after complex care, the surgery had been cancelled because the surgeon didn't feel confident enough that neurology was involved, and he was concerned, but that wasn't expressed to me directly, and I actually was able to get in on a cancellation in 4 days so the surgery didn't have to be cancelled. I could have come in. [My child] was supposed to have surgery August 8th, and it got postponed until September 26th. So that's a big deal because the whole family had changed the summer around so if it had been communicated to me from the surgeon, and he had said, you know, I really want you to see, even if it's not the neurologist you're going to see in the future, 'I want you to see neurology,' I would have come in so they could have scheduled something for me. Even complex care didn't say, 'Let's schedule neurology,' so there was miscommunication there.”

Again, this parent reports that surgery was cancelled unexpectedly for reasons that the parent did not feel like were in his or her control. This parent notes that had he or she been aware of the need for an in-house neurologist, one would have been consulted well

in advance of surgery, but that was not made known to the parent and led to cancellation of surgery. This parent also points out the turmoil that cancellation and rescheduling has, not only on the patient and primary caregiver, but everyone else in the household and anyone else directly affected by the cancellation. The entire family had to readjust their schedules because of the cancellation.

Scheduling problems - Complex Care

While the majority of scheduling problems revolved around scheduling of the surgery itself, multiple families had difficulty scheduling CCS appointments.

Outpatient CCS Scheduling

One family reported difficulty scheduling the outpatient CCS appointment prior to surgery.

“I hated coordinated care. That did not go well, I said that in my interview before. They did not accommodate any of my child’s schedule issues with respect to her sleep disorder, the location where they were is very tight for a wheelchair which is not convenient. It had nothing to do with the provider that we met there. The doctor did her job and was very thorough, it was just with how to coordinate everything, and that did not well. Honestly, I would not do coordinated care again. I would do it myself, like I’ve been doing. This was the first time in 14 years that I used coordinated care and I would not do it again.”

This parent notes the inflexibility of the timing of the pre-operative appointments with CCS. This was problematic given this child’s unique medical conditions which the parent did not feel were considered. This parent went on to say that complex care should be able to take all complex needs into account, and the parent did not feel like that happened.

Inpatient CCS Scheduling

Another parent of a different child with complex medical needs reported issues

with CCS inpatient visits.

“Yeah, I just think CCS, they’re [my child’s] head, they should always be involved in everything, and they didn’t consult. We had an appointment that we scheduled outpatient while we were in-house but we couldn’t go to it because it would be a different insurance billing they said, so I thought CCS would come to use. I did see a CCS doctor in the cafeteria and she’s like ‘I can’t do that,’ so you have to reschedule so it’s frustrating when I’m here for 5 weeks and can’t see a CCS doctor, [my child’s] CCS doctor, that [my child’s] seen for many, many years so I have to then schedule an outpatient, cancel the appointment we have while we’re right here in Boston, then schedule an outpatient so I’m going to drive 2 hours to get here, then see the doctor for 15 minutes, then drive 2 hours home, so that’s 5 hours of our day when I’m here for 5 weeks now. Who knows how long after surgery, it’s extremely frustrating that way. And we had a couple other appointments, like renal, and we couldn’t see them while we were here because it was scheduled as an outpatient appointment.”

This parent reports concern that CCS was unable to see the patient for the pre-operative visit. This child was admitted to the hospital five weeks prior to surgery, which would typically be when the pre-operative CCS visit occurred, but because the patient was admitted, CCS was not involved pre-operatively. The parent expressed frustration that CCS was in the same building as the child for the five weeks prior to surgery and still did not come see the patient, despite the patient being a long-standing patient of a CCS provider. This parent points out the problem of not receiving proper pre-operative care if a child is admitted several weeks prior to surgery, an issue that has not been addressed in the literature previously. Perhaps more importantly, it appears that there may not be a pathway in place for children who are pre-admitted to receive all necessary pre-operative consults in the current model at BCH.

Provider-specific interactions - Feedback on complex care unrelated to scheduling

Those patients and families who were able to schedule in-person and/or phone appointments with CCS report that the CCS providers were very helpful in planning for

the surgery. In particular, parents noted the role CCS played in communicating between interdisciplinary teams, both at BCH and at outside facilities.

“Jay was great because we spoke on the phone for at least an hour, and he really understood all of her different medical issues, and anything that would possibly come up. We talked about that our child had had C1 and C2 were very small and I said, ‘I’ve forgotten to have mentioned that to Dr. Glosbecker. I’m sure he realizes.’ And I just asked a few questions about that, and he made sure he got a note to Dr. Glosbecker about that so that was really helpful. I walked him through what it’s like every day with [my child] and what it’s like with her special needs and it’s pretty obvious that all the information was relayed because everybody has put all that in place.”

As noted, families of patients receiving CCS care made between 0-7 calls and send 0-65 emails to CCS providers throughout the spinal fusion process. Parents expressed that these calls and emails improved communication of the entire team and ensured that information would be passed to appropriate providers.

“Well, I would get phone calls that would say we’re going to call Jay and let him know this, or we’re going to fax this over to Jay, and Jay would also let me know when he got the information from Dartmouth. I did bring hard copies with me, but Jay coordinated that with Dartmouth so all I had to do was go pick them up.”

Parents also reported CCS communicating with outside hospitals and providers, obtaining records and addressing health concerns.

Additionally, those who met with CCS prior to surgery could make certain needs known, and two of these families were appointed a child life specialist or a behavioral specialist to help during their inpatient stays.

“I had told Jay how difficult it was for my child to have blood drawn, and that child life at Dartmouth would come in and help her, and so he at that point said that he would make sure that that was also put in place here.”

This parent reports CCS setting up child life visits for a patient who did not tolerate blood

draws very well. CCS was the service that looped in child life and behavioral therapy for two families, and these families reported the specialists making a big difference during the hospital stays. Perhaps an extended role CCS could take on in the future could be assessing the role child life or a behavioral specialist may play in every child's hospital stay, as the specialists clearly had a positive impact on all patients they provided care for.

Teamwork

Another common theme of many interviews was teamwork by the providers. While every parent reported visible, positive teamwork at BCH, parents who had to communicate with outside providers in addition to providers at BCH reported that there was no coherent communication outside of BCH.

“Here at Children's there's no question, there is a team going. Absolutely. The rest of our life, no. Not so much.”

“[I had] a few appointments before surgery and all of them were working together to have everything ready for the surgery. That's what I like about the preparation.”

Teamwork appears to be an area that is already successful in the spinal fusion surgery process at BCH, as noted by all parents.

Other Areas for Improvement noted in Pre-operative Interview

Other than numerous scheduling issues as noted previously, families reported that the overall pre-operative process went smoothly and was similar to what they expected. Families were asked if there was anything they would change, and the consensus was that, other than scheduling and not having to undergoing surgery at all, no changes to the pre-operative process were needed from their perspectives.

“It's hard to think of something I would change. It would have been nice to not

have dreaded it so much. This is something that our child, and by extension us, have been dreading since [our child] was five years old. That's ten years ago. I don't know. I don't know that you can make it better."

Interestingly, when asked about changes they would make to the overall surgical process during the pre-operative interviews, all parents either reported no changes or said that the only change they wished they could make was that their child never was ill in the first place. Parents reported a smooth process with all providers preparing parents on what to expect throughout the process.

Day of surgery interactions - Chaplain interaction

When asked about experiences during the surgery itself, one parent reported that the chaplain came and talked to the parent, making the experience better. The parent found this helpful, partly because the surgery was nine hours long and it was nice to converse with someone during that time, but also because the chaplain made suggestions about staying overnight in the hospital, which no one had told this parent about previously. The parent reported that this suggestion made her hospital stay more comfortable and allowed her to be rested when she otherwise would not have been.

"Honestly, it went better than expected. One part that was not addressed was that the chaplain came and saw me while I was in the waiting room while she was in surgery, and she knew what kind of surgery my child was going through and she knew a little about my child's medical conditions in general, [my child's] disabilities, she was a very nice person to talk to because my child's surgery was 9 hours long so it was a nice person to talk to, whether you're religious or not, it was just a nice person to speak to, and then she had recommendations for me, I did not know that because my child was going to be in the ICU, I could request a parent's sleeping suite in the hospital so she told me about that, and I went downstairs. She gave me her information and said if you need something, just give me a call. So I got actually the two nights my child was in ICU, I got to sleep in a bed outside of the ICU in this weird area of the hospitals, kind of spooky, but it was fine. Because my child was in an open bay area in the ICU so there was no

way that I could have stayed there so I got to sleep actually two great nights, and I did not expect that.”

A possible improvement to the current surgical pathway could be offering all parents the opportunity to speak with the Chaplain or a social worker during the surgery, given the length and intensity of the procedure. Additionally, providing all parents with the knowledge that they could stay in the hospital for free while their child was in ICU, given that ICU has no place for parents to stay, may be a positive addition to the spinal fusion process.

Post-operative recovery in the hospital

In their post-operative interviews, multiple parents noted that their children were in less pain than they anticipated, and all four post-operative interviewees noted that their children required much less pain medication than they anticipated. When asked to compare how the in-hospital recovery went compared to her expectations, one parent said:

“I think it was amazing honestly. I was really afraid of him being really uncomfortable and that just wasn’t true most of the time. There certainly were times when he was pretty uncomfortable, and there were times when he was restless in his bed and had trouble getting comfortable. But pain-wise, it was not nearly as problematic as I thought it would be.”

Surgical complications

Of the four families who were interviewed post-operatively, three of the patients experienced post-operative complications. One patient had problems with her halo moving after discharge, causing bleeding and pain. Another patient developed pneumonia while in the hospital after surgery, and a third patient had numbness and weakness in her

arm, requiring a second surgery to adjust the rods and screws that had been placed in the first surgery. Despite these complications, all parents still reported that recovery went better than they expected. All parents reported that the complications were unavoidable, not the fault of any provider, and all parents also noted that the entire surgical process went well, despite these complications.

Preparedness for discharge

All four parents who participated in post-operative interviews also reported that they felt extremely well-prepared for discharge. All parents noted that nurses provided detailed notes on medications and instructions for care at home. All parents reported that they knew who to contact if they had any problems, although this person varied from family to family, with some families receiving multiple phone numbers depending on what they had questions about or what time of day they were calling. When asked about her experience leaving the hospital, one parent said:

“The nurses had laid everything out so it was very seamless it seemed. We had very detailed notes about when medications need to be taken, what medications could be lessened when she was feeling better and all of that, so it wasn’t a guessing game. I never had to call and ask any questions because the nurses were very, very good about giving us extreme detail about the home care and everything so I think that that went very seamless.”

At-home recovery

All four parents noted that their children were generally weak to some degree when they were interviewed, which was approximately 6-8 weeks after surgery. However, parents noted that this was to be expected, and they reported that their children

all seemed to be recovering more quickly than they had anticipated. When asked about the extent of her child's recovery, the parent of the child who required two surgeries said:

“I would say it has reached all of my expectations. I'm much happier with how she gets around. She certainly gets tired. She still has some backaches and pains but I knew that that was going to happen just because of the muscle structure and how much the muscles had moved so getting her to realize that her body does still have limits and it does take some time to go back to its normal.”

Advice from Other Parents

When asked if anything made the entire process better, multiple parents reported that speaking with other parents whose children had undergone spinal fusion surgery in the past made them feel more comfortable and reassured.

“Hearing from another parent that the surgery went well and if she had to do it again, she would. And there was another parent, the same thing. I said, ‘Oh my gosh, my child is going to have this surgery,’ and she said, ‘I know it's a big thing but it went well.’ That really helped me. To hear from a parent. Because a surgeon can say it, but it's not the same at all.”

Several parents consulted other parents whose children had a spinal fusion in the past, and other parents consulted adults they knew who had undergone this procedure as a child. All parents who discussed the surgery with someone who had gone through the process reported that it made them feel more comfortable, and one parent even said that it was one of the main reasons she felt comfortable proceeding with the surgery. Providing parents an opportunity to speak with a parent of a child who had a spinal fusion surgery, if they do not have someone in their own life to ask, may be beneficial for both parents and children.

Advice to Future Families Undergoing Spinal Fusion Surgery

In addition to speaking with other parents of children who had undergone spinal

fusion surgery in the past, one parent suggested to remind parents to prepare for unexpected outcomes and complications post-surgery.

“Prepare yourself, [do] not just expect what the doctors say to you because you never know what could happen in the future. I was not prepared for many things that happened with the surgery, like the two times I had to end up in the emergency room, I was not prepared for that, so they have to prepare themselves. That’s the only thing I didn’t know.”

The child of this parent had two complications after surgery that were unexpected and unlike any of the complications he or she imagined might occur. This parent expressed a desire to mentally prepare for potential obstacles in the recovery process because this would have made the complications less scary and unknown.

Table 10: Summary of Pre-Operative Interviews

Total families interviewed (N = 10)
Provider in charge <i>Surgeon (N = 9)</i> <i>Other (N=1)</i> <i>CCS = 1</i>
Number of surgery cancellations <i>Cancellations due to acute illness (N = 3)</i> <i>Cancellations due to administrative or other causes (N =7)</i>
Patients who saw complex care (N = 8)
Cases where pediatrician/PCP was involved pre-operatively (N = 0)
Cases where child life/behavioral therapy was involved (N = 2)
Patients who saw other specialists (cardiology, pulmonology, neurology, etc.) (N = 10)
Patients pre-admitted prior to surgery (N = 2)

Provider Feedback

Of the nine patients who underwent spinal fusion surgery, all interacted with the surgeon, the surgical coordinator, and with anesthesiology, but only seven had pre-operative visits due to a few pre-surgery admissions. seven interacted with CCS, no patients interacted with their pediatrician or PCP, and all interacted with at least one other specialist, including cardiology, neurology, endocrinology, and pulmonology.

Patients in this study saw one of four surgeons. There were no negative comments made about any of the surgeons, however, one patient was uncomfortable with the orthopedic team rounding daily at 6:00am, waking up that patient and family. Likewise, there were no negative comments made about anesthesiology or the pre-operative visit. All comments about CCS providers were positive, although one family reported poor scheduling and accommodations for a pre-operative CCS visit. Experiences with the surgical coordinators were mixed, with parents either having no issues or having several issues, including cancellations, lack of communication, and inability to reach the surgical coordinator. Quotes on interactions with specific providers can be seen in Table 12.

All parents reported that the surgeon was the point person. Parents commented on the surgeon's patience in answering all questions thoroughly and explaining what was going to happen before, during, and after the surgery. Some surgeons gave out their emails to parents so parents could ask questions before and after surgery. Parents took advantage of this by emailing surgeons any interactions the patients and family had with other providers. Post-operatively, one parent would email the surgeon questions and pictures of the scar and wound care to make sure that the parent was taking care of the

child appropriately at home. No negative comments or suggestions for improvement were made regarding any of the surgeons.

As mentioned, the surgical coordinator received mixed feedback from parents. Two of the parents of children whose surgeries were cancelled still reported that the surgical coordinator was helpful and responsive, but the other parents whose children's surgeries were cancelled reported miscommunication and lack of communication on numerous occasions. One parent whose child's surgery was never cancelled or rescheduled also reported problems reaching the surgical coordinator. Interventions could target the responsiveness and the clarity with which the surgical coordinator provides dates for surgery and reasons for cancellations or rescheduling.

Complex care was generally found to be helpful for communicating between providers both internally and externally. However, no parent reported CCS to be the point person for the team. The only complaint regarding CCS involved scheduling of CCS visits as previously noted.

Seven patients had a pre-operative appointment with anesthesia as the other two patients were admitted for five weeks before surgery. All families reported that the pre-operative visit went well and was helpful for planning. Multiple families also were happy to find that at the pre-operative visit, anesthesiologists had already viewed the patients' charts and were knowledgeable about any past experiences with anesthesia, patients' medications, and any allergies or medical conditions that might interfere with anesthesia. There were no negative comments or suggestions for improvement regarding the pre-operative visit or the anesthesiology team.

Quantitative analysis

Data was collected on the amount of contact each patient and family had with CCS. Parents sent 0-65 emails to CCS, made 0-7 phone calls, and had 1-5 appointments with CCS at some point during the spinal fusion process.

Table 11: Provider-Specific Interactions

Provider type	Code	Quote
Surgeon	Positive interaction	He talks with people and he listens to them. He talks about what matters, the different sides of things. He doesn't just say, 'This is what has to be done.' He'll say, 'This is what I'm thinking. This is why. And this is a possible option, but this is why this is a better option.' There's certainly room to discuss things, it never felt like he was telling us what had to be done or we had to do what he was saying.
Surgical Coordinator	Positive interaction	I remember a day that I wanted to ask her some questions about surgery and she told me she couldn't answer it for me but she would go ahead and give that information to the doctor. And like 40 minutes after, [the surgeon] called me and answered all my questions. She got in touch with him, I think it was an email, and he called me back and answered all my questions right away.
Surgical Coordinator	Negative interaction	She was perfectly pleasant when I would get her on the phone, just getting to that point was tricky. And I would say that maybe in some situations, that's not a big deal. I mean, it's a pain in the butt. If you're trying to schedule a dental appointment, but this is sort of a big deal. There's a lot of stress around it. We're planning our life around it.
Complex Care Services	Positive interaction	I walked him through what it's like every day with [my child] and what it's like with her special needs and it's pretty obvious that all the information was relayed because everybody has put all that in place.
Complex Care	Negative	The doctor was wonderful. It was the inflexibility of the whole program to accommodate my child's

Services	interaction	needs because obviously complex care, the name says you have a child with complex needs, and it was very rigid. And I tried, and the person was not rude, but very dry about it, it was this or nothing. And there was something that she wanted done, and I said I don't know if I'm going to be able to do this. She said this will lead to cancellation of the surgery, and it wasn't anything that had to do with neurology so I felt like there was no comprehension of my daughter's needs and she didn't take anything into account.
Anesthesia	Positive interaction	The pre-op appointment that was a week or so ago, two weeks ago, was really beneficial to [my child] and us, but even more so to [my child] to get comfortable with a new hospital, meeting all the doctors and the team. That helped a lot.
Behavioral Specialist	Positive interaction	[Our child] was more comfortable here than we could have imagined [our child] being. There's no question there were some basic nervous things that we see in other public places that we see that just were not here most of the time, and that's because of what they created for him/her.
Child Life	Positive Interaction	What I thought was great with that, was when they came in, they already knew that [our child] was really freaked out by needles and were prepared for that and already had child life standing by and ready to help him/her through all of that.

DISCUSSION

Severe scoliosis, particularly NMS, is a challenging disease for patients, caregivers, and providers, given the complexity of both the disease and comorbidities often associated with it. The disease is associated with increased LOS, health care costs, and complications.^{9, 13} The objective of this study was to obtain feedback on the current surgical process for patients undergoing spinal fusion at Boston Children's Hospital. The information provided in our interviews will allow for the creation of an interdisciplinary approach to improve care for patients with severe scoliosis undergoing spinal fusion surgery.

Family and patient experiences of CMC undergoing spinal fusion were very positive overall.

One of the main goals of this project was to determine any areas that need improvement and could make the entire process better for patients and families. Provider-specific feedback confirmed that all providers in this process were viewed as doing an overall great job at providing care, answering patient and family questions, and making the experience more positive. Parents reported that communication at BCH was stellar and no internal communication problems were reported. However, if patients had specialists at other facilities, communication was problematic about half of the time. When CCS was used, two families reported strong inter-facility communication, while one family reported miscommunication between the outside provider and BCH, leading to cancellation of the surgery.

Scheduling and cancellations were most problematic for families and patients.

This study also exposed the frequency with which surgery was cancelled or rescheduled. More than half of the families reported at least one cancellation, with multiple families reporting between two and four cancellations. While acute illness may not be a preventable cancellation, miscommunication between specialists was the cause of multiple cancellations, as was communication problems with the surgical coordinator. These problems could be corrected if there was better communication between providers and if pre-operative tests and labs were done well in advance of the surgery to elucidate any issues ahead of time. For example, when a patient had a nutritional problem that the orthopedic surgeon was unaware of until the week prior to surgery, the surgery was cancelled. To prevent situations like this, the CAPHS program determined that all pre-operative appointments and visits should be conducted approximately six weeks prior to surgery to avoid cancellations.⁴² A similar pathway could be implemented at BCH to decrease the number of cancellations.

Both pre- and post-operative interviews are still being conducted and will provide more information on these and other issues with the current model for pediatric spinal fusion surgery. Although not enough data has been collected to date, we hypothesize that other factors will come up in future interviews, including preparedness for discharge, experiences at home after surgery, and surgical complications. These potential themes will allow for further suggestions to be made to the surgical process.

Quantitative measures are affected by heightened attention to qualitative measures.

While one surgeon at BCH observed that LOS for spinal fusion patients has decreased since this study began, data is still being collected to determine what combination of providers and services leads to optimal LOS and decreased complications. There have not been many successful programs created to decrease LOS and risks associated with spinal fusions in this patient population. One program at Children's Hospital Aurora did successfully implement a protocol with a multidisciplinary team.⁴² This CAPHS program determined three keys to successfully decreasing LOS and complications: 1) designation of a single coordinator, 2) investing time in the pre-operative planning period prior to surgery, and 3) flexibility of the program pathway.⁴² A single coordinator allowed parents and caregivers to have a constant resource during the surgical process. Allowing three to six weeks for pre-operative visits allowed multiple providers to assess patients prior to surgery, which may reduce surgery cancellations. Flexibility in the program allowed patients to see a variety of different providers, given the unique complexities of the patient population. The CAPSS program resulted in an 11-day decreased LOS, reduced healthcare costs, and decreased ICU LOS, which may contribute to the decreased costs.⁴²

Decreasing LOS is important, as hospitalizations are costly, time-consuming, and can put patients at risk for hospital-acquired infections.⁴³ Costs include both the charge of hospital bills, as well as lost wages of parents and caregivers staying with children hospitalized after surgery. Some families require pre-surgery hospitalizations which are both time-consuming and costly. One of our patients was admitted for five weeks pre-

operatively for testing and pre-operative management. Such hospitalizations affect family members, patients, and providers. Finally, hospitalizations post-operatively can lead to increased risk of infections, including MRSA, which can lead to delayed wound-healing and increased LOS.⁴³

CONCLUSION

This perioperative spinal fusion experience study has provided countless insights from parents and caregivers, and the study is still in its beginning stages. Given that spinal fusions are not as frequent as other procedures, the sample size is limited and therefore collecting data requires a long timeframe. However, this study is extremely valuable in that CMC, and more specifically CMC with NMS, account for a large percentage of healthcare spending and hospitalizations among all pediatric patients. Finding ways to decrease the personal, economic, and time burden spinal fusion surgery presents to families will make a huge impact in many areas. While a few pathways like CAPHS exist, these pathways are very hospital-dependent and are not exactly applicable to outside facilities. Though this study aims to evaluate pediatric spinal fusion patients and experiences at BCH, the hope is that results from this study will be able to help patients, families, and providers across the country.

This was not a study to solely assess CCS involvement in pediatric spinal fusion experiences, but initial findings raise questions about the importance of a point provider and the potential benefit parents found when using CCS. Final results will provide comparisons of both qualitative and quantitative data, like LOS, costs, and provider feedback to compare whether patients who used CCS had better outcomes than those who did not.

One surgeon has already reported that the initial findings of this study have made him closely consider LOS for CMC, and since the study began, he reports decreased LOS for his patients after spinal fusion surgery. It will be interesting to note whether tracking

measurements like cost, LOS, and blood loss make surgeons more attentive to what they are doing and where they can improve.

This study has many limitations. Subjects were restricted to spinal fusion patients at Boston Children's Hospital. A limited number of children undergo spinal fusions every year, and we only assessed patients at one hospital who have a residence in the United States, limiting generalizability. Additionally, insurance and family socioeconomic statuses were not considered, and this may play a large role in overall healthcare costs of spinal fusion surgery. Additionally, patients had a variety of types of scoliosis, including idiopathic scoliosis and NMS, and therefore, severity of disease varied which may affect surgical outcomes. Furthermore, patients with NMS had a wide variety of underlying conditions, including CP, DMD, epilepsy, and down syndrome, all of which present unique surgical and post-operative risks. Finally, those patients who did not require or chose not to use CCS may have been healthier at baseline and less complex than patients utilizing CCS. Thus, the quantitative data comparing those with CCS and those without CCS may not accurately reflect similar patient populations.

Future Directions

Semi-structured interviews will continue to be collected throughout 2018 to obtain more patient experience feedback. Based on the data collected, the next step is to implement a multidisciplinary pathway for children undergoing spinal fusion surgery. Such a pathway may involve an assessment of risk criteria, evaluation by a surgeon, specialist consultations, and further testing (advanced imaging, blood work). This pathway, similar to the CAPHS model, will be implemented to decrease LOS, decrease

costs, increase quality of life, and decrease surgical complications.

APPENDIX I

Patient and Family Experience Undergoing Spinal Fusion Guide for Interview about Pre-Op Experience

Thank you for taking time to meet with me. I am going to ask you questions about your child and family's experience preparing to undergo spinal fusion surgery. This should take no more than an hour. I am going to take notes and record the conversation so we can review it. I will only use your comments in aggregate or de-identified form, no identifiable information about you, your family or your child will be transcribed. You are welcome to skip any questions that you would prefer not to answer. You are also welcome to ask us to go back into the recording and strike anything you would prefer not to be recorded. Is it okay with you if I begin recording now? [Turn on recorder]

Today's date is _____.

My research team is interested in your child and family's experience undergoing surgery for spinal fusion.

First, I have a couple questions about the timing of the surgery:

Date of surgery: _____

Approximately when did you and your medical team begin thinking about spinal fusion surgery? _____

Now I would like to talk with you about three aspects of the preparation process. [First, we will talk about your experiences throughout the preparation process leading up to surgery. Second, we will talk about the specific providers you have interacted with. Finally, I would like to learn about any feedback or suggestions you have for how we can improve this process going forward.]

1. First, can you tell me your thoughts on how the surgery preparation went and about your experiences during the preparation process?
2. Do you feel that all of your child's health issues were addressed prior to surgery?
3. What about the preparation process leading up to surgery went well?
 - a. What aspects were organized?
 - b. What about the preparation process leading up to surgery has been difficult for you or your child?
 - c. What did not go well?
 - d. Other probes: Tell me more about that. Why do you think that happened?

4. Tell me about how your child's providers worked together to get him/her ready for surgery?
 - a. How did they interact and communicate?
 - b. How did that make you feel?
5. Did you feel like there was a provider in charge of your child's pre-op care?
 - a. Who was it: your surgeon or another provider? What did they do to make you feel that way?
 - b. How well did this person take charge of the process?

Now I would like you to think about the interactions you have had with different providers throughout the pre-op process.

6. First, let's talk about the surgical coordinator. This was the person who talked with you and the surgeon to help choose and arrange a date for surgery. Do you remember someone serving that role? Please tell me more about your interactions with the coordinator.
 - a. In what ways were your interactions with the surgical coordinator helpful for planning for your child's spinal fusion?
 - b. What could have gone better?
7. Now could you tell me about your interactions with the surgeon?
 - a. In what ways were your interactions with the surgeon helpful for planning for your child's spinal fusion?
 - b. What could have gone better?
8. **Only ask if child had CCS care:** Now I would like you to tell us about your interactions with the complex care service (CCS) providers who conducted your child's general health assessment.
 - a. In what ways were your interactions with CCS helpful for planning for your child's spinal fusion?
 - b. What could have gone better?
9. Now let's talk about your interactions with the anesthesiologist.
 - a. In what ways was your visit with anesthesia (where they reviewed your child's health assessment and explained the surgical procedure) helpful for planning for your child's spinal fusion?
 - b. What could have gone better?
10. Finally, please tell me about your interactions with your primary care provider.
 - a. In what ways was your primary care provider helpful for planning for your child's spinal fusion?
 - b. What could have gone better?

11. Did any other providers help you prepare for the surgery?
 - a. What was their involvement?
 - b. How did their involvement positively or negatively affect the preparation process?
12. Was your sense that this group of providers was acting like a team on your and your child's behalf?
13. If your child had to undergo surgery again, what would you change while preparing for the surgery?
14. What are your thoughts on how we could improve the process for preparing children for spinal fusion surgery?
15. Is there anything else that stood out to you that we have not already touched upon today?

Thank you for speaking with me.

APPENDIX II

Patient and Family Experience Undergoing Spinal Fusion Post-Op Interview Guide

*Thank you again for taking time to meet with me. I am going to ask you questions about your child and family's experience undergoing spinal fusion surgery. This should take no more than an hour. I am going to take notes and record the conversation so we can review it. I will only use your comments in aggregate or de-identified form, no identifiable information about you, your family or your child will be transcribed. You are welcome to skip any questions that you would prefer not to answer. You are also welcome to ask us to go back into the recording and strike anything you would prefer not to be recorded. Is it okay with you if I begin recording now? **[Turn on recorder]***

Today's date is _____ and this recording is about patient and family experience undergoing spinal fusion surgery.

Today, I would like to ask you about three aspects of your child's surgery and recovery. First, we will talk about your experiences during surgery. Second, we will talk about your child's recovery after surgery. Finally, we will talk about your child's transition out of the hospital.

First, I'd like to ask you about your experiences during the spinal fusion surgery and about the communication between you and the providers here at the hospital.

1. To begin, I would like you to think about your experience during your child's surgery.
 - b. What information was reviewed with you before the surgery?
2. Did you get updates about your child's progress during the surgery? Who kept you informed?
 - b. Did you have enough contact with this person during the surgery?

Now we would like to know more about your experiences while your child was recovering from surgery.

3. Was your child taken to the ICU after the surgery? Can you tell me about that experience?
4. Did you transition from the ICU to the regular medical floor? How did this process go?
5. How did your child's recovery compare to what you expected?

- c. Did your child have any health problems after surgery that made him/her stay in the hospital longer than anticipated?
 - d. Was your hospital stay longer or shorter than you expected?
6. Did you interact with the surgeon, anesthesiologist, surgical coordinator, PCP, CCS?
7. What part of the hospital experience went well? What could have gone better?

Now, I would like to ask about your transition out of the hospital.

8. Can you tell me about your experience ~~after~~ leaving the hospital? How do you think your child's transition from the hospital went?
9. Where did your child go after you left the hospital?
- 10. [PAC - skip if child went directly home]**
- e. Did you feel like the facility was prepared to care for your child after leaving the hospital?
 - f. Did you have clear rehabilitation goals in place?
- 11. [HOME]**
- g. When your child transitioned home, did you feel prepared to take care of your child at home?
 - i. Did you have a clear discharge plan in place?
 - ii. Did you have follow-up appointments in place?
 - iii. Did you have the adequate medications and supplies available?
 - h. What were your experiences caring for your child at home after the surgery?
 - i. Did you feel supported at home after the surgery?
 - i. Did you have someone to call after discharge? Who?
 - ii. Did you have to call them? Did they know your child, were they able to help?
12. How was your primary care physician involved in the transition out of the hospital?
- j. How well did your PCP work with the rest of the providers after your child had been discharged? **(repeat question for Complex Care Service physician - if the child and family were involved in CCS)**
13. How has your child's recovery progressed?
- k. Did your child experience any complications after you left the hospital?
14. What is your child's functioning and quality of life now after the spinal fusion compared to before the surgery?
- l. How does this compare to what you expected?

15. If you had to do this again, what would you change about your transition home/to a facility?
16. Considering the entire process from pre-op to post-op, what went well? What improvements could the team make?
17. Thank you for sharing these experiences. For my final question, 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?

Thank you for speaking with me.

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