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Current Concept Review

A Multidisciplinary Perioperative Care Coordination Pathway for Hip and Spine Reconstruction in Non-ambulatory Patients with Cerebral Palsy

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Abstract

Many non-ambulatory children with cerebral palsy (CP) who are indicated for hip reconstruction and/or spine surgery are medically complex and thus high-risk surgical candidates. A well-coordinated, multidisciplinary team approach for these individuals is essential to reduce the risk of perioperative complications. This review offers an evidence-based overview covering interventions that have been shown to improve safety and outcomes after hip and spine surgery in non-ambulatory patients with CP. Specifically, this review will focus on the team approach to perioperative care coordination with the goals of optimizing medical and nutritional status, reducing postoperative complications, and improving patient and family satisfaction. Further, this review will highlight the associated care pathway utilized at Nemours Children's Health-Delaware, in addition to highlighting key measures that may be adopted by other institutions to help foster organizational cultures that prioritize family-centered care.

Key Concepts

- Nonambulatory children with CP commonly develop significant hip and spinal deformity which can be considered for extensive reconstruction.
- It is important to identify co-morbid medical conditions as well as psychosocial factors for both patients and caregivers as these may contribute significantly to outcome.

- Ongoing, clear communication between team members allows for smooth transitions of care throughout the entire perioperative process.
- Employing a multidisciplinary team approach to the perioperative care of non-ambulatory patients with CP allows for a smooth transition into the postoperative period, limits last-minute care plan changes, and facilitates a quicker recovery for the patient and their family.

Introduction

Many non-ambulatory patients with cerebral palsy (CP) and other childhood-onset disabilities develop progressive hip displacement and/or spinal deformity that requires surgical intervention.[1-3] These patients often have complex medical comorbidities, including seizure disorders, vision and hearing impairments, speech and cognitive delays, gastrointestinal and nutritional problems, and respiratory issues.[4] While intended to prevent painful degeneration and improve function, these high-burden surgical procedures are associated with significant postoperative pain and complications in this medically fragile population.[5] Hip reconstruction has a 20-65% risk of postoperative complications and high revision rates that may approach 35%.[6-8] In addition to the high societal costs to manage these problems, parents rate it as one of their child's most significantly painful surgical experiences.[9] Posterior spinal fusion (PSF) for neuromuscular scoliosis has an overall complication rate that has been reported as high as 50%.[10] Yet, both of these procedures have been shown to improve health-related quality of life, with a risk-benefit profile that supports surgical intervention in the right operative setting.[11-14] Risks associated with these high-burden procedures often correlate with the level of neurologic impairment and associated medical problems. Based on this, the perioperative care of children with CP is complex and resource intensive.[15]

Family-centered care has emerged as the dominant theoretical framework for delivery of healthcare.[16,17] At the heart of this model is the belief that healthcare providers and the family are partners, working together to best meet the needs of the patient. His model encompasses a shared decision-making (SDM) framework wherein the risks and benefits of the proposed surgery can be understood fully by the family within the context of their own lives. Individualized treatment plans represent the gold standard of care.

Currently, there are no consensus guidelines in place to optimize perioperative outcomes in non-ambulatory youth with CP undergoing either hip or spine surgery. The purpose of this article is to discuss the known evidence in this area and to highlight a family-centered pathway that could be used as a model.

Multidisciplinary Team Approach

To meet the needs of patients with CP and their families, a well-coordinated, multidisciplinary team approach is important. The team must include members who have a keen understanding of the disease process and potential problems. The core members of this group typically consist of the orthopaedic surgeon and their respective advanced practice providers, a complex care pediatrician, a nutritionist, a nurse case manager, and a social worker.

Orthopaedic Surgeon

The orthopaedic surgeon serves as the keystone of the multidisciplinary team. Defining achievable and meaningful goals of care is the first step of any surgical discussion. While the decision to proceed with either hip or spine surgery is highly individualized, current and predicted levels of gross motor functioning can help shape discussions with patients and families to set expectations. The natural history of scoliosis and

hip dysplasia in non-ambulatory youth is often one of progressive worsening. These patients should have routine orthopaedic follow-up as well as radiographic hip and spine surveillance at intervals according to their gross motor function classification system (GMFCS) level. These surveillance guidelines are based on prior work from Australia, with adoption by other societies (e.g., AACPDM, POSNA).[18,19]

Regular visits with the surgeon give families an opportunity to ask questions regarding natural history, management options, and discussion of long-term outcomes. This patient-doctor relationship allows surgeons to introduce the concept of surgical intervention to the family with Shared Decision Making (SDM) techniques. The patient's age, medical complexity, functional status, pain level, degree of spine or hip deformity, and caregiver input must all be considered. By clearly delineating the risks associated with the individual patient, the surgeon will be better able to help address family expectations and thus allow them to have a better understanding of what the future holds for their child, well before a surgical decision needs to be made.[20]

In busy orthopaedic surgical practices, the use of orthopaedic Advanced Practice Providers (APP) can be offered as physician extenders, complementing the care of children with special healthcare needs and improving access to the care team. Appropriate identification of coexisting medical and psychosocial factors by the orthopaedic team is imperative to successful surgical outcomes. Orthopaedic APP's may be tasked with performing a comprehensive preoperative evaluation to identify those factors that contribute to successful surgical outcomes. This important step has been facilitated at centers with Complex Care Teams staffed by specialty pediatricians and pediatric APP's whose focus is on care coordination of all of the child's comorbidities including orthopaedic needs.

Pediatric Support

The American Academy of Pediatrics endorses perioperative involvement of pediatricians to help recognize and address health problems that could jeopardize a child's health as they undergo surgery.[21] It has been shown that including pediatricians in preoperative care is associated with increased attention and recommendations for the management of coexisting conditions[22,23] as well as fewer last-minute care coordination activities.[24] Ultimately, these key team members serve as the hub for communication between all subspecialties to coordinate medical optimization as well as to communicate with the family throughout the process.

The perioperative assessment should include evaluation of neurologic status, airway anomalies (e.g., difficult intubations, obstructive sleep apnea, history of airway surgery), cardiac and pulmonary function, and coagulation history. Pulmonary complications, such as pneumonia, respiratory failure requiring prolonged intubation, bronchospasm, and atelectasis are common following both hip reconstruction and posterior spinal fusion in GMFCS IV and V patients.[25-28]

Significant history of respiratory illnesses, including hospitalizations or concerns for sleep apnea, should trigger an evaluation by a pulmonologist. Not only does pediatrician input help to optimize preoperative health, but coordination and communication with pediatric hospitalists are further integrated into the management of postoperative concerns.

Nutrition Assessment

Malnutrition is frequent among patients with CP. Early literature suggested that decreases in traditional nutritional laboratory values, such as albumin, total protein, and lymphocyte count were associated with increased complications in pediatric spine surgery, specifically an increase in surgical site infections.[29] Low values in these same laboratory findings are strongly correlated with increased risk of infection in studies of large numbers of patients of high-risk total joint arthroplasty.[30] While there is a strong association between preoperative BMI percentile on GMFCS stratified growth charts and surgical site infection following spinal deformity surgery (odds ratio=13.6), a

similar relationship using Brooks CP growth charts has not been identified.[29-32]

Modifying nutritional risk factors to help improve outcomes can be very challenging. A nutritional consult alone does not decrease the risk of infection in neuromuscular PSF.[31,32] However, the initial nutritional assessment can identify those patients more at risk and potentially identify areas for nutritional improvement. There is very little consistent literature that definitely guides us on the management of nutritional factors. This is due to the heterogeneity of this patient population (ex: age, BMI, co-morbid conditions, social support) and the wide variety of treatment variables (surgical, non-surgical, and postoperative rehabilitation). It is incredibly hard to have a study where we control all of these variables with enough statistical power to define a reliable preoperative factor (BMI, G-tube, blood test) that is clearly associated with a high rate of complications. It is even harder to prove that correction of that factor reliably decreases those complications for the same reasons. Despite this, common sense and provider and parent preference do lead us to do the best we can to reasonably improve nutritional health in clearly debilitated patients. Occasionally, delaying surgical intervention may be wise for optimization to occur, particularly for cases where the child is especially cachectic. In some cases, insertion of a gastrostomy tube preoperatively can help in achieving this nutritional optimization.

Case Management

The role of nurse case managers is to determine what physical and environmental needs are necessary to allow safe passage through the perioperative period. They can address the many roadblocks to safe and expedient discharge. Delayed access to required medical equipment (e.g., wheelchairs, commode chairs, etc.) has been cited as a common barrier to discharge.[33] Often, the equipment needs of youth with CP can be anticipated preoperatively and delays can be avoided. Previous literature has shown that post-discharge transportation, access to home nursing care, and caregiver education are all causes of delayed discharge and increased length of stay and cost.[34] By having ongoing nursing case management involvement with clear interdisciplinary communication regarding patient and caregiver needs, efficient discharge goals may be met.

Social Workers

The primary role of the social worker is to help determine whether the patient and family are emotionally and practically prepared for surgery. Caring for a child with chronic functional limitations has been shown to have an impact on the health and quality of life of caregivers.[35,36] Mental health diagnoses and environmental stressors (affecting both the patient and/or caregivers) are important social determinants of health. These factors must be considered when setting goals, considering quality of life, and, ultimately, the patient and caregiver's ability to comply with rigorous postoperative rehabilitation programs. As such, successful surgical treatment should involve early social work assessment to support the needs of the entire family.

Nemours Children's Health Delaware Perioperative CP Care Coordination Pathway

The general recommendation for perioperative care coordination for patients with CP and CP-like conditions at our center follows a philosophy of family-centered care and SDM, which allows each encounter to be an opportunity for improved perioperative education. The following represents our institutional operations and aspirations.

Hip reconstruction and PSF should be generally scheduled *a minimum* of 6 months in advance in order to allow time to optimize patient health. This period of time is used for medical optimization, family education, and communicating with the patient's greater community care team (e.g., primary care team, home nursing agency, school) to employ support strategies.

Our highly experienced APPs play a critical role in the perioperative care of children with CP. Once the decision for surgery is made and a surgical date has been set, the

development of an individualized perioperative plan is started by an APP who is a member of the CP team. This begins with a comprehensive review of the patient's medical record and an in-depth discussion with the caregiver to determine the current needs of the patient and family. A personalized perioperative framework that is standardized for each procedure (hip reconstruction, PSF) is then applied to each patient. This structure allows for individualization while simultaneously ensuring quality and safety. These standardized pathways were developed with multidisciplinary input (Figure 1**)** and the plan is documented in the chart for easy reference by all members of the care team.

A tailored approach to perioperative planning, rather than the use of a 'one-size-fits-all' model which can overlook the unique needs of youth with CP, is recommended for a balance of efficiency and safety. Overlooking individual needs can cause either missed opportunities for care (e.g., extended use of incisional negative pressure wound therapy in patients with a risk of skin issues secondary to a pre-existing collagen disorder) or create situations where patients undergo evaluations or testing that are not medically necessary. An example of this would be requiring preoperative pulmonary evaluation for all patients scheduled for PSF. If the patient had no prior respiratory issues and a moderate, flexible thoracolumbar curve, then a pulmonology evaluation would not necessarily provide valuable input beyond what was already known through the patient interview. These unnecessary clinical evaluations can add to caregiver burden (e.g., missed work, transportation cost) and thus should be carefully considered.

All scheduling for perioperative appointments should be attempted through a collaboration of administrative

CP Hip Reconstruction Perioperative Pathway (GMFCS IV-V)			
Imaging	*Labs*	*Consults*	*Education*
Pelvis Xray (AP only) • Within 2 months preop CT Pelvis • Within 2 months preop	ASAP (to be done at time of decision for surgery): CBC with diff, CMP, PT &PTT, Vit D Within 2 weeks of surgery: CBC with diff, CMP, PT&PTT, Urine or serum HcG • *if female ≥ 12yo or has menses* • Within 72 hr of surgery Type and Screen • Within 14 days preop Urinalysis & Urine Cx • Within 10-14 days of surgery • If known/suspected neurogenic bowel bladder Blood Product Reserved: • 1 unit PRBCs per pelvic osteotomy **Additional labs pending individual patient needs based on preop assessment*	Medically complex Peds • Minimum 8 weeks prior to surgery • If have ≥2 systemic issues Nutrition: • If concern after initial screening Orthopaedics: • Need to be seen 4-8 weeks prior to surgery for preop visit Urology: • If history of neurogenic bowel/bladder, UTI within 6 months of surgery or ≤3 voids per day Rehab medicine: • Depending on functional goals.	Pre-Operative: • Risk/benefit alternatives • LOS • NPO, Skin prep • Pre-op consults • Contact school, home agency, workplace (FMLA) • Urine/bowel habits • Home equipment/needs Intra-operative: • Procedure • Hardware • Blood product Post-operative: • PICU vs Floor • Blood loss monitoring • Pain Control • Medical Co-Management Post-hospital: • Home pain management • Home ROM and PT ○ WB/ROM restrictions • +/- immobilization • Return to school Follow up: 2-3 weeks (incision check) 4-6 weeks (XR – AP/lateral pelvis) -3 months (XR 2vw pelvis) 6 months (XR 2 vw pelvis) 12 months (XR 2vw pelvis)

Figure 1. *Continued*

CP Neuromuscular Scoliosis Posterior Spinal Fusion Perioperative Pathway (GMFCS IV-V)			
Imaging	*Labs*	*Consults*	*Education*
2vw sitting scoliosis Xray • 2-4 weeks from surgery Bending Xrays: • 2-4 weeks from surgery	ASAP (to be done at time of decision for surgery): CBC with diff, CMP, PT &PTT, CRP, prealbumin, Vit D Within 2 weeks of surgery: CBC with diff, CMP, PT&PTT, prealbumin & CRP Urine or serum HcG • *if female ≥ 12yo or has menses* • Within 72 hr of surgery Type and Screen • Within 14 days preop Urinalysis & Urine Cx • Within 10-14 days of surgery • If known/suspected neurogenic bowel bladder **Additional labs pending individual patient needs based on preop assessment* Blood Product Reserved: • 4 unit PRBCs, 2 unit platelets and 1 unit FFP	Medically complex Peds • Minimum 8 weeks prior to surgery Nutrition: • ASAP: Baseline labs • FUV 2-4 weeks preop Social work: • ASAP: intake • +/- reassessment based on fneeds Orthopaedics: • Need to be seen 4-8 weeks prior to surgery for preop visit Urology: • If history of neurogenic bowel/bladder, UTI within 6 months of surgery or ≤3 voids per day Rehab medicine: • Depending on functional goals. Pulmonology: • Curve requiring anterior/posterior release • > 90° curve • Pulm history: repeat PNA, BPD, chronic respiratory failure, OSA, BIPAP/CPAP, Trach & vent dependent Cardiology: • If history of cardiac issue • +/- cardiac anesthesia screening Bone Health: • If history of fractures, seizure medications or PPI, GMFCS V	Pre-Operative: • Risk/benefit/alternatives • LOS • NPO, Skin prep • Pre-op consults • Contact school, home agency, workplace (FMLA) • Urine/bowel habits • Home equipment/needs Intra-operative: • Procedure • Hardware • Blood product • Cell saver & neuromonitoring Post-operative: • PICU vs floor (anticipate PICU) • Blood loss monitoring • Pain Control • Medical Co-Management • Incisional NPWT (min 5-7 days) Post-hospital: • Home pain management • Home ROM and PT • Wound care • Return to school Follow up: 3-4 weeks, incision check 4-6 weeks (XR 2vw scoliosis) 2-3 months (XR 2vw scoliosis) 6 months (XR 2 vw scoliosis) 12 months (XR 2vw scoliosis)

Figure 1. *Standardized Perioperative Care Pathway for Hip and Spine Reconstruction for Non-ambulatory patients.*

staff as dictated by the individualized care plan. These appointments are divided into three key time phases and are valid for both hip and spine procedures:

- Early appointments (scheduled as soon as possible after the family agrees to the surgical procedure):
    - Orthopaedic APP for perioperative plan development
    - Social Work assessment
    - Nutritionist assessment
- Intermediate appointments (scheduled for 1-3 months from surgery)
    - Complex Care Pediatrics assessment
    - Sub-specialty evaluation (as needed)
    - Nutritionist re-assessment
- Final appointments (scheduled for within 14 days of surgery):
    - Orthopaedic surgeon review of surgical plan and determination of any additional imaging required.
    - Preoperative diagnostics (e.g., CT scan)

In addition to interaction with the APP to discuss the perioperative plan, patients scheduled for hip reconstruction and PSF meet early with both social work (SW) and nutritionist teams. Early SW screening allows for relationship building that is vital to establishing family trust to allow the team to be aware of any sensitive issues that might impact care delivery or recovery (e.g., housing and food insecurity). This allows for strategy development to overcome barriers to accessing care. At our institution, this has decreased last-minute surgical cancellations due to non-medical causes.

The nutrition team reviews the patient's growth chart and has detailed discussions with caregivers regarding dietary habits or feeds. This assessment takes place approximately 6 months prior to surgery to allow time for any changes to take effect. All patients scheduled for PSF are referred for nutritional screening bloodwork (CBC w/differential, CMP, PT & PTT, prealbumin, serum vitamin D, bone-specific alkaline phosphate, and CRP). Hip reconstruction patients are referred as indicated through health review (e.g., low/high BMI or oral feeder with selective diet that limits fruits/vegetables and protein). The goal is not to normalize nutrition, since this has been reported to be an unrealistic goal.[32] A more appropriate goal would be to screen for and mitigate decreasing trends in growth and BMI well in advance of the operative procedure.

Evaluation by a complex care pediatrician/hospitalist for a preoperative assessment should occur 2-3 months prior to surgery. This allows ample time for additional medical workup or referral to additional sub-specialists (e.g., new onset neurogenic bladder). Sub-specialty evaluations are arranged at a minimum of 4 weeks prior to surgery.

Generally, the secondary nutritionist appointment is coordinated with these intermediate appointments, one to two months prior to surgery. It is used to assess the efficacy of previous nutritional interventions and to ensure a proper growth chart trajectory.

The orthopaedic attending continues to have routine encounters with patients approximately every 3 months leading up to surgery, with the final preoperative appointment occurring 1-2 weeks prior to surgery, with either the surgeon or APP. This is generally coordinated with final preoperative imaging, laboratory testing, and SW as needed. We feel that this approach maintains the therapeutic relationship and allows more opportunity for SDM discussions to occur between the surgeon and the family. The final appointment allows for the definitive examination (including skin integrity check) and the opportunity to recap prior education regarding the procedure, anticipated postoperative care burden on the family, the postoperative analgesic plan, and to recap the family's situation with respect to social determinants of health.

As a care team, there are standardized opportunities for multi-disciplinary case review. At our institution, these conferences occur 4-6 weeks prior to surgery, and again the week of surgery. At 4-6 weeks preop, the APP formally re-screens the patient chart to monitor the progress of the peri-operative plan, identify any red flags, and ensure that postoperative appointments have been scheduled. Then, there is a final, multidisciplinary team review done in the final days prior to surgery as part of weekly rounds. At this weekly meeting, there is transition of roles from outpatient to inpatient providers. The members of this multidisciplinary meeting are as follows: orthopaedic surgeons, orthopaedic CP APP, ortho administrative assistant, orthopaedic inpatient service APP, PMR, SW, Medically Complex hospitalist on service for the week, physical therapy representative (CP outpatient and acute care), bedside nursing leadership from orthopaedic floor, pain team/anesthesia, and inpatient case management. This ensures continuity of care while the patient moves from outpatient to inpatient level of care, then returns to the community. A smooth hand-off occurs from outpatient to inpatient APP along with dissemination of duties between CP social worker and case management.

Upon discharge, handoff is given between the inpatient ortho APP and outpatient ortho team, with appropriate follow-up visits arranged prior to discharge. Generally, initial appointments allow for assessment of wound healing, discussion of family coping at home, screen compliance with home therapy regimen, and assess efficacy of the postoperative pain regime. This also helps identify medical management concerns (e.g., constipation) and allows for further referral to the appropriate pediatric subspecialty when necessary (Figure 2).

Limitations & How to Generalize

The described approach involves an idealized setting with readily available specialists and longstanding experience. Socioeconomic factors, specialist availability,

Figure 2. *Timeline for CP perioperative care pathway.*

and access to a full complement of multi-disciplinary care team members will necessitate practice variations when caring for medically complex CP patients. The following are key features that can be introduced at many institutions without requiring significant hospital resources:

- Identify a complex care pediatrician who has a keen understanding of the medical issues faced by youth with CP and an interest in perioperative optimization.
- Identify a nurse or other APP who can serve as a liaison between the care team and family. This person is vital to help plan perioperative care coordination.
- Create a standardized perioperative framework for hip reconstruction and posterior spinal fusion that allows for individual tailoring to meet patient and family needs.
- Discuss with the hospital-based social workers the minimal needs to move typical postoperative discharge planning into the preoperative assessment and needs planning timeframe.
- Find a time for a preoperative care coordination meeting with all pertinent stakeholders.

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