Complex Care Journal

To advance the care of children with medical complexity with a focus on multi-disciplinary team approaches.

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complexcarejournal.org

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Instructions for Authors

Complex Care Journal (CCJ) is a self-published, peer-reviewed, practice-oriented journal whose purpose is to advance the care of children with medical complexity (CMC) with a focus on multi-disciplinary team approaches. The journal is open access with no article processing charges.

CCJ publishes literature relevant to pediatric complex care providers including program reports, complex care case reports focusing on multidisciplinary and care coordination aspects, reviews of recent literature and educational resources related to complex care, policy reports, innovations in systems of care, and other practice-based evidence updates aside from original research. *CCJ* does not define the term “children with medical complexity” but rather will defer to definitions commonly being used in the literature at present time.

Submitting: If you are interested in submitting an article (see example article types below), please email your manuscript to complexcarejournal@gmail.com. Please have contact information of the corresponding author in this email. Submission implies commitment to publish in *CCJ*. Authors should not submit the same manuscript to another journal at the same time nor should the work be previously published.

Peer Review Process: Once a manuscript has been received by the editorial board, it is reviewed for appropriateness for *CCJ*. If deemed appropriate, the board designates two (or more if indicated) reviewers to the manuscript. Our unique peer review process includes an open and collaborative method to reviewing the manuscript between the authors and the reviewers (non-blinded to authors or reviewers). The manuscript is placed in a shared, editable document where all members add comments through “track changes” over a four week time period. This process starts with the reviewers providing initial comments but then is open to this small team working together to come with a final manuscript. At the end of the comment period, the author has to approve the edited manuscript before it is brought again to the editorial board before publishing.

Article Types (not limited to but as an example of publications well suited for our journal)**:**

Program Reports: A comprehensive description of a medical program that provides care to CMC. Programs that qualify could be outpatient primary care programs, outpatient consultative services, inpatient primary or consultative services, multidisciplinary clinics which mainly serve children with medical complexity, or a combination thereof. Priority will be placed on publishing reports from programs serving all children with medical complexity and which do not limit their population to specific diagnoses. The format of a Program Report will be best determined by

the author and the function of the program being described, though editors will prioritize more comprehensive reports. A potential outline for the Program Report is on the website; components are not required for publication.

Education Report: A comprehensive description of a medical educational program that focuses on teaching on care to CMC. Programs that qualify could be rotations/electives, lecture series, or components of a larger curriculum for students (of all medical disciplines), interns/residents, fellows, or post-degree/CME. Priority will be placed on publishing reports from curriculums teaching on care of all children with medical complexity and which do not limit their population to specific diagnoses. The format will be best determined by the author and the function of the program being described though editors will prioritize more comprehensive reports. A potential outline for the report is on the website; components are not required for publication.

Complex Care Case Reports: Case reports are an import method to further clinical care in a developing field. Case Reports which involve multidisciplinary teamwork and care coordination will be prioritized for publication. We welcome cases of care coordination with community and non-medical agencies. We also highly encourage family involvement in the writing of the case report and support offering family co-authorship.

We will also consider case reports diagnosing unique manifestations or detailing novel symptom management of complications of chronic disease in CMC (ie: dysautonomia). We are generally not looking for initial diagnosis of a complex condition. Diagnostic dilemmas (without patient outcome at time of publication) will also be considered but must be discussed with editorial staff prior to submission.

All cases should be real cases and must have consent from patient or family and identified providers. Consent must be attested by authors in article (see *Informed Consent* on website).

Publication Reviews of Research Articles or Educational Resources: Reviews of recently published (within the last 6 months) research articles or educational resources relevant to care of children with medical complexity are welcome. Research articles should be indexed (have a DOI or PMID). Educational resources can come from MedEdPORTAL or other widely-available online educational resources. Format includes article/resource summary followed by a section with personal commentary. Reviews typically will be less than 1000 words with no abstract. You can not review your own literature or educational resources.

Commentaries: *CCJ* accepts commentaries in many domains related to pediatric complex care including but not limited to: clinical care advances, care coordination innovations, local and national health policy updates, and novel ideas related to systems of care.

Please see the following link for complete guidelines including policies, ethics, and publishing style: http://complexcarejournal.org/publication-guidelines.

A Simple Thanks

This journal could have not come to fruition without the support of many.

Authors: Our early adopters. Thank you for trust and patience; without you we would not have this first edition.

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Community: Thank you to the complex care community whose deep devotion to improving care for children with medical complexity has given us the motivation and momentum to develop this journal. Continue to provide ideas and experiences to further CMC care!

LETTER FROM THE EDITORS

The Rationale For *Complex Care Journal*

RISHI AGRAWAL MD MPH, KRISTINA MALIK MD

This is a singular time in health care and society at large. At this time, as we confront both pandemic and economic decline, sharing of information is more essential than ever. Research in pediatric complex care has been growing rapidly and there are many outstanding journals in which to publish original research in complex care. The purpose of this journal is not to compete with existing journals for the type of complex care content already being published; instead, the purpose of this journal is to provide a home for content that is not currently being published, or written for that matter, but nonetheless would be useful to advance complex care.

For example, much of the focus of complex care is building systems and programs of care delivery that are interdisciplinary and family-centered. There is tremendous innovation in health delivery occurring in many complex care programs in terms of staffing, use of technology, models of care coordination, interface with payers and governmental entities, etc. Yet many of those innovations are siloed when they ought to be shared and disseminated. By publishing "Program Reports," Complex Care Journal aims to provide a mechanism to share such information.

In our first edition, we highlight these innovations and variations in how care can be delivered in three different program reports. "The Milwaukee Program" provides a synopsis of an inpatient and outpatient complex care program including program expansion after a Health Care Innovation Award (HCIA); "Almost Home Kids" highlights a unique hospital-to-home transitional care center for children with medical complexity (CMC) with patient and family outcomes; "The Complex Care Service at the Montreal Children's Hospital" overviews a complex care program but also focuses on care innovations they have piloted.

Our clinical cases are singularly challenging. Often we have little evidence base from which to draw conclusions on how to manage our patients' problems, drawing instead on a combination of oral tradition, trial and error, and luck. The typical published case report narrowly focuses on a novel diagnosis or perhaps the initial pharmacological or surgical treatment of a single condition. Less typically do we see approaches for patients with multiple conditions. And almost never are novel approaches to coordinating care, addressing social determinants of health, incorporating families as partners in care, navigating community systems, advocating for

services, resolving ethical dilemmas, etc written about in case reports. Complex Care Journal welcomes case reports that provide insights helpful to other complex care practitioners.

In this edition, we present a case report embedded within a clinical care framework. “Chronic Pain in Children with Severe Impairment of the Central Nervous System: A Framework for Assessment and Initial Management” uses a case presentation to support a novel clinical pain assessment tool. This hybrid article focusing on a clinically important tool for an unique patient population would have hard time finding a home in many traditional journals; we hope to support innovative publication types such as this to further advance care.

Given the demands of complex care in terms of provider skills, there is much work to be done to determine how to train a workforce to meet the needs of children with medical complexity. Many academic institutions have novel ways of educating trainees at various levels and, as with complex care programs, we believe these innovative education programs ought to be described and shared. Complex Care Journal welcomes “Educational Reports” which would help inform others' efforts. In “Complex Care Elective”, we present the report of a learner-directed pediatric resident complex care elective.

Complex care is a field in its infancy. There are many great ideas among those in the field about how to advance care, improve health policy, make the profession sustainable, etc. Airing and debate of ideas is critically important at this stage, and Complex Care Journal welcomes commentaries on any and all topics relevant to complex care. This edition we share a commentary entitled “Crisis as an Engine of Change” which focuses on harnessing the current shifts in care during this pandemic to improve care for CMC.

When we say that our objective is not to compete with other journals, we mean it. We are not looking for typical original research studies that are intensive with data and statistics. In fact, Complex Care Journal promotes other journals’ work by publishing a list of new complex care articles in the literature and publication reviews so that the busy practitioner can be as well informed of new developments as possible. In this edition, we present “Two Recent Policy Statements About Safe Transportation” which reviews two recent policy statements by the American Academy of Pediatrics regarding safe transportation for children with special health care needs. We even hope other complex care focused journals will emerge or existing journals will morph into having more of an emphasis on complex care. We believe the field is best served by a variety of choices.

So, members of the complex care community, please do not keep your observations, innovations, and ruminations to yourself! Let’s share them for our collective benefit! This pandemic and its economic impact will challenge us and our patients greatly, but sharing our insights and experiences and ideas with each other will be to the collective benefit of all of us and our patients. If you have an idea, email us (complexcarejournal@gmail.com) and we’ll give you guidance.

PROGRAM REPORT

THE MILWAUKEE PROGRAM:

The Pediatric Complex Care Program (CCP) at the Children's Hospital of Wisconsin (CHW) / Medical College of Wisconsin (MCW)

Timothy E Corden, MD[1], Tera Bartelt, MS, RN[2]

ABSTRACT

Objective: Describe the complex care program at the Children's Hospital of Wisconsin, Medical College of Wisconsin – history, current structure, outcomes, research / quality improvement projects, and finances.

History: Program started by Dr. John Gordon and Holly Colby, RN Program Manager in 2002.

Current Structure: Program serves ~650 CMC and their families through care coordination and medical co-management in both the ambulatory and inpatient environments. Team is composed of Care Coordination Assistant-RN dyad with the RN as the families' main point of contact. Each patient also has a faculty physician or APNP serving in conjunction with the patient's assigned dyad. Clinical Research Coordinator, Social Workers, and administrative staff support the program.

Outcomes: Favorable satisfaction ratings from families, primary care providers, subspecialty colleagues; cost savings identified by pre-post analysis.

Research: Primarily focused on program function, financial outcome, and clinical and family impact.

Finances: Hybrid value-volume based reimbursement structure.

[1]Dr. Corden is Kaemmer Professor in Pediatrics, Vice-Chair of Population Health, Section Chief Special Needs, Department of Pediatrics, Medical College of Wisconsin and Medical Director of the Complex Care Program at the Children's Hospital of Wisconsin.
[2]Ms. Bartelt is Nurse Clinical Manager for Complex Care, HIV, and Down Syndrome programs, and is the Ambulatory Advanced Practice Nurse at the Children's Hospital of Wisconsin.

INTRODUCTION

The intent of this article is to provide a brief synopsis of the pediatric complex care program (CCP) at the Children's Hospital of Wisconsin (CHW) / Medical College of Wisconsin (MCW), "The Milwaukee Program." We describe the program's history, expansion and current structure after a Health Care Innovation Award (HCIA), recent outcomes, ongoing and future areas of research / quality improvement, and our thoughts on how the care of children with medical complexity can serve as a model for the enhancement of care delivered to all children. We strive to define "value" as the improvement of health for a population, one child and family at a time.[1,2]

HISTORY

The Milwaukee Program was co-developed in 2002 by Medical Director Dr. John Gordon, a pediatric critical care physician from MCW, and Holly Colby, RN MS CNS, Program Manager from CHW. As an intensivist, it was not difficult for Dr. Gordon to appreciate the growing population of children with medical complexity (CMC), often tied to technology and with frequent admissions to the pediatric critical care unit (PICU).[3] The hospital was very good at doing what it was designed for, treatment and discharge; but not well-equipped to optimize the ongoing health of CMC and the function of their primary caregivers, their families. The Special Needs Program (SNP), as it was originally titled, was designed to be a tertiary care – primary care partnership, assuring that each child would have comprehensive care. SNP provided care coordination services, helped families negotiate the maze of medical and community services, facilitated communication, provided medical co-management with pediatric subspecialists, and provided a single point of contact 24 hours a day for the child's health needs. The program brought services to children in their home, ambulatory, and inpatient environments.[3]

The Milwaukee Program, along with other early complex care programs began to publish reports illustrating the cost savings associated with CMC enrollment.[4] With CMC being pediatrics' "super-utilizer" high cost population, Wisconsin Medicaid came to appreciate the effective management and associated cost savings for children in the Milwaukee Program.[3] In 2006, Wisconsin Medicaid began paying a small monthly care coordination fee to program nurse coordinators and physicians in an effort to encourage growth of the program in support of CMC in Wisconsin. Leadership at CHW

and MCW were also early and strong supporters of the SNP, advocating for and providing “gap funding” that sustained the program when the program’s revenue did not cover expenses, funding that they continue to provide as needed today.

HCIA EXPANSION AND CURRENT PROGRAM STRUCTURE

In a further effort to build upon the demonstrated favorable clinical and financial outcomes produced by the Milwaukee Program, Wisconsin Medicaid was awarded a Health Care Innovation Award (HCIA) in 2014 entitled, “The Special Needs Program for Children with Medical Complexity.”[4] The award brought together the Milwaukee Program, Wisconsin Medicaid and American Family Children’s Hospital (AFCH) in Madison. HCIA awards grew out of the Affordable Care Act with an intention of exploring new service delivery and payment models leading to “better health, better health care, and lower costs” with a focus on unique populations with historically poor outcomes.[5] The grant objectives were to (1) extend the Milwaukee Program’s model to a larger number of Wisconsin CMC by expanding capacity in the Milwaukee Program and starting a similar program at AFCH and (2) use the expanded service population data to support the development of an innovative payment model for the population going forward. The population served prior to the HCIA award was approximately 200 CMC and their families; the Milwaukee Program is now serving over 650 CMC and their families. During the HCIA period Dr Gordon retired, and leadership transitioned to Dr. Timothy Corden, also a critical care physician.

PROGRAM ENTRY (Enrollment Criteria)

Children may be referred to the Milwaukee Program by anyone identifying the need for services, such as a PCP, subspecialists, bedside nurse, school nurse, or the family themselves. To enter the Milwaukee Program a child must meet both complexity and fragility criteria. *Complexity*: chronic conditions involving three or more organ systems and at least three subspecialists attending to the child’s care. *Fragility*: one or more inpatient admissions totaling at least five days or 10 subspecialty clinic appointments within the year prior to enrollment. For children entering the program out of the neonatal unit, clinical judgement is used to project anticipated fragility. Although not a formal component, social complexity (e.g. parent / guardian support at home, medical literacy, food and housing security, child protective services) is also taken into consideration when

considering program entry. Enrollment is voluntary for families, and children are rarely enrolled if their care coordination needs are met by another program within the CHW/MCW system.

ENROLLMENT VISIT and establishment of the primary complex care team

Each child and family meet with their primary complex care team face-to-face for an initial 90-minute enrollment visit. The team consists of a CCP medical provider, who is a faculty physician or advanced practice nurse practitioner (APNP), an RN care coordinator and a care coordination assistant (CCA). Care coordination assistants are not required to have a degree, many are Certified Nurse Assistants and most come to the complex care program from administrative supportive roles within CHW and therefore know the CHW system well.

The RN and CCA function as a standing dyad for all the children they care for. Typically, prior to the enrollment visit the CCP physician or APNP prepares by reviewing the child's medical record including outside records when available, a potentially lengthy process. At the visit, a medical history and exam is documented by the physician or APNP; the RN and CCA explore resources, social impacts, catalog medications and technologies, review community interactions, and insurance needs and create an RN/CCA care plan that is included in the initial documentation. The primary products of the enrollment visit are a detailed medical assessment and plan by systems including documentation of family goals, and a to-do list table. These items, along with the social and resource notation from the RN and CCA, make up the child's Plan of Care. The provider also reviews and edit the child's problem list in the EHR and creates a brief summary of the child's medical state referred to as the Care Coordination note (see inpatient section for details of Care Coordination note). The team spends an average of 13.5 hours total time in the first month on the review, enrollment visit, and developing the Plan of Care.

ONGOING CARE

After the enrollment visit, the complex care team sets about helping the family put their Plan of Care into action. The "go to" contact for families is the RN-CCA dyad, with frequent contact by phone, through EHR messaging, or in person. The RN triages family questions, brings in the complex care physician or APNP as needed to assist with medical concerns, attends key subspecialty appointments and care conferences with families, and works with the CCAs to

arrange clinical appointments, work through community resource needs including insurance, school, home health and respite accommodations. The addition of the CCA was a key component of the grant expansion. Prior to the CCAs being added to the team, RN caseloads were capped at 35-40 families; with the addition of the CCA the RN/CCA dyads now care for up to 90 families. The Milwaukee Program currently has nine CCA-RN dyads. For complex social issues the program also has 1 FTE dedicated social work professional for the team and family to utilize. Families are contacted by their CCP team's CCA at least once per month to check in on the child's health and ongoing needs, and the RN calls shortly after each inpatient admission. After enrollment, children are seen in the CCP clinic at a minimum of every six months to update their Plan of Care.

Program physicians and APNPs are actively involved with medical co-management once a child is enrolled. The CCP physicians and APNPs work closely with the child's primary care physician and subspecialists, offering a holistic perspective for the child's care, helping to optimize the interaction of all the different types of care being delivered. Over time, the primary CCP physician or APNP often becomes the person who knows the child's tertiary medical perspective the best. Families come to value the CCP provider as a trusted advocate for medical decisions. The trusting relationship developed between families and their CCP team is felt to be the foundation for the program's effectiveness. The Milwaukee Program also continues to offer a 24-hour phone access for families to reach a CCP provider at any time to discuss urgent health care concerns.

Patient panel sizes per FTE are ~80 for APNPs and ~65 for faculty physicians; faculty ratios are lower due to their responsibilities beyond clinical work and also to accommodate the time needed to serve as collaborating providers for the APNPs. Currently the Milwaukee Program has nine APNPs representing 8.5 FTEs and three physician faculty representing 2.75 FTEs with two open fulltime faculty positions.

Patient graduation from the program is discussed if a child no longer meets criteria, or if the CCP team and family feels they no longer need programs services. Transitioning children to adult care as they age beyond the traditional pediatric time range remains a challenge.

INPATIENT SERVICE

The Milwaukee Program's inpatient service consults on all program enrolled-children

admitted to CHW, participating during bedside rounds and documenting daily progress notes.

The team also is available to consult on children being seen in the emergency department. Daily CCP inpatient census prior to the HCIA award averaged ~8 patients; the current average is over 20 patients with spikes to over 40 children during respiratory season. The CCP providers rotate through inpatient service, with one CCP faculty physician and two APNPs on service at any time. The faculty physicians are on service for a week at a time and are the identified collaborating physician for the APNPs for that week. For inpatient continuity, APNPs also try to schedule their inpatient time in week blocks. The inpatient team brings historical knowledge of the child's medical and social situation to the inpatient environment, emphasizing what has worked or not worked in the past, awareness of medications and baseline technical equipment needs and settings, and knowledge of what the child is like when well and when ill. The team can aid the primary admitting service with management decisions, smooth out environment of care transitions, and are strong advocates for a family's knowledge and wishes for their child. Because a child's primary complex care physician or APNP may not be on inpatient service when a child is hospitalized, the inpatient staff remains in contact with the primary complex care team when needed. The child's primary CCP team – physician or APNP, RN, and CCA communicate regularly with the inpatient team to discuss care and visit the child and family in the hospital when the team member's time allows.

The CCP inpatient team and our other hospital colleagues are reliant on the documentation and input from the child's primary CCP team. The Milwaukee Program is continuously trying to optimize our various note templates to provide useful and easily-accessible information to aid each child's care; documentation impact is also an active area of research (see next section). All of The Milwaukee Program's note templates are available on request, including: *inpatient consult, daily rounding, hospitalization summary*, and *care coordination* notes. The *hospitalization summary* lives as a shared document during the hospital stay and is updated daily by the physician or APNP seeing the child; at discharge, the document is edited for clarity, signed, and routed to the child's primary complex care team. The *care coordination* note (figure 1) is a brief summary that highlights who the child is and what a

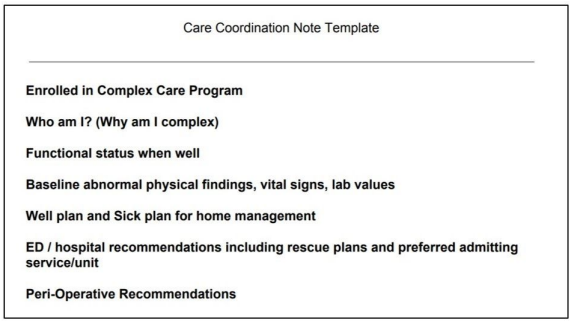

Figure 1. Care Coordination Note template

caregiver needs to know to directly render care; the note is also strategically placed within the EHR to make it hard to overlook. The "who am I and why am I complex" initial portion of the *care coordination* note is intended to influence hospital culture to view children with medical complexity as individuals with distinct stories and not simply as a group of chronic conditions. Creating the *care coordination* note also allows us to reach out to our subspecialty colleagues to help formulate and update action or sick plans; a process that not only improves care but also fosters a team approach across subspecialties.

PAYMENT MODEL

Through the HCIA grant process our program along with our CMC partners at AFCH developed a strong relationship with our assigned WI Medicaid team. Payer and clinician partners developed trust in each other, an understanding of the clinical goals and the process needed to serve CMC and their families, and an appreciation of each other's position on what was and what was not possible regarding a payment model. This relationship was the main reason behind the successful negotiation of a sustainable payment model, achieving one of the HCIA goals. Details of the plan can be found at https://www.forwardhealth.wi.gov/kw/pdf/2018-13.pdf. Of note, it became apparent to Wisconsin Medicaid and the other HCIA partners that the actuarial risk presented by the small and highly volatile CMC population was too great for a health care system to enter into risk-based contracting. Instead, the model continues to allow the complex care programs to bill fee for service for face-to-face encounters, but now also pays a team-based sum for previously non-reimbursable care coordination time and effort. Support for the payment structure was heavily reliant on time-based studies, which documented the amount of time each CCP team member spent on each individual patient as well as other CCP general patient-related activities on a daily basis. With this data, a relatively simple model was developed based on the costs of the program (i.e. time and personnel required to deliver the CCP services) and the impact of the CCP services on health care costs. Two team-based payments were established: an *enrollment fee* for effort surrounding the enrollment visit and

development of the initial Plan of Care; and an *ongoing fee*, a monthly payment for all enrolled children with a meaningful interaction with the program. The payment model outcome reflects Dr. Gordon's initial simple yet elegant concept, "the program saves money, the program costs money, make the program sustainable and it will continue to save health care dollars beyond its costs."

Although the current model is not considered innovative to some audiences, we feel this team-based payment structure offers novel and unique advantages by ensuring payment for all essential personnel involved in the care of CMC (research coordinator, administrative assistants, CCAs, RNs, physicians and APNPs). The payment model aligns incentives for the team approach - all members are needed for a positive clinical outcome and are valued. Both of our oversight clinical/financial centers, CHW (RNs, CCAs, Social Workers) and MCW (physicians, APNPs, administrative assistants, research analyst) also had to work collegially on apportioning the new fees relative to the effort of the employees of each parent institution - useful institutional learning that can be applied to future value-based contracting.

OUTCOMES

We regularly report outcomes that reflect our stakeholders' desires and goals: primary care physicians, subspecialty colleagues, affiliated institutions (CHW, MCW), primary payer (WI MA), and most importantly the children and families we serve. The program sends out annual satisfaction surveys to partnering primary care physicians and enrolled families; we also receive similar information from the CHW/MCW annual survey reflecting all subspecialty areas. We engage in financial analysis with information provided by our institutions (resource use, costs, payment and billing data), along with claims information provided by our primary payer, Wisconsin Medicaid, through an ongoing data sharing agreement. The institutional and Medicaid data have allowed us to do pre-post enrollment evaluations of total cost of care and the contributing components. Although pre-post methodology has flaws including regression to the mean and not being able to attribute changes solely to CCP enrollment we are buoyed by how closely our financial outcomes match controlled studies.[4,6] We continue to search for a valid control group to demonstrate greater rigor for an analysis. Fortunately, the pre-post approach has offered enough credibility in the eyes of our primary payer to

not wait for the perfect to bring sustainable financing to the care of Wisconsin's CMC population.

Summary of most recent outcome data:
Primary Care partner survey, 2018:

- 140 responses, 40% response rate.
- 93% of respondents very satisfied or satisfied with program service.

Family survey, 2018:

- 159 responses, 25% response rate.
- 97% of respondents very satisfied or satisfied with program service.

Financial impact to WI MA:

- *n* of 352 children, pre-post analysis, 9/1/14-8/31/17.[7]
- Savings of over 25 million dollars per year.
- Reduction in inpatient utilization accounts for over 90% of the savings.

RESEARCH / QUALITY IMPROVEMENT

The Milwaukee Program has a strong history of contributing to the still relatively young complex care subspecialty. Our goal is to remain good stewards and continue to make contributions where our strengths allow. We primarily focus our research and QI projects on how we bring value to the local population and stakeholders we serve.

The program benefits from our active family advisory council in planning our research and QI agendas. Below is a list of active projects with brief descriptions. We encourage anyone interested in collaborating on these ventures or learning more about them to contact us.

Inpatient

- Explore the value the complex care program brings to different inpatient environments of care, starting with the hospitalist service, and to families while in the hospital. Goal is to optimize CCP efficiency as the program grows and to ensure that growth is not adversely affecting the quality of care.
- Comparative study of CCP impact on the pediatric critical care unit (PICU) environment of care; patient safety, utilization, and family satisfaction in tertiary care centers with and without active CCP programs.
- Impact of pharmacy personnel involvement on CMC compliance and safety of medication use.

Documentation

- Internally, along with hospital EHR staff we are formulating a living note that represents CMC by systems.

The goal is to make documentation more efficient and to better represent the complexities of the patients to all involved in their care. We still struggle with the use of a systems approach vs problem list approach in the EHR.

- Development of a longitudinal inpatient care plan generated with families, allowing them to indicate what does or does not work for their child's care. The project is intended to capture the knowledge families have about how to best care for their children given their vast home care experience, e.g. schedule for cares and feedings, optimal communication approach, representation of child when well. The goal is to create a reference for inpatient caregivers, reduce the family burden of having to repeat information with each new encounter, and ultimately for families to easily update the document electronically.

Perioperative program

- The CCP provides perioperative consultation for enrolled and non-enrolled CMC, primarily for orthopedic and neurosurgical procedures. In conjunction with surgical, anesthesia, critical care, and hospitalist teams, we are examining effects on utilization (LOS, readmission rate) and outcomes of care (post-operative complications, healing time).

Family Support and Wellness

- Impact of CCP on family-care team dynamics in the PICU environment, in collaboration with critical care, palliative care, and psychology colleagues from CHW, MCW and the University of Wisconsin-Milwaukee.
- Implementing a Trauma Informed Care approach using the Sanctuary Model in collaboration with the CHW social work and community services departments. Goals are to 1) promote CCP staff resilience as an aid for avoiding burnout by fostering a trauma-informed culture, and 2) encourage a trauma-informed approach to caring for families and CMC: identifying trauma histories, helping children and families to process traumatic events, and preventing re-traumatization in the health care setting.
- Understanding the value the CCP provides to families, what helps families the most, what would you

miss if the program was not here? Project is being done in collaboration with psychology department at Marquette University. The goal is to improve CCP efficiency, directing activities to those most important to families while trying to support wellness and build resilience.

- Collaborative for Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity, a four-year HRSA learning cooperative with nine other states. The WI team consists of our partners at AFCH, Department of Family and Health Services, Family Voices of Wisconsin, Children and Youth with Special Health Care Needs Regional Centers, and parent representatives. The project goals are focused on reducing unmet needs by helping families connect with their local regional centers and enrolling in the Medicaid Children's Long Term Support waiver. The team is also working on developing an approach that helps families come to meaningful and attainable goals for CMC.
- Development and testing of a mobile app based on the Bridge to Independence family care coordination curriculum (https://www.chw.org/medical-care/special-needs-services/bridge-to-independence), in collaboration with colleagues from the University of Wisconsin-Milwaukee and Universidade Federal do Rio Grande do Sul in Brazil. This app is being produced and piloted in English, Spanish, and Portuguese.

CMC Finances

- Ongoing analysis of CCP-enrolled patients using institutional information and Wisconsin Medicaid claims data.
- Defining the financial revenue impact of CMC on the health care system and how changes in reimbursement for this high utilizer population can impact care for all children across a pediatric enterprise.

DEFINING HEALTH CARE VALUE

In a health care environment era where a positive financial margin is increasingly viewed as a growing portion of how success is defined, it is worth noting a company's positive financial return is associated with the company's purpose, and clarity of

purpose transmitted to their employees; inspiring the company's workforce to maintain strong beliefs in the meaning of their work.[8] John Gordon and Holly Colby started the Milwaukee Program "because it is the right thing to do for these children and families" and with a strong belief that medical co-management and intensive care coordination will ultimately improve health, health care delivery, and the costs of care. The Milwaukee Program continues to strive to improve health outcomes for CMC and support the wellbeing for their families as our purpose. We are confident that the value elements needed for financial sustainability will continue to follow. CMC care crosses almost every aspect of a pediatric tertiary care institution's work and is impacted by multiple community resources. Complex care programs are ideally positioned to serve as examples for how team-based care across medical environments and in the community can improve health and family function as a primary goal, favorably bend the cost curve and contribute to a positive financial margin for their respective institutions. Do the right thing and good things happen. We invite interested groups to visit us in Milwaukee so that we can continue to learn from each other, and together continue to do good things for children with medical complexity and their families.

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FIGURES

Figure 1.

Care Coordination Note Template

Enrolled in Complex Care Program

Who am I? (Why am I complex)

Functional status when well

Baseline abnormal physical findings, vital signs, lab values

Well plan and Sick plan for home management

ED / hospital recommendations including rescue plans and preferred admitting service/unit

Peri-Operative Recommendations

The goal of this brief note is to make information readily available to immediately care for a child with medical complexity. The note is intended to be short and to the point. The Care Coordination Note lives at the top of the problem list section within Children's Wisconsin's EHR; one or two "clicks" to access (this could be better). The note is routinely updated at the comprehensive Complex Care Program (CCP) outpatient visits every 6 months and at hospital discharge. The CCP encourages subspecialty colleagues to contribute to the note; they are cited as the source of recommendations. Day of the last update is also displayed.

Sections:
Who am I? – This is a brief, few sentence description of the child's medical conditions; e.g. toddler male, former 23 week premature neonate, IVH history with subsequent hydrocephalus, VP shunt, past multiple revisions, seizure disorder, chronic lung disease, tracheostomy device in place, on home mechanical ventilation support, G-tube dependent for nutrition, exhibits dysautonomia when ill.

Functional status when well – Describes family's and CCP staff's impression of the child when well; e.g. smiles with familiar voices, enjoys company of family pet, enjoys taking tastes of food, loves to hear books and music, laughs with siblings, understands

everything but cannot vocalize. The goal is to humanize the child to the care team, the things they may never see when the child is ill, what to look for as the child improves.

Baseline abnormal physical findings, vital signs, lab values – Describes baseline findings that in general may be seen as abnormal by caregivers that are not familiar with the child but are actually part of the child's conditional baseline e.g. rt pupil is always dilated, persistent nystagmus, left sided weakness, copious secretions common, heart murmur, body temperature 96 F, 35.5 C - "normal" temperature may indicate fever, typical pulse oximetry saturations, seizure frequency and duration, platelet count runs low 50-100K.

Well plan and Sick plan for home management – These are listed per organ system or condition most imperative to the child's well being e.g –

Respiratory -

Well plan: baseline pulmonary hygiene (aerosol type and frequency, CPT – vest, IPV, cough assist); home O2 use – delivery, FIO2; mechanical ventilation mode, settings, tracheostomy device specifics.

Sick plan: escalation of pulmonary hygiene frequency and additions to baseline care, degree of upper O2 titration, aerosol frequency, CPT mode escalation; upper limit of when to call medical support, or bring to medical care.

Neurology –

Well plan: seizure medications, ketogenic diet,
Sick plan: use of emergency benzodiazepines, escalate dose of Keppra at sign of illness or fever, when to seek medical attention.

Metabolic –

Well plan: special formula need, frequency of feedings, glucose checks; adrenal function.
Sick plan: When to seek medical attention to support metabolic needs, unable to tolerate nutrition, need for adrenal steroid support when ill.

ED / hospital recommendations including rescue plans and preferred admitting service/unit –
Similar to well and sick plans above, subcategorized by condition or organ system affected e.g.

Seizures – check glucose, often hypoglycemic with prolonged seizures, responds best to barbiturates instead of benzodiazepines, may need to support the airway when adding additional anticonvulsants; VP shunt in place, malfunction often presents with seizure activity.

Metabolic – if presenting with metabolic acidosis, must immediately establish IV access and start following IV fluid to maintain GIR of …; Adrenal insufficient give the following steroid support when ill / stressed.

Cardiac – has a history of pulmonary hypertension, support saturations to at least 95%, call cardiology service for consultation. LVOT obstructive lesion, may not tolerate anemia or hypovolemia well.

Difficult IV access – move quickly to PIC line placement with IR or IO placement in emergency

Difficult Airway – small jaw, see anesthesia note dated … for details; consider initiating difficult airway protocol if artificial airway is needed.

Hospital area – PICU placement due to mechanical ventilation needs, usual location in PICU …

Peri-Operative Recommendations – Immediate considerations for a child needing to undergo a procedure, e.g.

Difficult Airway – small jaw, past experience required fiber optic assistance, see anesthesia note dated …

Consider cardiac anesthesia consult due to underlying condition …

Adrenal support, stress steroid use

Difficult IV access, required IR supported PIC line in the past

PROGRAM REPORT

ALMOST HOME KIDS:

A Unique Hospital-to-Home Transitional Care Model for Children with Technology Dependency

Sarah A. Sobotka, MD, MSc,[a] Emma Lynch, MPH,[a] Wendy Tian, BA,[b] Michael E. Msall, MD,[a] Monica E. Peek, MD MPH[c]

ABSTRACT

BACKGROUND: Children with medical technology dependency often remain hospitalized for long periods while preparing to transition home. To our knowledge, no comprehensive reports of alternative locations for hospital-to-home transition have been described in the literature.

OBJECTIVES: We present a comprehensive report and evaluation of patient and family outcomes before and after admission to Almost Home Kids (AHK), a hospital-to-home transitional care center, which provides a home-like setting for parent training, care coordination, and case management for children with medical technology dependency.

OUTCOMES: Descriptive statistics were used to characterize the children and their parents during the transitional care admission and following discharge. Parents were given questionnaires which assessed their community support, knowledge and skills with medical technology management, physical and mental health, and discharge readiness. After admission to the AHK transition program as compared to before, children had significantly increased access to primary care and home nursing, more referrals to Early Intervention and more received speech therapy services. Parents reported increased comfort with responding to ventilator alarms, checking back-up ventilators, and managing feeding tubes.

CONCLUSIONS: For children with technology dependency, enrollment in the AHK hospital-to-home transitional care program may effectively deliver parent training and broaden the child's access to community health, rehabilitation and nursing resources.

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INTRODUCTION

Children living with technology dependence, needing both a medical device to compensate for the loss of a vital body function and substantial nursing care to avert death or further disability,[1] are increasing in pediatric populations[2-5] and are overrepresented in hospitalizations.[6,7] The discharge process for this population is complicated because of elaborate care coordination and training needs, and frequent delays in staffing home nursing. Before children with new technology dependence can be discharged, children must be medically stable and linked to community resources, their parents trained, and their home equipped to sustain the technology.[8,9] This requires an interdisciplinary team which may include clinicians, case managers, and respiratory, speech, feeding, occupational, and physical therapists.[10,11] Often the greatest obstacles to hospital discharge are non-medical, e.g. approval for home care funding, home nursing, and social issues.[12,13] Most parent training programs are time-intensive and delivered in the context of the child's inpatient hospital stay.[14,15] Additionally, there is evidence that home nursing shortages are a national impediment to discharge.[16] Thus, the hospitalizations when a medical technology is first placed often require lengths of stay (LOS) of many months in order to prepare families to transition home. For example, children undergoing tracheotomy are reported to have with median hospitalization LOS between 1.5 to 9.6 months. [17,18]

Long hospital LOS can also be detrimental to child neurodevelopment and family well-being. In a study of children with congenital heart disease, longer LOS after heart surgery seemed to be potentially associated with worse cognitive outcomes after controlling for demographic and surgical outcome variables.[19] After PICU hospitalizations, parents of children have been found to have significantly increased stress,[20] with a quarter experiencing Post Traumatic Stress Disorder,[21] and many experiencing depression and anxiety.[22,23]

Therefore, it is imperative that health systems consider alternatives that minimize hospital LOS, especially for neurodevelopmentally vulnerable patients with technology dependence. Although interventions have been described which standardize inpatient discharge practices for teams caring for children with home mechanical ventilation,[24] there is a dearth of evidence-based alternatives to the hospital for transition planning and training. The objective of this paper is to describe an

innovative community-based model for hospital-to-home transition and to evaluate child and parent outcomes assessing knowledge, technical skills, and utilization of community-based health services.

PROGRAM DESCRIPTION

ALMOST HOME KIDS (AHK): AHK was originally established in 1999 by two mothers who saw the need for a respite care center for children with medical technology dependence. AHK now has three free-standing centers that provide hospital-to-home transition care and respite care for children. (Figure 1) The programs aim to empower families to care for complex children at home and family training is a core focus. Over time, many families who complete hospital-to-home transitional care return to AHK for respite care.[25]

AHK is a unique model that is different from a hospital, long term care facility or rehabilitation center. The hospital-to-home transitional care program at AHK is specifically for children who are medically ready for discharge, but cannot go home due to social and/or other resource obstacles. Hospital discharge planners, social workers, nurses and physicians refer eligible children to AHK transitional care by contacting the director of case management. AHK is designed to simulate

Figure 1. Clockwise from upper right: Nurse training parents; Almost Home Kids - Chicago suburban site; Therapists work with a young child; Almost Home Kids - downtown Chicago site.

a home, with brightly decorated bedrooms, a large kitchen, and several play areas for families to engage with their child and other families. This environment allows for families to learn and practice caring for their children in a home-like setting. Case managers, social workers, and nurses teach families the skills needed to care for their children when they transition home. Room pairings are by age or developmental stage and all children who are not on infectious isolation spend the majority of their time in common areas. There are two locations in the Chicagoland area, each with a 12-bed capacity, and in 2018 a third location opened in central Illinois. The centers serve children from all of the pediatric hospitals in the region. Although parents are unable to room-in with their children at the Naperville center, in the downtown Chicago location, parents and siblings can stay at a Ronald McDonald House located within the same building.

The focus of the AHK hospital-to-home transition program is parent training, which consists of nurses providing bedside education on medical equipment and medication administration. Nursing staff teach parents to understand key drug interactions and how to troubleshoot equipment malfunctions. Before discharge, parents must demonstrate mastery of medical tasks. In between parent training sessions, children are transported to and from AHK for outpatient appointments, receive nursing support (as they would at home) and have access to an on-call physician or advanced practice nurse. Additionally, parents receive education from case management on resource coordination. This family-centered approach provides additional support for families as they learn to independently manage the medical care and become the central care coordinator for their child.

PROGRAM SUPPORT

FUNDING AND TEAM COMPOSITION: AHK is funded by a combination of provider billing to insurance, grant funding, and private donations. Each site has a medical director and advanced practice nurse who round weekly on all patients. Case management and social work are available daily and skilled nurses support each patient with at most a 1:3 patient ratio. A full-time child life specialist helps to craft developmental goals for each child, and Early Intervention (EI) services are provided at the center. A robust volunteer program infuses AHK with vibrant visitors and playmates for the children throughout their day.

OUTCOMES

A descriptive study was implemented consisting of children and their parents who participated in the AHK transitional care program between December 2013 and April 2016. For those parents who gave consent to participate in this research project, questionnaires were administered on admission, discharge, and in follow-up after discharge from the center.

PARTICIPANT RECRUITMENT: Parents of children admitted to AHK were eligible for study inclusion if: 1. Their child was dependent upon medical technology; 2. Parents were receiving first-time training at AHK on new medical technology they had never been home with, or new foster parents were receiving training on a foster child's existing medical technology; 3. The child was expected to transition to home. Additionally, parents/guardians must have had full custody of their children. The University of Chicago Institutional Review Board (IRB) approved this study in November 2013, and the Department of Child and Family Services (DCFS) IRB approved it in May 2014. AHK staff invited eligible parents to participate. Consent was obtained from parents; no children were of age and developmental stage to provide assent. Parents received an incentive ($20 gift card) for each questionnaire completed after AHK discharge.

MEASURES: Questionnaires included items from validated surveys, e.g. The National Survey of Children with Special Healthcare Needs.[26] For constructs without a previously validated measure, questionnaire items were developed and cognitively tested. Researchers consulted with senior nursing staff to determine appropriate questions to assess parents' mastery of medical technology management. Study participants were provided an iPad with a keyboard to complete the questionnaires, which were managed using Research Electronic Data Capture.[27] Each questionnaire took approximately 20 minutes.

Sociodemographic characteristics: Parent respondents were asked their relationship to the child; four relationship types were reported: mother, father, foster parent, and adoptive parent. Parents reported household income in 12 categories which were dichotomized into <$50,000 versus at least $50,000 on median distribution for the analysis. Parents were asked about their current work status with close-coded options being full-time, part-time or not working.

Parents provided information about their child. Maternal answers were used for child

characteristics when two parents responded. Age was reported in months and grouped into three categories: <4 months, 4-35 months, and 3-14 years. Race was defined by the question, “What is your child’s race? (check all that apply).” Ethnicity was defined by, “Is your child of Hispanic, Latino, or Spanish origin?” The U.S. federal government and the National Academy of Medicine recommend self-report for identification of patient race/ethnicity.[28] Parents were asked two questions about the home environment: number of children and primary language spoken.

Administrative data from the AHK center was used to compare data on non-participants in aggregate.

Medical Complexity: Parents reported their child’s medical technologies (e.g. feeding tubes, tracheostomies, and ventilators) from a list generated in consultation with AHK nursing supervisors.

Medical Technology Management: All parents were asked, “Were you trained to use the same equipment you will use at home?” Parents were also asked questions specific to their child’s medical technologies. Parents of children with a ventilator were asked if they had received CPR training, how comfortable they felt responding to ventilator alarms, if they knew ventilator settings, and if they could perform a back-up ventilator check. Parents of children with tracheostomies were asked if they had ever changed a tracheostomy with a second caregiver, and if they had ever changed one independently. Parents of children with feeding tubes were asked about their comfort level cleaning and changing a feeding tube and using a feeding pump. Questions about parental comfort level had close-coded Likert-type response options ranging from “very comfortable” to “very uncomfortable,” which were dichotomized in the analysis to “very comfortable” versus less, based on response distribution.

Healthcare access: Healthcare access was assessed at each of the three data collection time points in order to measure changes in service referral and utilization over time. Parents provided information about the number of home nursing hours they received and if they had a place for usual medical care. All parents were asked about therapy services. For children under the age of three, these services were provided through the EI program.

Parent well-being: Two questions, adapted from the Medical Outcomes Study,[29] were asked about self-reported parent health: “In general, how would you rate your own

current physical health?" "In general, how would you rate your own current mental health?" Responses were collapsed into three categories: Excellent, Very Good/Good, and Fair/Poor, based on response distribution frequencies.

STATISTICAL METHODS: Descriptive statistics were used to characterize the children admitted to AHK and their parents. Questionnaire response items for child and parent outcomes were compared using Chi-squared tests of proportions, McNemar's test or a generalized estimating equation (GEE) logistic regression model that accounted for the correlation between multiple observations per patient. Statistical analyses were completed with STATA/SE 14 (Stata Corp, College Station, TX). Statistical significance was defined as a two-tailed p-value less than 0.05.

RESULTS: Seventy families met the medical inclusion criteria. (Figure 2) Six families had DCFS involvement without full DCFS custody and therefore were determined to be ineligible. Forty-three parents enrolled from a total of 32 families. Twenty-three parents declined participation and nine families were missed recruitment opportunities. A number of participants had brief acute care hospital visits for medical illnesses during their AHK transitional stay, however completed training at AHK before discharge to home. One participant transferred to a hospital before discharge home and was lost to follow-up. Two parents did not complete discharge questionnaires and were lost to follow-up. Thirty-eight discharge questionnaires were analyzed. Four parents were not contacted for follow-up, three because their child had passed away before the follow-up interval and one because the parent had lost custody. Six parents were lost to follow-up after AHK discharge. Thirty parents completed follow-up questionnaires an average of 3.6 months after AHK discharge. There were no statistically significant differences between non-participant and participant children regarding age, gender,

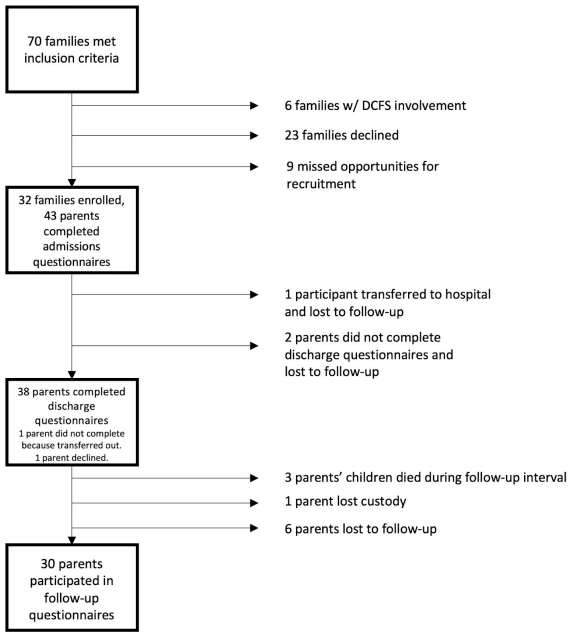

Figure 2. Recruitment and Retention Flow Chart

	Participants (N=32)	Non-participants (N = 38)	P-value*
Characteristic			
Child Characteristics			
Age of child			0.08
< 4 months	7 (22)	3 (8)	
4-35 months	19 (60)	23 (61)	
3-14 years	6 (19)	12 (31)	
Male child	20 (63)	22 (58)	0.62
Race/Ethnicity of Child (N=31)			0.78
Non-Hispanic White	10 (32)	10 (26)	
Non-Hispanic Black	10 (32)	11 (29)	
Hispanic	9 (29)	15 (39)	
Mixed/Other	2 (6)	2 (5)	
Household Income° (N=31)			<0.001
< $50,000	15 (48)	34 (92)	
≥ $50,000	16 (52)	3 (8)	
Medical Equipment			
Feeding tube	29 (91)	36 (97)	0.25
Tracheostomy	16 (50)	21 (57)	0.49
Ventilator	11 (34)	13 (35)	0.87
Home Characteristics			
Number of children in the home			0.66
1-2 children	19 (61)	23 (68)	
3 or more	12 (39)	11 (32)	
Primary language not English	4 (13)	12 (32)	0.05
Parent Characteristics (N=43)			
Relationship to child			
Mother	23 (53)		
Father	9 (21)		
Foster/Adoptive Parent	11 (26)		
Work Status (N=42)			
Full-time or part-time	22 (52)		
Not currently working	20 (48)		

*p-values generated using Chi-square tests. Wilcoxon rank-sum test used for age of child comparison
°One response missing for each of the discharge and admission questionnaires (N=31 and N=36, respectively)

Table 1. Characteristics of Parents (N=43) & Children (N=32)

ethnicity, and the frequency of medical equipment. (Table 1) However, non-participants were more likely than participants to have lower household incomes and be from non-primary English-speaking households.

In regard to the duration of hospital and AHK stays, before AHK, one-third of participating families had acute care stays less than two months, half of families had stays of 2-6 months, and 15% had stays of greater than six months. The average length of stay at AHK was 101 days with a median (range) length of 74 (12-251) days.

Sociodemographic characteristics: Parents were primarily mothers (53%); 26% were foster or adoptive parents. Children ranged between 4 months and 14 years old, the majority of which were under 3 years old (82%). Thirty-one percent were Non-Hispanic White, 31% Non-Hispanic Black, and 28% Hispanic. Nearly half of respondents came from households making less than $50,000 per year.

Medical Complexity: Ninety-one percent of children had feeding tubes, 48% had tracheostomies, and 33% required ventilators. Thirty percent of children had both a feeding tube and a ventilator.

Child Outcomes: Overall, parents reported increased connectedness to community resources: 84% of parents reported having a usual place for their child's medical care (versus only 64% at admission), and this was sustained at follow-up (83%) (p=0.02). (Table 2) For the population under age three, after discharge from AHK significantly more were referred to EI and receiving speech therapy than prior to discharge (p<0.001 and p<0.05, respectively).

	Admission (%)	Discharge (%)	Follow-Up (%)	P-value*
Connection to Community Resources (N=42)				
Has usual place for medical care	64	84	83	0.02
***Early Intervention (EI) if child under 3 years* (N=36)**				
Initial Referral to EI	61	93	100	<0.001
Receiving Physical Therapy	28	44	42	0.17
Receiving Occupational Therapy	14	33	17	0.10
Receiving Speech Therapy	19	39	42	0.05
Receiving Developmental Therapy	17	31	39	0.16
Receiving Feeding Therapy	6	8	17	0.07
Receiving Nutritional Therapy	3	6	19	0.07
Home nursing hours received per week (N=32)				<0.001
None/Unknown	84	43	42	
1-24 hours	3	3	4	
25-72 hours	9	27	21	
> 72 hours	3	27	33	

*p-values generated using GEE poisson regression in order to compare trend over time. Nursing hours compared using mixed-effects ordinal logistic regression. Statistical significance defined as two-tailed p-value <0.05

Table 2. Community Resources after AHK Transitional Care Stay (%)

Increased receipt of feeding and nutritional therapies showed a trend toward significance (p=0.07).

There was also a meaningful increase in the number of approved home nursing hours. On discharge, fifty-four percent of parents reported having at least 25 nursing hours weekly for their child, versus only 13% on admission (p<0.001). Nursing care was sustained in follow-up.

Parent Outcomes:There were improvements in parent training on medical equipment during the AHK admission. (Table 3) Nearly all (95%) of parents report being trained on the same equipment they would use at home compared to 58% on AHK admission (p<0.001). Parents of children with tracheostomies and ventilators were all CPR trained and significantly more parents reported feeling very comfortable

	N°	Admission	Discharge	Follow-up	P-value*
Medical Technology Management					
Trained using home equipment	42	58	95	N/A	<0.001
Trach/Vent Management					
Received CPR training	23	59	100	94	0.006
Very comfortable responding to vent alarms	16	19	78	78	0.02
Knows ventilator settings	12	33	88	83	0.14
Can do back-up ventilator check	16	38	89	100	0.01
Has ever changed tracheostomy independently	21	33	69	75	0.10
Has changed tracheostomy with second caregiver	14	69	100	100	0.06
Feeding Tube Management					
Very comfortable cleaning & changing tube/site	43	60	87	93	0.007
Very comfortable using feeding pump	41	79	97	95	0.10
Parental well-being					
Parent self-reported medical health	42				0.49
Excellent		21	26	20	
Very Good/good		67	66	73	
Fair/poor		12	8	7	
Parent self-reported mental health	43				0.43
Excellent		44	45	33	
Very Good/Good		47	53	63	
Fair/Poor		9	3	3	

*p-values generated using GEE poisson regression. Parental well-being responses compared using mixed-effects ordinal logistic regression; statistical significance defined as two-tailed p-value <0.05
°N varies by item due to missing responses over three time intervals and branching logic of questionnaire; e.g. only parents of a child with a ventilator responded to questions about ventilators, etc.

Table 3. Impact of AHK Transitional Care (%)- Parent Outcomes

responding to alarms and performing back-up ventilator checks (p=0.02 and p=0.01, respectively). Parents of children with feeding tubes reported increased comfort with cleaning and changing the tubes (p=0.007). Technology management skills were sustained during follow-up. Parent-reported physical and mental health ratings were unchanged over time.

PROGRAM SUMMARY

This program report provides preliminary evidence that AHK, an alternative to the hospital during hospital-to-home transition, is an effective program for parents to develop the necessary skills for managing their complex children in the home and for care coordination to arrange essential home services before discharge. Additionally, our follow-up data suggest that parent skills and community services are maintained. Due to the descriptive nature of this cohort, it is not known to what extent parent skills in follow-up reflect one's natural mastery of skills over time, so we are cautious to over interpret follow-up results as a function of AHK's role in the transition. However, the continued access to community resources identifies the strong case management that AHK transition provided for these families.

Children staying at AHK would have likely spent several additional months in the

hospital at higher financial cost without the availability of this program.[30] AHK estimates their program costs per patient bed day by determining the program revenue minus the program expense divided by census bed days. Caring for the most complicated patients, those dependent upon mechanical ventilation who require intensive skilled nursing 6-8 hours per day, is estimated to cost approximately $1,250/day. Patients with less technology (e.g. a feeding tube) cost the center approximately $850/day. For children with ventilators, this compares to an estimated $2,052 for hospital days on a pediatric ventilator unit and $3,565 for hospital days in intensive care units.[31]

Over the course of a few months, parents describe an increase in skills and comfort managing medical technology. The graduates of this program are more connected with primary care, rehabilitative therapy services, and home nursing than before their transition.

Our data should be considered in light of important limitations. First, our response rate around 50% of eligible families was not ideal for generalizing conclusions across this population. Parents of children with medical technology dependence, particularly in the challenging time of initial transition to home, are spread thin between obligations. We suspect the same stressors that have been reported to challenge parents' ability to complete parent training[32] also limited our ability to recruit families. Using administrative data from the AHK center, we note that participant and non-participant families were similar in regard to many relevant child characteristics (age, gender, ethnicity, and medical equipment), however participant families were more affluent. Poverty certainly impacts a family's ability to care for a child with medical complexity. Therefore, our results may not be completely generalizable to populations with greater socioeconomic adversity, although this response pattern is common for research conducted with underserved populations.[33,34] Second, the data presented in this paper reflect the immediate hospital-to-home transition period. Longer follow-up studies are needed and we hope to provide data from this center over time when available.

CONCLUSION

This preliminary study of an innovative hospital-to-home transitional care model, which prioritizes parent training, care coordination, and accessing community resources, shows promise as a family-centered alternative to prolonged inpatient hospitalizations. Ongoing investigation will determine the model's long-term impacts on child health,

community participation, family well-being, and health care costs.

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IMAGES AND TABLES

Figure 1. Clockwise from upper right: Nurse training parents; Almost Home Kids - Chicago suburban site; Therapists work with a young child; Almost Home Kids - downtown Chicago site.

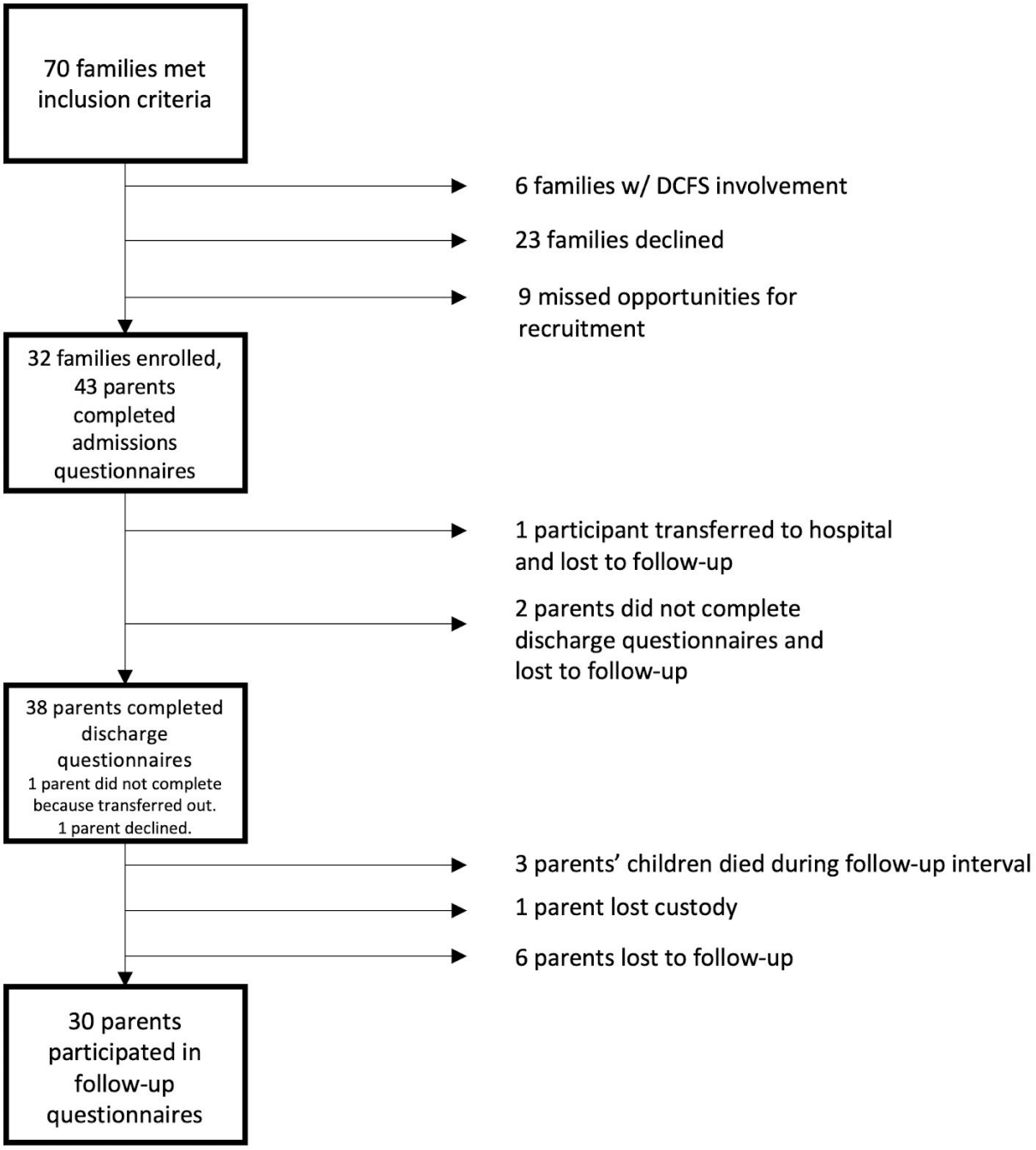


Figure 2. Recruitment and Retention Flow Chart

Characteristic	Participants (N=32)	Non-participants (N = 38)	P-value*
Child Characteristics			
Age of child			0.08
< 4 months	7 (22)	3 (8)	
4-35 months	19 (60)	23 (61)	
3-14 years	6 (19)	12 (31)	
Male child	20 (63)	22 (58)	0.62
Race/Ethnicity of Child (N=31)			0.78
Non-Hispanic White	10 (32)	10 (26)	
Non-Hispanic Black	10 (32)	11 (29)	
Hispanic	9 (29)	15 (39)	
Mixed/Other	2 (6)	2 (5)	
Household Income° (N=31)			<0.001
< $50,000	15 (48)	34 (92)	
≥ $50,000	16 (52)	3 (8)	
Medical Equipment			
Feeding tube	29 (91)	36 (97)	0.25
Tracheostomy	16 (50)	21 (57)	0.49
Ventilator	11 (34)	13 (35)	0.87
Home Characteristics			
Number of children in the home			0.66
1-2 children	19 (61)	23 (68)	
3 or more	12 (39)	11 (32)	
Primary language not English	4 (13)	12 (32)	0.05
Parent Characteristics (N=43)			
Relationship to child			
Mother	23 (53)		
Father	9 (21)		
Foster/Adoptive Parent	11 (26)		
Work Status (N=42)			
Full-time or part-time	22 (52)		
Not currently working	20 (48)		

*p-values generated using Chi-square tests. Wilcoxon rank-sum test used for age of child comparison
°One response missing for each of the discharge and admission questionnaires (N=31 and N=36, respectively)

Table 1. Characteristics of Parents (N=43) & Children (N=32)

	Admission (%)	Discharge (%)	Follow-Up (%)	P-value*
Connection to Community Resources (N=42)				
Has usual place for medical care	64	84	83	0.02
***Early Intervention (EI) if child under 3 years* (N=36)**				
Initial Referral to EI	61	93	100	<0.001
Receiving Physical Therapy	28	44	42	0.17
Receiving Occupational Therapy	14	33	17	0.10
Receiving Speech Therapy	19	39	42	0.05
Receiving Developmental Therapy	17	31	39	0.16
Receiving Feeding Therapy	6	8	17	0.07
Receiving Nutritional Therapy	3	6	19	0.07
Home nursing hours received per week (N=32)				<0.001
None/Unknown	84	43	42	
1-24 hours	3	3	4	
25-72 hours	9	27	21	
> 72 hours	3	27	33	

*p-values generated using GEE poisson regression in order to compare trend over time. Nursing hours compared using mixed-effects ordinal logistic regression. Statistical significance defined as two-tailed p-value <0.05

Table 2. Community Resources after AHK Transitional Care Stay (%)

	N°	Admission	Discharge	Follow-up	P-value*
Medical Technology Management					
Trained using home equipment	42	58	95	N/A	<0.001
Trach/Vent Management					
Received CPR training	23	59	100	94	0.006
Very comfortable responding to vent alarms	16	19	78	78	0.02
Knows ventilator settings	12	33	88	83	0.14
Can do back-up ventilator check	16	38	89	100	0.01
Has ever changed tracheostomy independently	21	33	69	75	0.10
Has changed tracheostomy with second caregiver	14	69	100	100	0.06
Feeding Tube Management					
Very comfortable cleaning & changing tube/site	43	60	87	93	0.007
Very comfortable using feeding pump	41	79	97	95	0.10
Parental well-being					
Parent self-reported medical health	42				0.49
Excellent		21	26	20	
Very Good/good		67	66	73	
Fair/poor		12	8	7	
Parent self-reported mental health	43				0.43
Excellent		44	45	33	
Very Good/Good		47	53	63	
Fair/Poor		9	3	3	

*p-values generated using GEE poisson regression. Parental well-being responses compared using mixed-effects ordinal logistic regression; statistical significance defined as two-tailed p-value <0.05
°N varies by item due to missing responses over three time intervals and branching logic of questionnaire; e.g. only parents of a child with a ventilator responded to questions about ventilators, etc.

Table 3. Impact of AHK Transitional Care (%)- Parent Outcomes

PROGRAM REPORT

THE COMPLEX CARE SERVICE

at the Montreal Children's Hospital, McGill University Health Centre

Hema Patel, MD, FRCPC, MSc (Clin Epi),[a] Isabelle St-Sauveur, BSc(N), MSc(N)[a]

PROGRAM SUMMARY

The Complex Care Service (CCS) offers multidisciplinary comprehensive pediatric care for children with significant degrees of medical complexity, focusing on children with multiple care needs, technology dependence and fragility. Families receive the services of a dedicated nurse care coordinator, consultant pediatrician and allied health professionals. In addition to scheduled inpatient and outpatient consultations and clinic visits, the CCS team also offers: a daily urgent care clinic and a 24/7 on call service. Program innovations include a: complex care clinical fellowship, standardized curriculum for pediatric postgraduate trainees, home/community visitation program and a collaborative website of evidence-based standardized homecare practices.

[a]The Montreal Children's Hospital, McGill University Health Centre, Montreal, QC

PROGRAM DESCRIPTION

More than 50 years ago, a small avant-garde group of health care professionals based at the Montreal Children's Hospital (MCH) observed what seems obvious today:

1) that prolonged hospitalizations were detrimental to children in many ways,
2) that parents and caregivers were willing and capable of caring for their children with complex needs in their own homes and
3) that comprehensive and coordinated health care was crucial for these special children.

Starting in 1964, the Complex Care Service (CCS) began to transition children from hospital to home-based care and an era of innovation began. Children with rheumatological diseases, neuromuscular conditions and hematological disorders were amongst the first served by the program, which was originally called the "Homecare Program", a nickname which remains in use. Through teaching and hands-on practice, parents were enabled to look after their child's needs. Sparse community services were accessed and coordinated for families; outreach education became an important CCS objective. From the earliest days, nurse care coordinators and empowered parents have formed the basis of CCS.

While the population served by the MCH CCS has evolved with changing demographics of children with medical complexity (CMC), the service has retained the original mission which is to provide safe, effective and family-centered care to children with complex medical needs, in their own home environment. Our multidisciplinary team believes that caregivers, and most children, should participate in the processes of health care assessment, therapy implementation, preventive efforts and evaluation. Our goals are to:

1. improve the quality of life of children with complex medical conditions by
    a. maintaining and encouraging child/family autonomy
    b. minimizing the physical and psychosocial impacts of intensive home care on the child and family
    c. encouraging joy and development of every child
2. decrease unscheduled hospitalizations and emergency visits
3. effectively coordinate the needs of the child/family with home, community, and hospital services.

SERVICES PROVIDED

PATIENT CARE SERVICES: Today, the CCS serves approximately 500 children, with an annual turnover of 75-100, with a combination of highly complex conditions, medical fragility and dependence upon technology (Table 1). Through a standard consultation procedure, patients are referred from both inpatient and outpatient medical and surgical services at our institution. Referrals are also received from community providers and other hospitals in Quebec.

Location	Montreal Children's Hospital, McGill University Health Centre
Staffing	Core Staff includes: • 5 Pediatricians (each attending 5-15 weeks year in CCS + scheduled visits clinics) • 1 FTE Clinical Manager • 1 FTE Assistant Nurse Manager • 1 FTE Advance practice nurse • 7 FTE Nurse coordinators • 1 FTE Discharge Coordinator • Nurse Educator • Allied health support

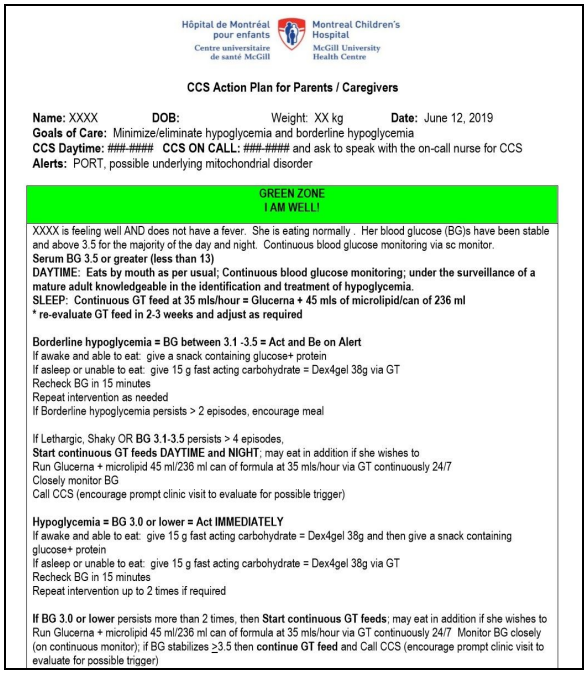
Patient Demographics	Patients 0 to 18 years of age with the following characteristics:
	• Chronicity
	• Complexity
	• Fragility
	• Technology dependency/high intensity care needs grouped as follows:
	  ○ Neuromuscular conditions
	  ○ Tracheostomy/Home Ventilation
	  ○ Bronchopulmonary Dysplasia on home oxygen support
	  ○ Home parenteral nutrition
	  ○ Long-term enteral nutrition
	  ○ Immunocompromised
	  ○ Multiplex- children with rare genetic/neurological/metabolic conditions with multiple co-morbidities
	  ○ Heart transplant
	  ○ Thalassemia
	  ○ Congenital hemostasis disorders

Key Services	• Designated nurse coordinator/ pediatrician for longitudinal care • Daily urgent care clinic • Scheduled comprehensive multi-disciplinary visits • 24/7 on-call nurse-pediatrician team • Consultations (inpatient and outpatient) • Home visits
Teaching Services	• Elective (medical students) • Clinical Rotation (PGY2, PGY4) • Clinical Fellowship (one year) • International visitors (2-3 per year)
Education Innovations	• *Complexcareathomeforchildren.com* • National curriculum for pediatric postgraduate trainees

Table 1. Snapshot of CCS at MCH

Scheduled, comprehensive consultative care is provided by a dedicated team of nurses and physicians, along with allied health partners. In addition, urgent care visits are offered daily through a medical day hospital clinical setting. Acutely ill children may be seen as needed, with assessments and interventions, preventing or decreasing the duration of both emergency department visits and inpatient hospitalization. This, along with a 24/7 on call service, is considered by families as a "lifeline". By design, the CCS program is situated adjacent to the general medical day hospital; sharing administrative and some clinical services.

Proactive care plans for predictable decompensations (eg. ketotic hypoglycemia, seizures, respiratory infections) are developed with families, subspecialists and the CCS team such that parents are empowered to care for their children safely at home as much as possible (Figure 1). These care plans are frequently structured as colour coded schemes: green light plans for usual care days, yellow light for moderate decompensation and red light for more severe illness. For children with more complex algorithms, additional plans are made for Emergency Department and inpatient care (eg. ongoing seizures despite home use of vagal nerve stimulator,



Hôpital de Montréal pour enfants
Centre universitaire de santé McGill
Montreal Children's Hospital
McGill University Health Centre

CCS Action Plan for Parents / Caregivers

Name: XXXX **DOB:** Weight: XX kg **Date:** June 12, 2019
Goals of Care: Minimize/eliminate hypoglycemia and borderline hypoglycemia
CCS Daytime: ###-#### **CCS ON CALL:** ###-#### and ask to speak with the on-call nurse for CCS
Alerts: PORT, possible underlying mitochondrial disorder

GREEN ZONE
I AM WELL!

XXXX is feeling well AND does not have a fever. She is eating normally . Her blood glucose (BG)s have been stable and above 3.5 for the majority of the day and night. Continuous blood glucose monitoring via sc monitor.
Serum BG 3.5 or greater (less than 13)
DAYTIME: Eats by mouth as per usual; Continuous blood glucose monitoring; under the surveillance of a mature adult knowledgeable in the identification and treatment of hypoglycemia.
SLEEP: Continuous GT feed at 35 mls/hour = Glucerna + 45 mls of microlipid/can of 236 ml
*** re-evaluate GT feed in 2-3 weeks and adjust as required**

Borderline hypoglycemia = BG between 3.1 -3.5 = Act and Be on Alert
If awake and able to eat: give a snack containing glucose+ protein
If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
Recheck BG in 15 minutes
Repeat intervention as needed
If Borderline hypoglycemia persists > 2 episodes, encourage meal

If Lethargic, Shaky OR **BG 3.1-3.5** persists > 4 episodes,
Start continuous GT feeds DAYTIME and NIGHT; may eat in addition if she wishes to
Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7
Closely monitor BG
Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

Hypoglycemia = BG 3.0 or lower = Act IMMEDIATELY
If awake and able to eat: give 15 g fast acting carbohydrate = Dex4gel 38g and then give a snack containing glucose+ protein
If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
Recheck BG in 15 minutes
Repeat intervention up to 2 times if required

If BG 3.0 or lower persists more than 2 times, then **Start continuous GT feeds**; may eat in addition if she wishes to Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7 Monitor BG closely (on continuous monitor); if BG stabilizes ≥3.5 then **continue GT feed** and Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

Figure 1. Sample of care plan, see complete care plan in appendix.

intranasal midazolam, etc.). The care plans are part of the electronic medical record.

The unique blend of acute and chronic care services has been a key factor in the long term sustainability of the program; meeting important needs of the families, the CCS healthcare team and the broader hospital services. For the children and families, they have the benefits and security of longitudinal care by a team that knows their child and family well and with whom a trusting relationship exists. They highly value avoiding the emergency department (ED) for the majority of acute care. Periodic family satisfaction surveys indicate that we are meeting our care goals and parental

expectations (see PROGRAM OUTCOMES below).

For the CCS healthcare team, delivery of acute care services balances the time and psychological investment of chronic care management, continually broadening our skill set and offering a rich learning environment. To be frank, we enjoy the fast paced environment of acute care and the immediately tangible rewards of acute interventions. This 'adrenaline' sustains the team as we deal with the much more complicated chronic issues that are sometimes unsolvable. As a result, we have remarkable staff retention, allowing for expertise through experience.

The broader hospital services, including subspecialists and acute care teams, value our contributions and the subsequent facilitation or reduction in the care that they provide. Over the years, we have built solid relationships with key subspecialty providers, especially in Neurology, Respirology, Gastroenterology, Intensive Care, and Interventional Radiology. The most tangible outcomes of this collaboration are the "one-site" combined visits in the CCS clinic area which are routine for most children and the ease of communication between the CCS team and subspecialists.

EDUCATIONAL AND ADVOCACY: Beyond clinical care, the MCH CCS team has been involved in a variety of educational projects and advocacy aimed at improving the quality and quantity of care for CMC.

Our team has led the development of a national curriculum in complex care, intended for postgraduate trainees in pediatrics. In partnership with the Royal College of Physicians and Surgeons of Canada, our accreditation body in pediatrics, exit examinations now have increased content on the care of CMC, in keeping with the reality of consultant pediatric care in Canada.

We offer a clinical fellowship in Complex Care, training the next generation of 'builders' in this field. For more information on this competitive fellowship, please contact the corresponding author of this paper or visit the McGill fellowship website: *http://www.mcgill.ca/pgme/programs/fellowship-programs.*

In concert with families and community care providers, we have spent the last several years standardizing evidence-based and evidence-informed homecare practices for the most common nursing interventions in CMC and have developed a website with detailed step by step instructions for

caregivers (Figure 2). Website address: *complexcareathomeforchildren.com*. Topics covered include how to use medical technologies (Figure 3) and everyday care of medical technologies (Figure 4) to how to prepare children and families for a life with medical technologies (Figure 5).

Healthcare in Canada is managed at a provincial level and in our province of Quebec, our team has been active in advocacy for improved homecare supports and have successfully brokered meaningful policy change and funding for these children and their families.

FINANCIAL PLAN

Healthcare in Canada is publicly funded by province; the CCS is funded through the McGill University Health Centre by the Ministry of Health and Social Services in Quebec. The annual operating budget is approximately 1.5 million dollars Canadian and primarily covers the salaries of nurses, administrative personnel and allied health partners; some of whom have multiple roles in other hospital services also. A smaller proportion of funds is designated for equipment and homecare supplies not otherwise covered by the provincial healthcare plan or private insurance. Physicians work on a fee-for-service basis and are not salaried by the hospital.

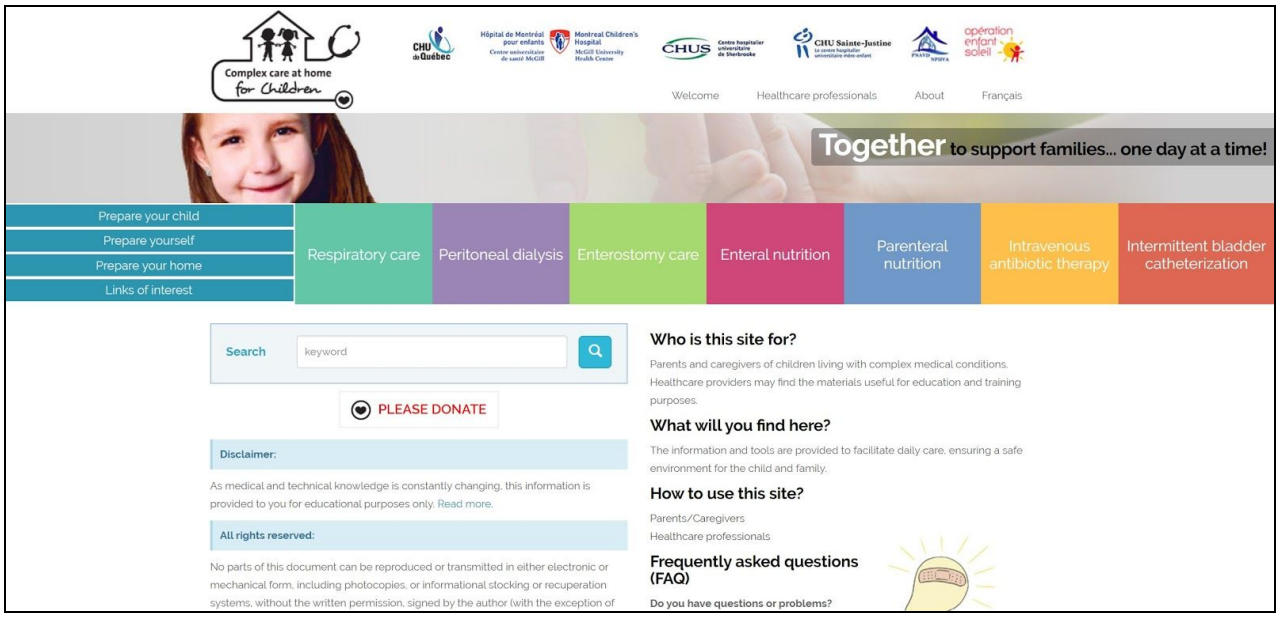


Figure 2. Home page of *Complex Care at Home for Children*.

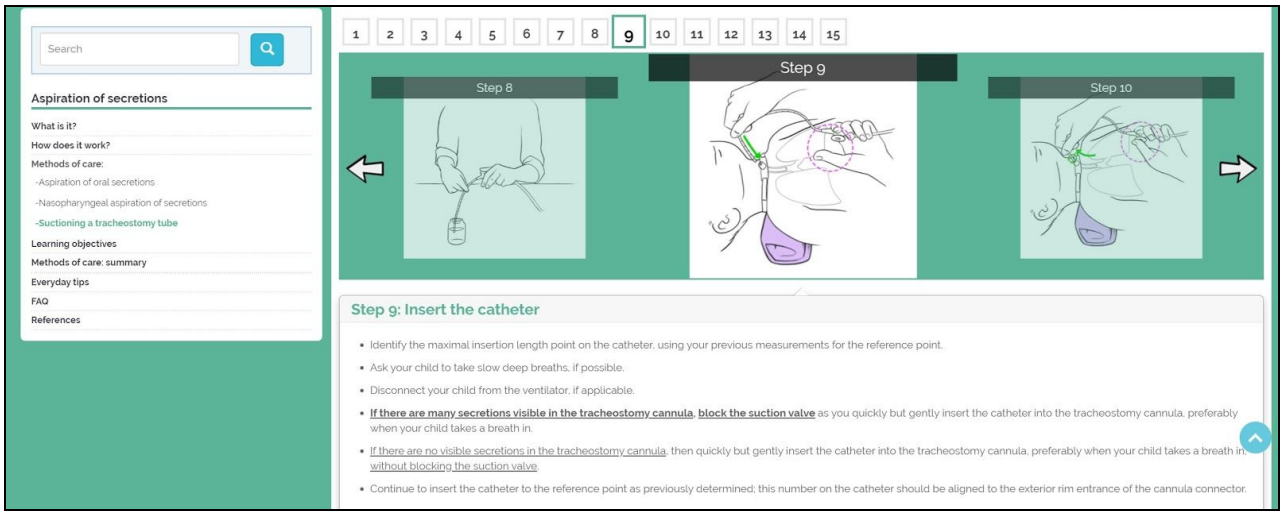


Figure 3. Step 9 of "Suctioning a tracheostomy tube"

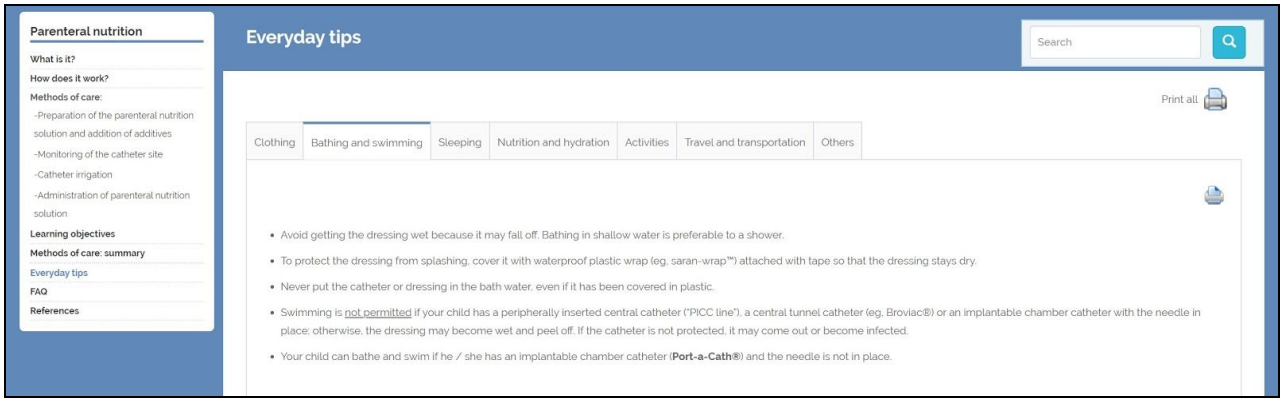


Figure 4. "Everyday tips: bathing and swimming" of Parenteral Nutrition section

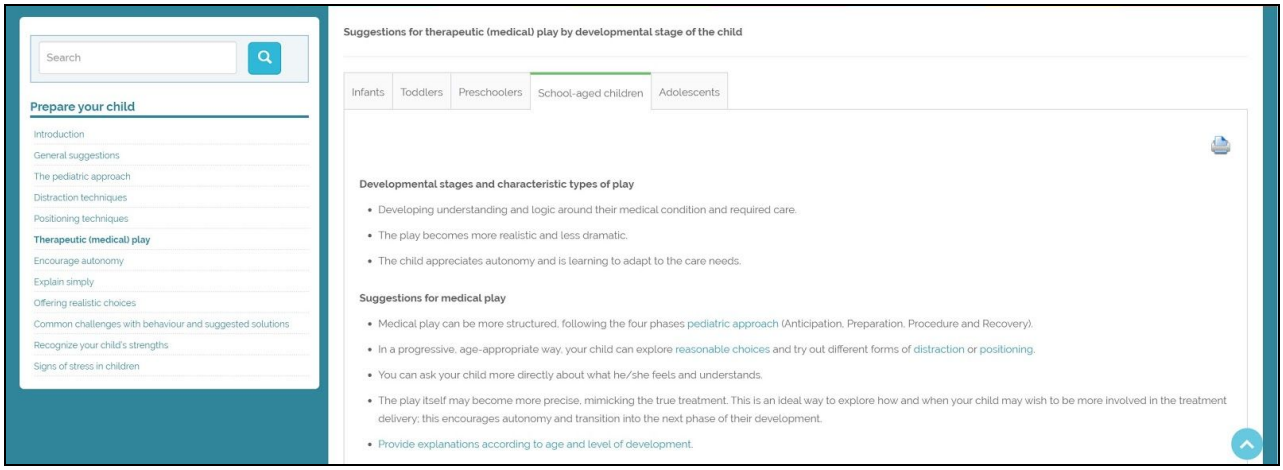


Figure 5. "Suggestions for therapeutic (medical) play by developmental stage: school-aged children"

The CCS has built an important relationship with the hospital Foundation and has been grateful to receive private donations through a variety of fundraisers; these resources have been invaluable in facilitating care.

PROGRAM OUTCOMES

Along with basic demographic statistics (enrollments, discharges, deaths and transfers), the CCS also tracks: acute care visits, hospital admissions, referrals to the Emergency Department, home/community visits and the use of the after hours telephone service. These results are not being published in this report.

Family satisfaction surveys are undertaken every few years; the last one collected in spring of 2018 focused on “medical home” quality indicators. We used the "Measure of Processes of Care", a self-report measure of parent's perceptions of the care they and their child received (assessment of family-centred behaviors of the healthcare team) in 5 domains.[1] We collected 29 surveys during the most recent survey period. While we are not publishing the results of that survey in this report, the results showed that we could improve in two of the domains: ‘providing specific information about the child’ and ‘providing general information’. Specifically, parents wanted more written take home materials. We are responding to this with a new project: care binders.

PROGRAM LIMITATIONS

Like most complex care services elsewhere, we are challenged with an ever increasing number of referrals and resource restriction. Transition to adult care remains a daunting task. The care of children with moderate complexity; that is, those ‘not sick enough’ for admission to the CCS, is problematic and insufficient. Research remains a priority but has minimal remuneration making it a costly necessity, both in terms of time and money. Nonetheless, we are known, nationally and internationally as a centre of innovation for CMC, with specific expertise in educational outreach.

DISCLOSURES/CONFLICTS OF INTEREST & FUNDING: The authors do not have any disclosures.

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IMAGES AND TABLES

Location	Montreal Children's Hospital, McGill University Health Centre
Staffing	Core Staff includes: • 5 Pediatricians (each attending 5-15 weeks year in CCS + scheduled visits clinics) • 1 FTE Clinical Manager • 1 FTE Assistant Nurse Manager • 1 FTE Advance practice nurse • 7 FTE Nurse coordinators • 1 FTE Discharge Coordinator • Nurse Educator • Allied health support
Patient Demographics	Patients 0 to 18 years of age with the following characteristics: • Chronicity • Complexity • Fragility • Technology dependency/high intensity care needs grouped as follows: ○ Neuromuscular conditions ○ Tracheostomy/Home Ventilation ○ Bronchopulmonary Dysplasia on home oxygen support ○ Home parenteral nutrition ○ Long-term enteral nutrition ○ Immunocompromised ○ Multiplex- children with rare genetic/neurological/metabolic conditions with multiple co-morbidities ○ Heart transplant ○ Thalassemia ○ Congenital hemostasis disorders
Key Services	• Designated nurse coordinator/ pediatrician for longitudinal care • Daily urgent care clinic • Scheduled comprehensive multi-disciplinary visits • 24/7 on-call nurse-pediatrician team • Consultations (inpatient and outpatient) • Home visits
Teaching Services	• Elective (medical students) • Clinical Rotation (PGY2, PGY4) • Clinical Fellowship (one year) • International visitors (2-3 per year)
Education Innovations	• *Complexcareathomeforchildren.com* • National curriculum for pediatric postgraduate trainees

Table 1. Snapshot of CCS at MCH

Hôpital de Montréal pour enfants
Centre universitaire de santé McGill

Montreal Children's Hospital
McGill University Health Centre

CCS Action Plan for Parents / Caregivers

Name: XXXX **DOB:** Weight: XX kg **Date:** June 12, 2019
Goals of Care: Minimize/eliminate hypoglycemia and borderline hypoglycemia
CCS Daytime: ### #### **CCS ON CALL:** ### #### and ask to speak with the on-call nurse for CCS
Alerts: PORT, possible underlying mitochondrial disorder

GREEN ZONE
I AM WELL!

XXXX is feeling well AND does not have a fever. She is eating normally . Her blood glucose (BG)s have been stable and above 3.5 for the majority of the day and night. Continuous blood glucose monitoring via sc monitor.
Serum BG 3.5 or greater (less than 13)
DAYTIME: Eats by mouth as per usual; Continuous blood glucose monitoring; under the surveillance of a mature adult knowledgeable in the identification and treatment of hypoglycemia.
SLEEP: Continuous GT feed at 35 mls/hour = Glucerna + 45 mls of microlipid/can of 236 ml
*** re-evaluate GT feed in 2-3 weeks and adjust as required**

Borderline hypoglycemia = BG between 3.1 -3.5 = Act and Be on Alert
If awake and able to eat: give a snack containing glucose+ protein
If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
Recheck BG in 15 minutes
Repeat intervention as needed
If Borderline hypoglycemia persists > 2 episodes, encourage meal

If Lethargic, Shaky OR **BG 3.1-3.5** persists > 4 episodes,
Start continuous GT feeds DAYTIME and NIGHT; may eat in addition if she wishes to
Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7
Closely monitor BG
Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

Hypoglycemia = BG 3.0 or lower = Act IMMEDIATELY
If awake and able to eat: give 15 g fast acting carbohydrate = Dex4gel 38g and then give a snack containing glucose+ protein
If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
Recheck BG in 15 minutes
Repeat intervention up to 2 times if required

If BG 3.0 or lower persists more than 2 times, then **Start continuous GT feeds**; may eat in addition if she wishes to Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7 Monitor BG closely (on continuous monitor); if BG stabilizes ≥3.5 then **continue GT feed** and Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

If **BG 3.0 or lower** persists more than 2 times while ALREADY ON continuous GT feeds (eg. nighttime) then **ACCESS PORT** and **START** IV D10W infusion at 60mls/hour and alert CCS team; recommend evaluation in clinic at next available time; consider D10TPN solution for next 5-7 days if intercurrent illness present.

Figure 1. Page 1 of complete care plan

Hôpital de Montréal pour enfants
Centre universitaire de santé McGill

Montreal Children's Hospital
McGill University Health Centre

YELLOW ZONE
I AM SICK – ACT EARLY!

XXXX is feeling unwell, even if mild symptoms OR has ANY of the following features:

- Not eating regular food/meals by mouth
- Diarrhea
- Fever
- Signs of a viral illness (cough, congestion, fatigue, refusal to eat)

Call CCS (available 24/7) to organize prompt clinic visit to evaluate for possible trigger)
Start continuous GT feeds DAYTIME and NIGHT even if BG >3.5; may eat in addition if she wishes to
Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7
Closely monitor BG

If **BG 3.0 or lower** while ALREADY ON continuous GT feeds (eg. nighttime) then **Access PORT and start IV D10W at 60 ml/hour; monitor closely. Call CCS.**

If Lethargic, Shaky OR **BG 3.1-3.5** persists > 2 episodes while ALREADY ON continuous GT feeds then **Access PORT and start IV D10W at 60 ml/hour; monitor closely. Call CCS.**

*** If BG< 3.1 while on D10W at 60 mls/hour then increase rate to 90mls/hour. Call CCS.**

RED ZONE
I AM IN DANGER AND NEED HELP

XXXX is having recurrent or resistant hypoglycemia OR
XXXX is vomiting or otherwise unable to tolerate GT feeds OR
XXXX is lethargic or unresponsive OR
XXXX has severe abdominal pain

Access PORT and start D10W at 90 mls/hr
Hold feeds by mouth and by GT

GO TO EMERGENCY ASAP; Call 911 if unresponsive
Call CCS
Show this plan to health care team

Figure 1. Page 2 of complete care plan

Hôpital de Montréal pour enfants
Centre universitaire de santé McGill

Montreal Children's Hospital
McGill University Health Centre

EMERGENCY and INPATIENT CARE RECOMMENDATIONS

X year old girl XXkg with ketotic hypoglycemia NYD ? mitochondrial disease; GT, continuous SC glucose monitor
Known for recurrent hypoglycemia, muscle spasms, generalized weakness, intermittent urinary incontinence. Has a PORT central line.

Start or continue D10W at 1.2X maintenance = 70 mls/hr ASAP
Provides 6 mg CHO/kg/min
****Monitor BG closely** Q 30 min or more often (do not rely on continuous blood glucose monitor)**
If BG≤3.0, give 30 ml of D50 via GT or 1-2 ml/kg IV of D50W

Do serum lytes, LFTs, gas, glucose and urinary ketones

Evaluate underlying trigger, concurrent stress (eg. infection)
Avoid PO and GT feeds while acutely ill as this may trigger severe abdominal pain
Continue IV D10W with in-hospital monitoring for hypoglycemia

If BG≤3.0 while on D10W infusion, then after treating hypoglycemia, change IV fluids to:
D10W at 35 mls/hour (3 mg CHO/kg.min) + Intralipid at 12 ml/hour (3 g/kg/day)
This will provide 2:1 ratio similar to ketogenic diet; may develop nausea and vomiting

If there are more than 3 episodes of BG≤3.0 while on D10W + Intralipid, then consult Endocrinology.

Preparation for discharge
If no BG≤ 3.0 for 24 hours, then start continuous GT Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour AND decrease IV rate to 75% of original rate for one hour, continuing to monitor BG.
If she remains normoglycemic, further decrease IV rate to 50% of original rate for one hour, continuing enteral feeds and BG monitoring.
If she remains normoglycemic, further decrease IV rate of 25% of original rate for one hour, continuing enteral feeds and BG monitoring.
If she remains normoglycemic, stop IV fluids, maintain IV access with saline lock, monitor closely for 2 hours.
If tolerating continuous GT feed and having no hypoglycemia, consider discharge home with follow up in CCS on the next calendar day (by phone if on a holiday).
Aim to transition to Green zone plan after 1-2 days of normoglycemia (discuss with CCS team)

Figure 1. Page 3 of complete care plan

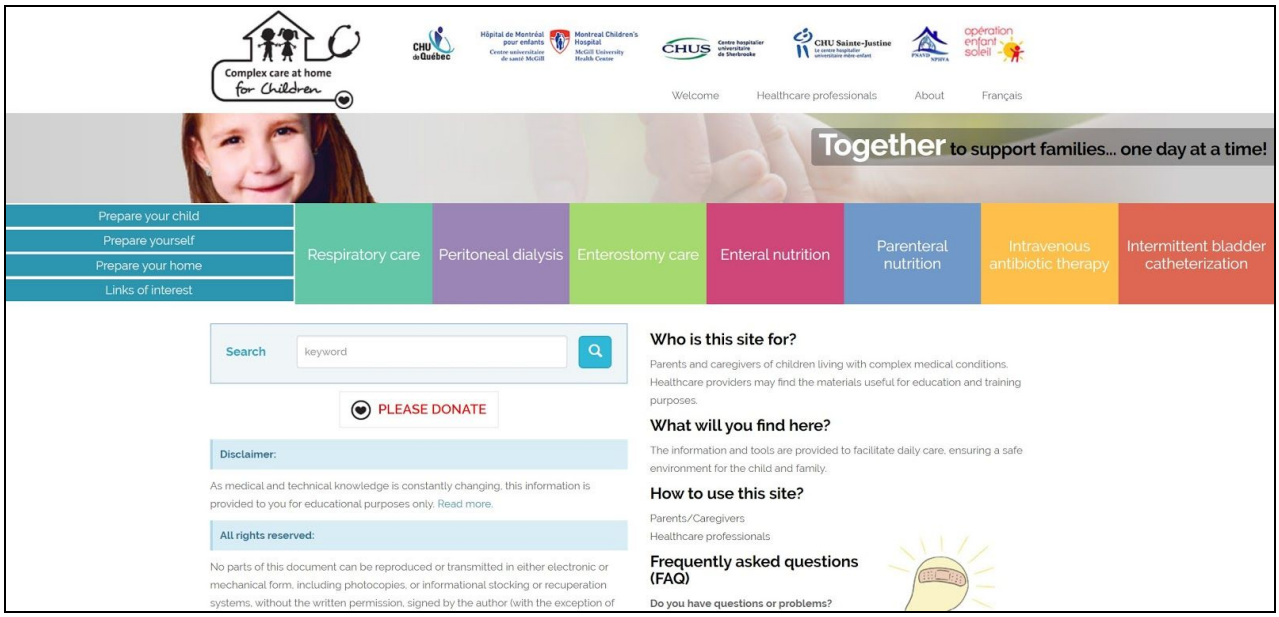

Figure 2. Home page of *Complex Care at Home for Children.*

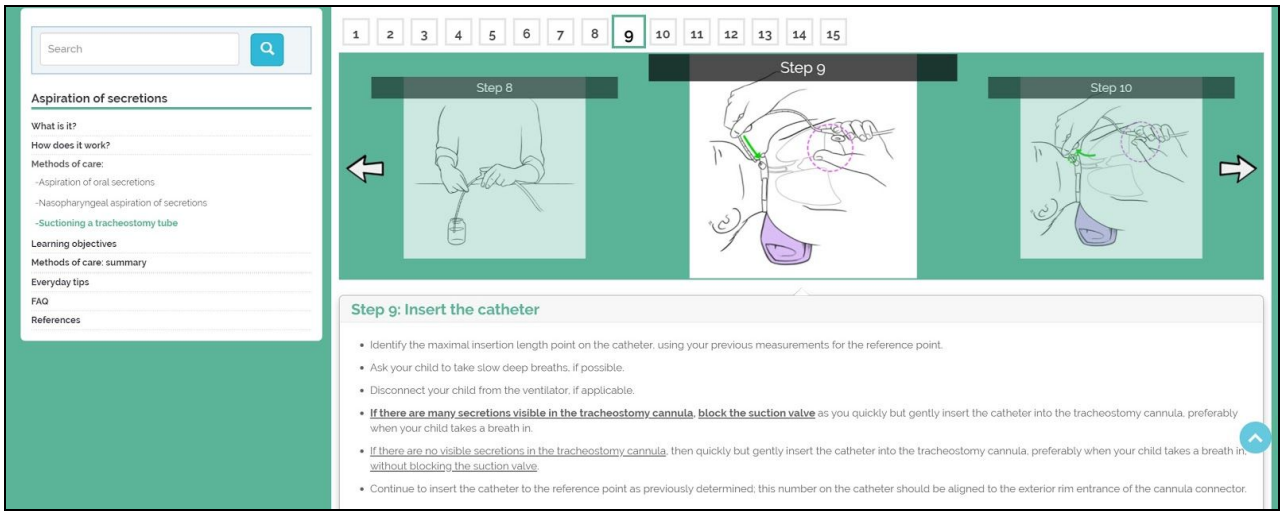

Figure 3. Step 9 of “Suctioning a tracheostomy tube”

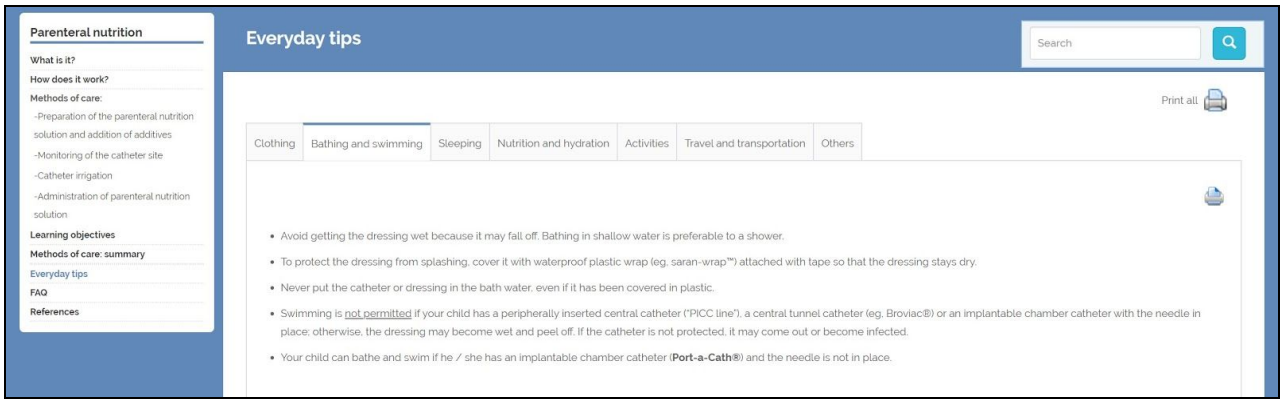

Figure 4. "Everyday tips: bathing and swimming" of Parenteral Nutrition section

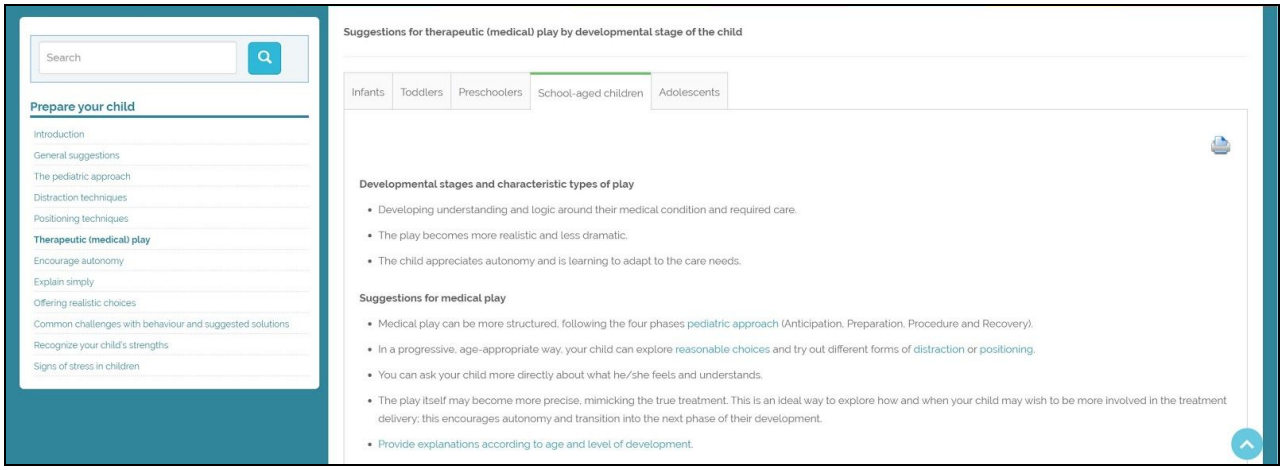

Figure 5. "Suggestions for therapeutic (medical) play by developmental stage: school-aged children"

COMMENTARY

CRISIS AS AN ENGINE OF CHANGE

MATTHEW SADOF, MD[a]

Coronavirus disease 2019 (COVID-19) is a novel contagious respiratory illness caused by a virus thought to spread mainly between people through respiratory droplets produced when an infected person coughs or sneezes.[1] Heeding the CDC advice for social distancing, we health care providers have been forced to look at our daily practice to find new ways to care for our patients without unduly exposing them to infection. As this current health crisis drives innovations to safely and efficiently care for children with medical complexity (CMC), we are compelled to reexamine the way we practice, creating opportunity to gather evidence that can transform care.

Across the country there may be shifts driven by a need to rapidly adapt and evolve to heed the imperative to keep children away from health care settings unless absolutely necessary. A great deal of rapid cycle testing and prototyping of new approaches to old problems has arisen, catalyzed by interim liberalization of telehealth rules by federal or state authorities. This provides an opportunity to pilot new approaches and assess their value and impact.

Certain existing programs show promise of what success looks like. During a webinar entitled "Telehealth for CMC in the Pandemic" hosted by the Academic Pediatric Association Complex Care Special Interest Group, multiple complex care programs reported preliminary data of improved patient outcomes and patient satisfaction while using telehealth.[2] Those who participate in the care of CMC best take note of salient examples.

In the past decade, a number of studies in many different settings have demonstrated that care coordination when properly structured can improve the quality of life for CMC and their families and lower cost.[3,4,5,6,7,8,9]

[a]University of Massachusetts Medical School Baystate, Springfield, Massachusetts

Published reports have also demonstrated that telehealth-based care coordination does not adversely affect care and may improve upon the experience of families. In a randomized controlled trial of 148 families with CMC between the ages of 2 and 15, investigators used the Consumer Assessment of Healthcare Providers and Systems survey as an outcome measure at baseline and after 1 and 2 years. They found that participants in the intervention group had higher ratings on measures of the child's provider, provider communication, overall health care, and care coordination adequacy, compared with control subjects.[10] A second RCT of 168 patients from the same center compared Health Related Quality of Life HRQL as measured by the PedsQL. This study compares telehealth care coordination to office-based care coordination in families' existing medical homes. They found no difference in outcomes and patient satisfaction between the two groups.[11]

Telehealth can represent a range of services. Encounters may involve a simple telephone call, a video-assisted call using the patient's smartphone and a secure video chat application, or it can include devices that monitor the patient and auscultate the patient noninvasively. A new pediatric telehealth research network, Supporting Pediatric Research and Outcomes and Utilization (SPROUT) is conducting ongoing prospective research to promote evidence-based practice as this new modality grows to scale.[12]

The technology available for home monitoring of CMC, still quite underdeveloped for pediatrics, is a potential area that is ripe for research and development. A recent focus group of family caregivers on the use of mobile health (mHealth) suggests that the ideal application should include: symptom tracking, an optimized user experience with real time text and email messaging options to post a video and/or photograph of the child to allow a visual assessment by the healthcare provider.[13]

Now as medical providers across the country are converting from office-based care to video and audio telehealth to provide care and lower the risk of infection,[14,15] we in pediatrics need to acknowledge that patients may come to expect this practice to continue after the current health crisis. We also need to ensure that if the transformational effect of this crisis endures

that it allows patients and families to feel cared and not just taken care of.

It may be helpful to look at this change through three different lenses; the patient, the provider/care team, the health system. This is depicted below in Table 1.[16]

	Benefits	Potential Harms
Patient and family perspective	Convenience Reduced transportation barriers Better access to specialty care Less time missed from work Improved patient provider connection Lower infection risk Better DME access	Perceived lack of caring Limited knowledge of local landscape Decreased patient provider connection Increase health disparity and enhanced digital divide
Provider and care team	Improved access to families Improved show rates Lower infection risk Improved patient provider connection Closed loop communication	Poor video quality/Poor connectivity Absence of in person nonverbal cues with cultural miscommunication Lack of physical exam Limited ability for diagnostic testing Decreased patient provider connection Open loop communication
Population health/ health system	Improved access to specialty care Lowered transportation barriers Improved no show rates Lowered health care utilization costs	Lowered demand for in person visits Increase health disparity and enhanced digital divide Decreased quality of care Impaired antibiotic stewardship

Table 1. Potential changes caused by telehealth through three different lenses

While there are many benefits from the families' and patients' perspective, there remains potential for unintended harm. Inequitable access to internet based services abounds, and a lack of universal telehealth may unintentionally worsen health disparity. Large telehealth "call centers" may not possess adequate knowledge of local resources applicable to CMC and may lack the personal connections required to build an adequate community of caring for individual patients and families.

While telehealth has existed in some health systems for decades, others are working to catch up and understand what gaps they need to address to fully implement this in practice. A holistic assessment will be critical. Current documentation requirements relating to prescribing of medications, treatments, durable medical equipment and homecare may need to be reexamined to improve access. For CMC, the needs may be correspondingly complex, including integrating forms or templates that enhance care coordination and care management. Electronic prescribing may need to be expanded or modified, moving home care documentation (485 forms), DME requests, from open loop paper and fax systems to online closed loop systems with shorter turnaround times and more rapid feedback loops. As we look to enhance our efficiency, we may also need to consider shifting the current paradigm and have documentation driven by medical need instead of billing requirements. How much documentation is really needed for care? How much needs to be physician driven and how much can be team driven? How can the EMR be simplified and redesigned around this?

The current pandemic has created a crisis of resources and a need for healthcare systems to reexamine how care is best delivered for all patients in an environment

of resources under stress and high demand. In this crisis comes a great opportunity that is best seized upon as a chance to look at how we can provide care that is safer and more efficient for patients and providers. Some changes will be rapid and some will take longer. To be successful we must continue to re-examine our approach to everything, and to apply creative solutions, assess their impact while focusing on what is primary: the needs of families and patients during this time of transformation.

Acknowledgement

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FIGURES

	Benefits	Potential Harms
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Table 1. Potential changes caused by telehealth through three different lenses

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CLINICAL CARE FRAMEWORK

Chronic Pain in Children with Severe Impairment of the Central Nervous System: A Framework for Assessment and Initial Management

JULIE M HAUER MD[a,b]

ABSTRACT

Children with severe impairment of the central nervous system (CNS), often referred to as children with severe neurological impairment (SNI), have a significantly higher incidence of acute and chronic pain compared to children with mild impairment or with typical development. This article is focused on chronic pain sources due to the altered CNS, referred to as neuro-pain in this article. Chronic pain has a significant impact on quality of life and health outcomes of the child and family. It requires a distinctly different approach from acute pain, including goals of treatment. A case example highlights many of the challenges that delay treatment for neuro-pain, including lack of diagnostic tests or criteria, risk for multiple comorbid problems, and the impact of cognitive bias. A proposed screening process and assessment tool are provided, intended to identify children at risk for neuro-pain as a reason for recurrent symptoms who therefore may benefit from a medication trial for neuro-pain. Parents also face many worries throughout this process. Language strategies are provided to assist with needed support.

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INTRODUCTION

Children with severe impairment of the central nervous system (CNS), often indicated as children with severe neurological impairment (SNI), have a significantly higher incidence of pain compared to children with mild impairment or with typical development.[1] This includes both acute pain, which alerts to a cause of tissue injury in need of identification and treatment, and chronic pain often due to the altered nervous system.

A child with SNI and pain without a clear source may be described as irritable or agitated, terms that indicate a problem in need of attention. Irritability is defined as an abnormal response to stimuli or physiological arousal that can be in response to pain, a medication, an emotional situation, an acute illness or medical condition.[2] Pain is a frequent cause of irritability in children with SNI, highest in those with severe to profound intellectual disability and with cerebral palsy classified as Gross Motor Function Classification System (GMFCS) level 4 and 5 or indicated to have limited to no use of extremities.[3-6] Those with the greatest impairment were identified to have recurrent pain that is weekly to daily.[3-6]

The American Academy of Pediatrics (AAP) clinical report on pain in children with SNI provides a comprehensive review of the assessment and management of acute and chronic pain in such children.[1] This article will focus on chronic pain that is due to the altered nervous system. This focus is essential given the high incidence of chronic pain in children with SNI, the lack of diagnostic tests to guide identification, and the significant impact on quality of life and health outcomes of the child and family. Ensuring symptom control has been identified by parents as one of the essential domains of care.[7,8]

Chronic pain, defined as pain that recurs for more than 3 months, requires a distinctly different approach from acute pain, including goals of treatment as noted in

Table 1. Acute versus Chronic Pain

	Acute	Chronic
Cause	Expected with surgery or due to causes of tissue inflammation and injury (i.e. nociceptive pain)	Pain that recurs for more than 3 months; categories include musculoskeletal, visceral, post-surgical, and neuropathic
Duration	Hours to days	> 3 months, persists
Identification	Sources typically identified by diagnostic tests	No routine diagnostic tests or criteria for sources due to the impaired nervous system
Goals	Resolution after treatment of cause and healing of tissue injury	Pain control, not cure

Table 2. Chronic neuro-pain sources

Problem	Features, Comments, and Treatment Options
Central neuropathic pain	Symptoms include pain localized to the GI tract, such as pain triggered by normal distention of the GI tract; this can be suggested by pain associated with tube feedings or intestinal gas, with relief following a bowel movement or flatus Pain features can occur spontaneously and with no trigger, described by adults as "shock-like" and "out of the blue" Due to impairment of the spinothalamic tract and thalamus Treatment: gabapentinoids, tricyclic antidepressants, SNRIs, methadone
Visceral hyperalgesia	Decreased threshold to pain generation in response to a stimulus in the GI tract, including a decrease in the amount of distention that triggers a pain signal Attributable to sensitization of visceral afferents and central sensitization in the CNS Treatment: gabapentinoids, tricyclic antidepressants, clonidine
Chronic post-surgical pain (CPSP)	Defined as pain that lasts more than 2 months post-surgery without other causes of pain such as chronic infection or pain from a chronic condition preceding surgery The mechanisms leading to chronic CPSP can include inflammation, tissue and nerve damage, and alterations in central pain processing Treatment: gabapentinoids, tricyclic antidepressants
Autonomic dysfunction (dysautonomia)	Features include skin flushing, hyperthermia, pain localized to the GI tract, retching, bowel dysmotility, discomfort, agitation, tachycardia, sweating, arching, stiffening Dysautonomia can be a source of discomfort, and pain can trigger the features that occur with dysautonomia Treatment: gabapentinoids, clonidine
Dystonia	Involuntary sustained or intermittent muscle contractions cause twisting and repetitive movements, abnormal postures, or both Pain from other sources can trigger and worsen dystonic movement Treatment: baclofen, trihexyphenidyl, gabapentinoids, clonidine
Paroxysmal autonomic instability with dystonia (PAID)	Involves features of both autonomic dysfunction and dystonia Indicates altered function of the CNS areas that regulate autonomic function and movement; such children are also at risk for co-morbid central neuropathic pain Pain from other sources can trigger and worsen the observed features Treatment: see dysautonomia and dystonia
Spasticity	Velocity-dependent increase in muscle tone that results in muscles that are resistant to movement Spasticity is often not painful but can result in musculoskeletal pain over time Treatment: baclofen, alpha2-agonists (clonidine or tizanidine)
Muscle spasms	Sudden involuntary contraction of a muscle or group of muscles; associated features can include arching, stiffening, tremors, and clonus Pain behaviors can indicate pain from muscle spasms and indicate pain from another source as the trigger for muscle spasms Treatment: interventions for spasticity, chronic neuro-pain, and other triggers

GI: gastrointestinal; SNRIs: serotonin norepinephrine reuptake inhibitors

Table 1.[9] Chronic pain sources due to the altered nervous system are reviewed in Table 2. Neuro-pain is used in this article to refer to these sources given the overlap in presenting features of each. A case example highlights the many challenges that delay treatment for neuro-pain, including the lack of diagnostic tests or criteria, risk for multiple comorbid problems, and the impact of cognitive bias.

Figure 1 provides a proposed screening process when symptoms recur in a child with SNI. The neuro-pain risk assessment tool (N-PRAT) is a hypothesis-generated tool developed to screen for a reasonable likelihood of benefit from an empirical trial directed at neuro-pain sources (Figure 2). The case illustrates the need for a screening process and tool. Experts in managing chronic pain in children with SNI, such as pediatric palliative care clinicians, can assist those with limited experience. For others, expertise might be sought when a child has continued symptoms following the first medication trial.

Figure 1

Screening children with SNI for risk of chronic neuro-pain

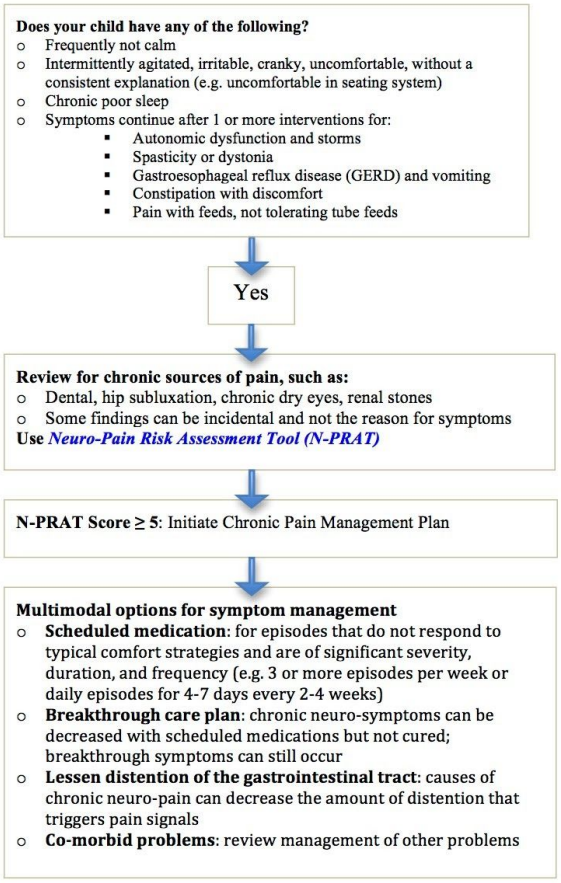

Figure 2. Neuro-Pain Risk Assessment Tool (N-PRAT)

Neuro-Pain Risk Assessment Tool (N-PRAT)	Score: Circle if present
Episodes with pain behaviors from 2 or more of the following categories, recurring for more than 3 months without a consistent source*; episodes may be weekly or cyclical (e.g. daily for 3 to 5 days every 2 to 4 weeks) • *Vocalizations*: crying, moaning • *Facial expression*: grimacing, frowning, eyes wide open • *Unable to console*: difficult to calm, not soothed by parent comfort actions • *Interaction*: withdrawn, seeking comfort • *Physiological*: tachycardia, sweating, pale or flushed skin, tears • *Muscle tone*: intermittent stiffening of extremities, clenching of fists, muscle tensing, tremors, back arching • *Movement*: increased movement, restless, startles easily, pulls away when touched, twisting	1 point for 2 or 3 categories 2 points for 4 or more categories
GMFCS* level 4 and moderate to severe intellectual disability OR	1
GMFCS* level 5 and severe to profound intellectual disability	2
Some episodes occur rapidly and out of the blue with no known trigger, quickly changing from calm to agitated / irritable / in pain	1
Intermittent increase in muscle tone, movement and posture: features continue following 1 or more drugs for spasticity or dystonia	1
Autonomic dysfunction and storms: features remain significant following 1 or more drugs for autonomic dysfunction	1
GI symptoms: Pain behavior episodes noted with tube feeds, intestinal gas, and constipation, with improvement when feeds are held and following a bowel movement; symptoms continue following 1 or more drugs for GERD	1
Chronic poor sleep with symptoms of agitation / discomfort	1
Post-surgical: new or worsening pain behavior episodes for > 2 months following surgery without a clear cause	1
Intractable seizures following 3 or more anti-seizure drugs	1
Planned surgery: prior to surgical interventions for GERD, spasticity, or dystonia to determine if chronic neuro-pain is a trigger; gabapentinoids may decrease need for post-surgical opioids and development of postsurgical pain[28]	1
Total score (highest score = 12)	

Total score ≥ 5: initiate multimodal approach to symptom management (Figure 1)

*__Nociceptive assessment noted in Figure 1 of AAP clinical report__.[1] Consider cognitive bias towards positive tests that may result in recurrent treatment in a symptomatic child with SNI, yet the positive test may represent colonization or an incidental finding and not be the source of symptoms (e.g. positive urine culture with less than 10 white blood cells in urinalysis, positive clostridium difficile with test that does not distinguish carrier from infection, gallstones with no other abnormal findings on labs or ultrasound)

*__GMFCS:__ used here as an indicator of motor function level in children with severe impairment of CNS

CASE

Parents gave informed written consent. This case series was structured as per the case report guidelines.[10]

A 14-year-old boy with Bohring-Opitz syndrome (BOS), a condition caused by mutations in the ASLX1 gene, has multiple features reported with BOS, including profound intellectual disability, hypotonic cerebral palsy (CP) GMFCS level 5, characteristic facial features, seizure disorder, and recurrent emesis and retching over years that is classified as cyclic vomiting syndrome.[11] He also has has a long-standing history of severe sleep disruption that has been assessed by a sleep specialist. Other problems include multiple congenital anomalies, right hip subluxation and progression of scoliosis. Head MRI identified agenesis of the corpus callosum and parenchymal volume loss of the frontal lobe. All feeds, fluids, and medications are given by a gastrostomy feeding tube. There has been no sustained weight gain in 3 years, due to the recurrent emesis and need to hold feeds intermittently. His respiratory status remains stable with occasional use of supplemental oxygen overnight.

Past major surgeries include: bilateral complete cleft lip and palate repair and open gastrostomy tube placement (2005), craniofacial surgery (2005, 2006), tracheotomy (2005), laryngotracheal reconstruction reconstruction and decannulation (2007), adenoidectomy (2011), bilateral orchidopexy (2012), diagnostic laparoscopy, gastrocutaneous fistula closure and placement of new gastrostomy button (2015), lower extremity orthopedic surgery (2018). Fundoplication surgery is being considered.

Diagnostic assessment has been unremarkable and included: abdominal ultrasound (2007, 2017, 2018), gastric emptying (2008, 2010), upper GI endoscopy (2008, 2011), and sinus radiographs (2012, 2015). Interventions for recurrent emesis

have “not made a clear difference” per parent report, including proton pump inhibitors, carafate, various interventions for constipation, and other medication trials including ondansetron, lorazepam, and cyproheptadine. There was limited benefit in sleep with melatonin and lorazepam, followed by improvement with clonidine, initially started at 0.003 mg/kg then increased to 0.006 mg/kg at nighttime.

Emesis occurs daily for 2 to 4 days, with a cycle every 2 to 4 weeks. He is irritable during these events as well as irritable at other times. Irritability can be triggered by intestinal gas and prior to a bowel movement; other irritably can occur “out of the blue” without an identified trigger. Pain behaviors during these events include facial grimacing, tightening of extremities, appearing restless, increased movement, tachycardia, and difficult to soothe. Other associated problems include the long-standing history of severely disrupted sleep. It is unclear if symptoms worsened following any specific surgery. Assessment with the N-PRAT identified a total score of 8. Gabapentin was initiated and titrated to a dose of 40 mg/kg/day. There has been a significant sustained benefit 7 months later, including almost no episodes of emesis, further improvement in sleep, and described as much more comfortable and interactive during the day, “like a new kid”. This improvement included a 24% increase in weight 5 months after starting gabapentin.

Figure 3. Case N-PRAT Score

Neuro-Pain Risk Assessment Tool (N-PRAT)	Score:
Episodes with pain behaviors from 2 or more categories, recurring for more than 3 months without a consistent source; episodes are cyclical, occurring for 2 to 4 days every 2 to 4 weeks	2 points (features from 6 categories: moaning, frowning, restless, movement, tachycardia, difficult to soothe)
GMFCS level 5 and severe to profound intellectual disability	2
Some episodes occur rapidly and out of the blue	1
Intermittent increase in muscle tone, movement and posture	1
Autonomic dysfunction and storms	0
GI symptoms	1
Chronic poor sleep	1
Post-surgical	0 (unclear given surgeries in infancy)
Intractable seizures	0
Planned surgery	0
Total score (highest score = 12)	**8**

CHRONIC PAIN DUE TO THE ALTERED NERVOUS SYSTEM

Chronic pain categories identified by the International Association for the Study of Pain (IASP) include musculoskeletal, neuropathic, visceral, and post-surgical pain, categories that are relevant to children with SNI.[9] Other sources in children with SNI include autonomic dysfunction, spasticity, and dystonia as both sources of intermittent pain and with features that are triggered by the other causes of chronic pain.[1]

This article uses the term neuro-pain to indicate chronic pain sources due to the altered nervous system yet without diagnostic tests to identify or to distinguish one source from another. Children with SNI

are at risk for more than 1 of the causes noted in Table 2. The term neuro-pain is recommended over neuro-irritability when episodes are recurrent and include pain behaviors. With recurrent episodes, word choice can impact how the problem is approached. A child might be described as "this is what he does" when neuro-irritability is used versus a problem that may benefit from further assessment and interventions when neuro-pain is used.[12]

Table 3 provides language strategies that anticipate parental worry when discussing neuro-pain. Parents experience many worries throughout this process. Parents can benefit from time to reflect on this complex information, as well as a process that supports shared decision making.

Table 3. Language Strategies

	Language suggestions: balance with pauses for questions and worries
Introducing the framework of chronic neuro-pain	The brain receives sensory signals from the body. These signals alert us when there is a cause of pain due to injury or inflammation of tissue in the body. Examples include a bladder infection or bone fracture. Another type of pain occurs when the area of the brain that receives these signals or the nerves that send the signals are altered, called neuropathic pain. There is no test to confirm chronic neuro-pain. Instead, we review information that indicates if a child is at risk for this type of pain. Your son has features that indicate he likely has this type of pain causing some of his recurrent symptoms.
Use of a scheduled medication	There are medications to dampen pain signals from neuro-pain, yet no treatment to fix this cause of pain. These medications can lessen this type of pain in children like your son. Medications for neuro-pain will not stop the generation of pain signals from a new cause of tissue injury pain. We will know if there is a new cause of pain. We will know the drug is working if the frequency and severity of neuro-pain episodes decrease. Some children have enough benefit from the first medication we try. Others have greater benefit from 2 medications over either one given alone. We will discuss next options if we don't see the amount of benefit we hope for after 3 to 4 weeks.
Sleeping and sedation	Increased sleeping in the first 1 to 2 weeks means the drug is working, given that chronic pain is exhausting and lessens restful sleep. We will give you an information sheet that reviews this and other worries, and how you can contact us each day to discuss any worry. We will not continue a medication dose that is causing too much sleep. Your son is on other medications that may make better sense to decrease first, given that sedation from these other drugs can increase when pain is decreased by a drug for neuro-pain.
General worries: "Are we doing the right thing?"	Thank you for sharing this important worry. I wish there was an easy answer to thi complex problem. Though I can't know with certainty that this drug will help until we try it, I know your son deserves us trying to improve his comfort. I also don't want you to feel rushed as we decide together what makes the best sense for your son. It will take time to know if this medication will help your son. Our team will check in to see how you are doing and you can call as needed as we monitor to see what is possible. You are a great parent to be asking these hard questions.
When symptoms persist after the 2nd or 3rd medication	As we start this 3rd drug we will continue to aim for both improved comfort and to not be sleepy. Sometimes it is not possible to meet both goals. This can mean that the problem is greater than the best treatments available. It might make sense to focus on making him comfortable first and allow him to be sleepier for the next 2 weeks, then adjust the plan after we see what is possible. I am glad he remains comfortable. We will continue to work on improving his wakefulness. Given what you have shared as important to you, if we do not see him more wakeful during the day with the next medication adjustment, I will suggest that we not support his breathing if a ventilator is needed. There is no need to make a decision today; I want you to have time to reflect on this. My worry is we can support his breathing but not improve other problems to a level you would want for your son.

PRESENTING FEATURES OF NEURO-PAIN

Identifying neuro-pain requires knowledge of pain behaviors, which are the observable features expressed by a nonverbal child with SNI when in pain, with examples noted in the N-PRAT.[1] Behavioral pain assessment tools for such children are reviewed in the AAP clinical report.[1] The revised Face, Legs, Activity, Cry, Consolability scale and the Individualized Numeric Rating Scale can be individualized with a child's specific behaviors, useful for new providers unfamiliar with the child.[13,14] These tools were validated in the acute care and post-surgical settings. The pain behaviors noted in these and other tools can assist parents and providers in identifying an individual child's specific features.

Pain assessment tools can assist with rating the worst and typical pain episodes. Chronic pain requires broader considerations beyond rating, including the frequency and duration of episodes along with the impact on sleep and engagement in activities. This holistic approach aids in determining benefit when a scheduled medication is initiated. Some children will have cyclical episodes, such as daily episodes for 3 to 7 days every

2 to 4 weeks, as noted in this case example and in other case reports.[15]

Children with SNI and chronic neuro-pain can present with the other features noted in Table 2. These include GI symptoms (i.e. pain localized to the GI tract, emesis, and feeding intolerance), recurrent muscle spasms, tensing and movement, intermittent autonomic storms, and pain that persists following surgery.[1,16] Such children can have irritability and pain that recurs without a clear source, or keeps returning following interventions for gastroesophageal reflux disease (GERD), constipation, spasticity, dystonia, and autonomic dysfunction. Figure 1 incorporates this information into the proposed screening process to identify children with SNI in need of further assessment. The case had many of the features noted in “Does your child have any of the following?” from Figure 1, with a subsequent score of 8 with the N-PRAT, following recurrent assessment and a variety of interventions for constipation, GERD, cyclic vomiting, and sleep.

THE IMPACT OF COGNITIVE BIAS

Cognitive bias results in ways of thinking that influence decision making and judgment.17 Anchoring bias, a tendency to rely heavily on one piece of information, and availability heuristic, the tendency to overestimate the likelihood of explanations that are more readily available in one's memory, are examples that can interfere with the consideration of neuro-pain in children with SNI. A focus on spasticity as the primary reason for recurrent muscle spasms is one example; cognitive bias awareness can then increase consideration of chronic neuro-pain sources as another reason for recurrent spasms. Other examples include remaining focused on GERD, cyclic vomiting, and constipation as the reasons for recurrent GI symptoms, and dystonia with intermittent dystonic movement as the cause of associated pain during these episodes.

Attributing an etiology of neuro-pain behaviors to a positive bacterial culture that may be due to colonization is a form of cognitive bias. Examples include a positive tracheal culture, a positive urine culture in someone with clean intermittent catheterization for neurogenic bladder with less than 10 white blood cells per high-power field in the urinalysis, and a positive clostridium difficile test that does not distinguish carrier from infection.18-20 A decision to treat a positive test is a result of the patient being symptomatic, with the understandable anchoring bias that the recurrent symptoms are due to the positive

test. Yet symptoms may be due to underlying neuro-pain, a category of problems without diagnostic tests. Other examples of positive tests in children with SNI that in retrospect were incidental include persistent symptoms following cholecystectomy and following anti-inflammatory treatment for nonspecific colitis identified by colonoscopy.1,21 In these cases, symptoms improved after medication use for neuro-pain.

Awareness of cognitive bias is not about being right or wrong; instead, awareness of the impact of cognitive bias can loop us back to other considerations, given the many inherent challenges in children with SNI and risk for multiple comorbid problems. These examples highlight the benefit of considering neuro-pain sources when symptoms continue to recur after treatment for infectious sources that might represent colonization, and considering a medication trial prior to an invasive diagnostic test or surgery. Treatment can then determine how much neuro-pain is contributing to recurrent symptoms that may be attributed to these other problems. Transparent discussions and support will help parents throughout this complex process.

TREATMENT WHEN SYMPTOMS ARE RECURRENT

Figure 1 outlines a proposed process for children with SNI and recurrent symptoms. The N-PRAT screens for risk of neuro-pain and therefore guides a decision to start an empirical medication trial. The GMFCS is used with the N-PRAT to identify those who have the greatest impairment in motor function. Identifying children with SNI who are GMFCS level 4 or 5, along with severe to profound intellectual disability, assists with identifying individuals who have the highest risk for chronic pain. Some children will not meet the criteria for CP due to having a neurodegenerative disease or injury of the CNS beyond the age cut-off used for CP.

The N-PRAT was applied retrospectively to the last 22 children with SNI and recurrent symptoms assessed by this author and viewed as benefitting from gabapentin, some with greater benefit following a second medication. All were on treatment for other problems, including GERD, spasticity, and seizures. The total score with the N-PRAT was 5 or greater in each child, greater than 6 in most. This tool addresses the lack of diagnostic tests or criteria for neuro-pain sources in children with SNI, which contribute to treatment delay. The

criteria used to diagnose central neuropathic pain in adults is not valid for children with SNI given a need for input from the patient.[22] The N-PRAT is intended as a screening tool to prompt the steps outlined in Figure 1. A score of 5 or greater identifies those who have a greater potential for benefit than risk with a medication trial for neuro-pain. This tool is needed and promising, but is also in need of prospective study to determine its usefulness, including its validity, interrater reliability, and the sensitivity of the identified cutoff score of 5.

A gabapentinoid is recommended as a first line medication trial, based on evidence and safety.[1] The goal of a scheduled medication is to decrease the frequency, severity, and duration of episodes, along with improvement in other associated problems, such as sleep. Parents can be asked if it is more important to avoid sedation by using a slower titration in the medication dose or to improve comfort with a faster titration even if it means some initial sedation. The AAP clinical report provides dosing guidelines to ensure an adequate trial.[1] Other considerations in chronic neuro-pain management include:

- Developing breakthrough care plans
- Minimizing GI tract distention as a trigger for symptoms
- Managing other comorbid problems, such as spasticity

Distention of the GI tract can trigger symptoms given that causes of chronic neuro-pain can decrease the amount of distention needed to trigger pain signals.[23,24] Parents can be instructed to use a suppository or enema during a persistent pain episode to determine if distention of the colon prior to a bowel movement is contributing to symptom generation. This can be part of the breakthrough care plan if the intervention results in a bowel movement followed by a significant decrease in the acute symptoms. Overestimation of calories can also contribute to symptoms. Children with SNI at high risk for calorie overestimation include those with limited to no movement of extremities, with intermittent hypothermia, or with declining health resulting in less activity. These circumstances can decrease estimated metabolic expenditure by 30-50% for non-ambulatory children with cerebral palsy.[23]

BREAKTHROUGH SYMPTOMS AND CARE PLANS

Following a medication trial for neuro-pain, intermittent symptoms may decrease in frequency and intensity yet still occur, given that symptoms generated by these sources can be modified but not eliminated. At other times, persistent breakthrough symptoms

can be from a new nociceptive pain source. Medications for neuro-pain will not eliminate the generation of pain signals from a new cause of nociceptive pain.

Breakthrough care plans can be developed to manage breakthrough symptoms due to chronic neuro-pain sources. The AAP clinical report provides details about developing a breakthrough care plan, including examples.[1] Care plans can be updated as experience determines which interventions are useful for each child. Interventions to consider include non-pharmacologic (repositioning, swaddling, vibration, rocking) and pharmacologic (ibuprofen, acetaminophen, clonidine, opioid, and benzodiazepine).[1]

Experience will also guide when to evaluate for a new nociceptive source. This might include a time when symptoms persist following breakthrough interventions that typically help, when new features are observed, or when something seems worrisome to the parent. Likewise, as tests are repeated and are normal, parents and clinicians might feel more comfortable not repeating tests. The breakthrough care plan can also be adjusted and a new medication trial considered. This process can be distressing, given the worry about a new pain source and the risk that symptoms due to neuro-pain can persist following the first medication trial.

SEDATION THAT PERSISTS FOLLOWING A MEDICATION TRIAL

Increased sleeping can initially mean the drug is working if a medication for neuro-pain results in improved comfort (Table 3). Sedation in the first 1-2 weeks may be a marker of pain control given that chronic pain is exhausting and alters sleep.

The sedating effects of other medications can increase when pain control is achieved. Medications for spasticity or dystonia are important examples when 2 or more drugs are being used for ongoing muscle spasms or dystonic movement that might also be triggered by chronic neuro-pain. The sedating effect from medications such as benzodiazepines, baclofen, and trihexiphenidyl can increase, if a medication for neuro-pain manages a primary trigger of these features. It may be of greater benefit to wean the dose of such medications, rather than decrease the dose of the medication for neuro-pain if pain control is achieved.

Parents benefit from frequent support throughout this process, as they worry about the balance between comfort and sedation. It can be helpful to identify, validate, and

spend time supporting these worries, while offering options to how the problem might be best managed. This process can take several months in a child with improved comfort and persistent sedation who is on multiple medications that can contribute to sedation. A slow and methodical process can minimize a beneficial neuro-pain medication being decreased or discontinued too soon, with frequent check-ins for parental support. This can take 2-3 months when medications such as benzodiazepines need to be weaned slowly so as to avoid withdrawal symptoms, which can involve decreasing by 10% of the original dose every 7 days when a benzodiazepine has been used for an extended time.

BEFORE ADDING A SECOND OR THIRD MEDICATION

When symptoms persist, 2 medications for neuropathic pain with different mechanisms of action can provide greater benefit compared to either one used solely.[1] To lessen polypharmacy, the following should be considered:

- Maximize dose of medication being used for neuro-pain
- Review and manage GI tract distention triggers
- Review event frequency and effectiveness of breakthrough care plan
- Review management of other comorbid problems (e.g. spasticity, dystonia, sleep)

A decision to add a 2nd medication can make sense in a child with 3 or more prolonged pain episodes occurring on average each week and when there is inconsistent benefit from the breakthrough care plan. The first medication should be continued when adding another.[1] In contrast, it can make sense not to add a 3rd medication when episodes are less frequent and routinely improve within 1 to 2 hours after initiating the breakthrough care plan, the length of time for the onset of action of as needed medications and for the nervous system to “quiet” down.

The goal is symptom free, yet this goal is not possible for some if not many children with SNI. We can strive to maximize symptom control with a balance to minimize side effect risk from multiple medications. This process requires a team with expertise and availability given the complex decision-making and inherent worries, as well as expertise in the use of 2nd and 3rd line medications.[1]

COMMUNICATION WITH FAMILIES

Parents face many worries throughout this process. Table 3 covers some of these

worries, with language suggestions provided. There is further information covered in an information sheet for parents at the Courageous Parents Network.[25] General worries that do not have a definitive answer still benefit from validation, by providing recognition of the importance of the worry, as noted in Table 3.

CONCLUSIONS

Chronic pain in children with SNI is a significant and challenging problem. There is a need for better screening and defined criteria to guide initiation of an empirical medication trial for neuro-pain. The proposed screening process and N-PRAT provide guidance given the lack of diagnostic tests to confirm neuro-pain as a source. The strength of this tool is its ease of use that allows application at point of care. Limitations include the need to validate the usefulness of this tool and the sensitivity of the identified cutoff score of 5 or greater. This case also highlights the impact of cognitive bias when the focus remains on commonly recognized problems, such as spasticity and GERD. Criteria for the identification and management of chronic neuro-pain can improve comfort in this vulnerable group of children.

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Tables & Figures

Table 1. Acute versus Chronic Pain

	Acute	Chronic
Cause	Expected with surgery or due to causes of tissue inflammation and injury (i.e. nociceptive pain)	Pain that recurs for more than 3 months; categories include musculoskeletal, visceral, post-surgical, and neuropathic
Duration	Hours to days	> 3 months, persists
Identification	Sources typically identified by diagnostic tests	No routine diagnostic tests or criteria for sources due to the impaired nervous system
Goals	Resolution after treatment of cause and healing of tissue injury	Pain control, not cure

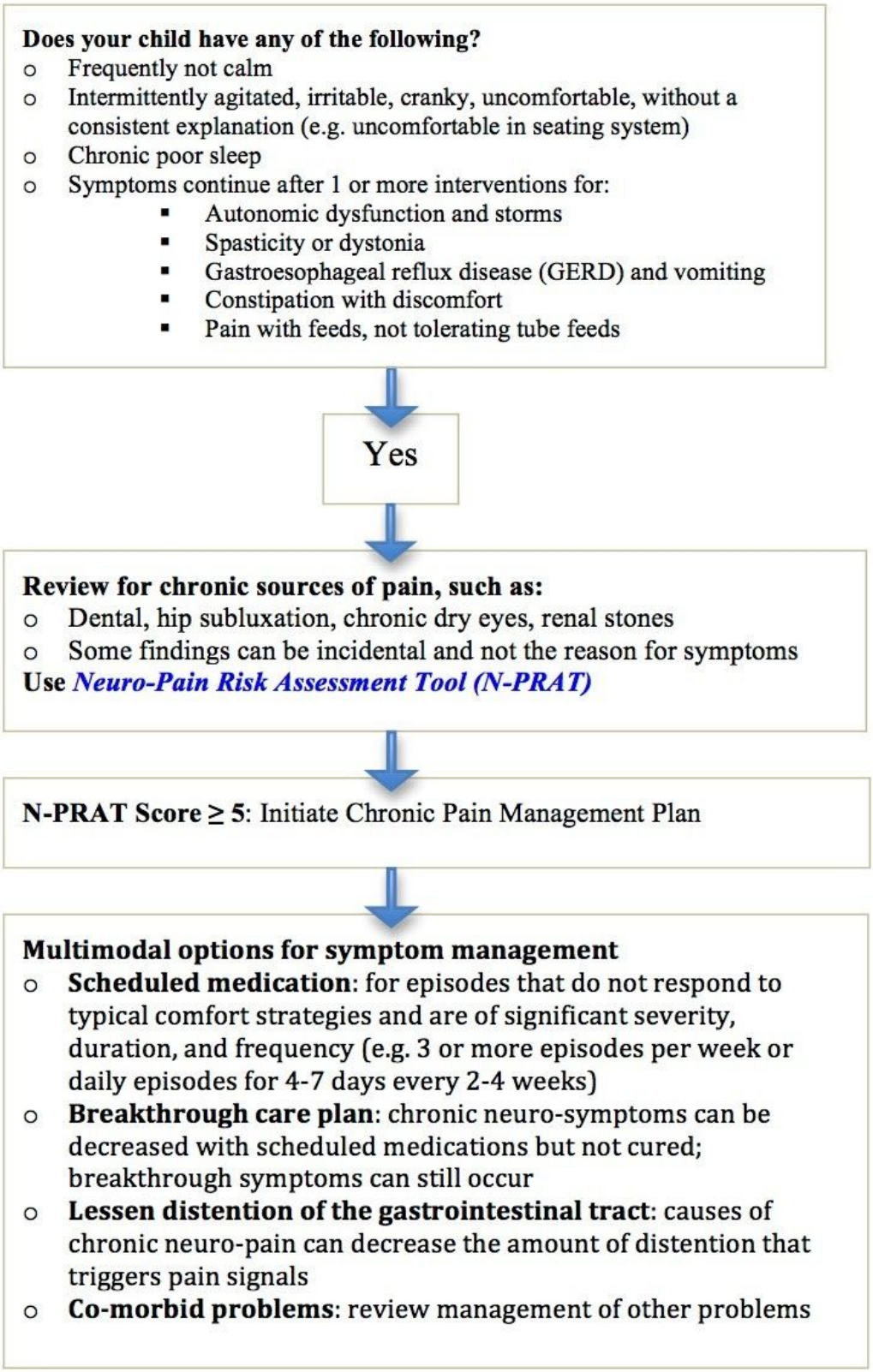
Table 2. Chronic neuro-pain sources

Problem	Features, Comments, and Treatment Options
Central neuropathic pain	Symptoms include pain localized to the GI tract, such as pain triggered by normal distention of the GI tract; this can be suggested by pain associated with tube feedings or intestinal gas, with relief following a bowel movement or flatus Pain features can occur spontaneously and with no trigger, described by adults as "shock-like" and "out of the blue" Due to impairment of the spinothalamic tract and thalamus Treatment: gabapentinoids, tricyclic antidepressants, SNRIs, methadone
Visceral hyperalgesia	Decreased threshold to pain generation in response to a stimulus in the GI tract, including a decrease in the amount of distention that triggers a pain signal Attributable to sensitization of visceral afferents and central sensitization in the CNS Treatment: gabapentinoids, tricyclic antidepressants, clonidine
Chronic post-surgical pain (CPSP)	Defined as pain that lasts more than 2 months post-surgery without other causes of pain such as chronic infection or pain from a chronic condition preceding surgery The mechanisms leading to chronic CPSP can include inflammation, tissue and nerve damage, and alterations in central pain processing Treatment: gabapentinoids, tricyclic antidepressants
Autonomic dysfunction (dysautonomia)	Features include skin flushing, hyperthermia, pain localized to the GI tract, retching, bowel dysmotility, discomfort, agitation, tachycardia, sweating, arching, stiffening Dysautonomia can be a source of discomfort, and pain can trigger the features that occur with dysautonomia Treatment: gabapentinoids, clonidine
Dystonia	Involuntary sustained or intermittent muscle contractions cause twisting and repetitive movements, abnormal postures, or both Pain from other sources can trigger and worsen dystonic movement Treatment: baclofen, trihexyphenidyl, gabapentinoids, clonidine
Paroxysmal autonomic instability with dystonia (PAID)	Involves features of both autonomic dysfunction and dystonia Indicates altered function of the CNS areas that regulate autonomic function and movement; such children are also at risk for co-morbid central neuropathic pain Pain from other sources can trigger and worsen the observed features Treatment: see dysautonomia and dystonia
Spasticity	Velocity-dependent increase in muscle tone that results in muscles that are resistant to movement Spasticity is often not painful but can result in musculoskeletal pain over time Treatment: baclofen, alpha2-agonists (clonidine or tizanidine)
Muscle spasms	Sudden involuntary contraction of a muscle or group of muscles; associated features can include arching, stiffening, tremors, and clonus Pain behaviors can indicate pain from muscle spasms and indicate pain from another source as the trigger for muscle spasms Treatment: interventions for spasticity, chronic neuro-pain, and other triggers

GI: gastrointestinal; SNRIs: serotonin norepinephrine reuptake inhibitors

Figure 1

Screening children with SNI for risk of chronic neuro-pain



N-PRAT

Figure 2. Neuro-Pain Risk Assessment Tool (N-PRAT)

Neuro-Pain Risk Assessment Tool (N-PRAT)	Score: Circle if present
Episodes with pain behaviors from 2 or more of the following categories, recurring for more than 3 months without a consistent source*; episodes may be weekly or cyclical (e.g. daily for 3 to 5 days every 2 to 4 weeks) • *Vocalizations*: crying, moaning • *Facial expression*: grimacing, frowning, eyes wide open • *Unable to console*: difficult to calm, not soothed by parent comfort actions • *Interaction*: withdrawn, seeking comfort • *Physiological*: tachycardia, sweating, pale or flushed skin, tears • *Muscle tone*: intermittent stiffening of extremities, clenching of fists, muscle tensing, tremors, back arching • *Movement*: increased movement, restless, startles easily, pulls away when touched, twisting	1 point for 2 or 3 categories 2 points for 4 or more categories
GMFCS* level 4 and moderate to severe intellectual disability OR	1
GMFCS* level 5 and severe to profound intellectual disability	2
Some episodes occur rapidly and out of the blue with no known trigger, quickly changing from calm to agitated / irritable / in pain	1
Intermittent increase in muscle tone, movement and posture: features continue following 1 or more drugs for spasticity or dystonia	1
Autonomic dysfunction and storms: features remain significant following 1 or more drugs for autonomic dysfunction	1
GI symptoms: Pain behavior episodes noted with tube feeds, intestinal gas, and constipation, with improvement when feeds are held and following a bowel movement; symptoms continue following 1 or more drugs for GERD	1
Chronic poor sleep with symptoms of agitation / discomfort	1
Post-surgical: new or worsening pain behavior episodes for > 2 months following surgery without a clear cause	1
Intractable seizures following 3 or more anti-seizure drugs	1
Planned surgery: prior to surgical interventions for GERD, spasticity, or dystonia to determine if chronic neuro-pain is a trigger; gabapentinoids may decrease need for post-surgical opioids and development of postsurgical pain[26]	1
Total score (highest score = 12)	

Total score ≥ 5: initiate multimodal approach to symptom management (Figure 1)

***Nociceptive assessment noted in Figure 1 of AAP clinical report**.[1] Consider cognitive bias towards positive tests that may result in recurrent treatment in a symptomatic child with SNI, yet the positive test may represent colonization or an incidental finding and not be the source of symptoms (e.g. positive urine culture with less than 10 white blood cells in urinalysis, positive clostridium difficile with test that does not distinguish carrier from infection, gallstones with no other abnormal findings on labs or ultrasound)

***GMFCS:** used here as an indicator of motor function level in children with severe impairment of CNS

Figure 3. Case N-PRAT Score

Neuro-Pain Risk Assessment Tool (N-PRAT)	Score:
Episodes with pain behaviors from 2 or more categories, recurring for more than 3 months without a consistent source; episodes are cyclical, occurring for 2 to 4 days every 2 to 4 weeks	2 points (features from 6 categories: moaning, frowning, restless, movement, tachycardia, difficult to soothe)
GMFCS level 5 and severe to profound intellectual disability	2
Some episodes occur rapidly and out of the blue	1
Intermittent increase in muscle tone, movement and posture	1
Autonomic dysfunction and storms	0
GI symptoms	1
Chronic poor sleep	1
Post-surgical	0 (unclear given surgeries in infancy)
Intractable seizures	0
Planned surgery	0
Total score (highest score = 12)	**8**

Table 3. Language Strategies

	Language suggestions: balance with pauses for questions and worries
Introducing the framework of chronic neuro-pain	The brain receives sensory signals from the body. These signals alert us when there is a cause of pain due to injury or inflammation of tissue in the body. Examples include a bladder infection or bone fracture. Another type of pain occurs when the area of the brain that receives these signals or the nerves that send the signals are altered, called neuropathic pain. There is no test to confirm chronic neuro-pain. Instead, we review information that indicates if a child is at risk for this type of pain. Your son has features that indicate he likely has this type of pain causing some of his recurrent symptoms.
Use of a scheduled medication	There are medications to dampen pain signals from neuro-pain, yet no treatment to fix this cause of pain. These medications can lessen this type of pain in children like your son. Medications for neuro-pain will not stop the generation of pain signals from a new cause of tissue injury pain. We will know if there is a new cause of pain. We will know the drug is working if the frequency and severity of neuro-pain episodes decrease. Some children have enough benefit from the first medication we try. Others have greater benefit from 2 medications over either one given alone. We will discuss next options if we don't see the amount of benefit we hope for after 3 to 4 weeks.
Sleeping and sedation	Increased sleeping in the first 1 to 2 weeks means the drug is working, given that chronic pain is exhausting and lessens restful sleep. We will give you an information sheet that reviews this and other worries, and how you can contact us each day to discuss any worry. We will not continue a medication dose that is causing too much sleep. Your son is on other medications that may make better sense to decrease first, given that sedation from these other drugs can increase when pain is decreased by a drug for neuro-pain.
General worries: "Are we doing the right thing?"	Thank you for sharing this important worry. I wish there was an easy answer to thi complex problem. Though I can't know with certainty that this drug will help until we try it, I know your son deserves us trying to improve his comfort. I also don't want you to feel rushed as we decide together what makes the best sense for your son. It will take time to know if this medication will help your son. Our team will check in to see how you are doing and you can call as needed as we monitor to see what is possible. You are a great parent to be asking these hard questions.
When symptoms persist after the 2nd or 3rd medication	As we start this 3rd drug we will continue to aim for both improved comfort and to not be sleepy. Sometimes it is not possible to meet both goals. This can mean that the problem is greater than the best treatments available. It might make sense to focus on making him comfortable first and allow him to be sleepier for the next 2 weeks, then adjust the plan after we see what is possible. I am glad he remains comfortable. We will continue to work on improving his wakefulness. Given what you have shared as important to you, if we do not see him more wakeful during the day with the next medication adjustment, I will suggest that we not support his breathing if a ventilator is needed. There is no need to make a decision today; I want you to have time to reflect on this. My worry is we can support his breathing but not improve other problems to a level you would want for your son.

EDUCATIONAL PROGRAM REPORT

COMPLEX CARE ELECTIVE:

An Outpatient Learner-Directed Complex Care Elective for Pediatric Residents

Breann Butts[a], MD, Rebecca Steuart[a], MD, Jennifer Lail[b], MD

ABSTRACT

As the population of children with medical complexity (CMC) increases, the physician workforce needed to provide outpatient medical care for these children is also increasing. Currently, few published formal training opportunities exist to support pediatric residents with particular interest in pursuing careers caring for CMC. Here we report our experience creating and implementing a resident-designed, resident-directed elective in the emerging field of outpatient complex care pediatrics at our institution. With the assistance of an expert faculty advisor, we designed and completed a two-week outpatient complex care pediatrics elective as part of our pediatric residency training. The elective included supervised clinical experiences in our institution's Complex Care Center and subspecialty clinics, observation of specialized therapy visits, interactive lectures on funding mechanisms by financial advocates, and opportunities to learn from families of CMC during informal interviews. Two residents have completed the elective to date; during unstructured curricular assessments, residents reported the elective increased knowledge, skills, and comfort in caring for CMC, as well as offered networking opportunities and insight into career pathways within complex care pediatrics. Further development of formalized training opportunities in the emerging field of outpatient complex care pediatrics is crucial to the growth of a physician workforce passionate about and prepared to provide experienced, expert care for CMC.

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INTRODUCTION: Children with Medical Complexity and Resident Education

The field of complex care pediatrics has rapidly emerged as the framework for medical providers who care for children with medical complexity (CMC). CMC are a subset of children with special health care needs who have one or more serious chronic conditions, functional limitations frequently requiring medical technology, considerable family-identified health and other service needs, and high health care utilization.[1] The CMC population is growing substantially in number, in large part due to the advances in pediatric medicine that allow these children to survive much longer than in the past.[1] The proportion of children with a chronic condition that interferes with daily activities has increased >400% since the 1960s.[2] Although CMC comprise less than 1% of children, they consume up to one-third (> $100 billion annually) of all child health expenditures.[3] Furthermore, CMC have "high risk of hospital readmissions, total and preventable adverse events, and unnecessary variation in hospital care".[4] To address the ongoing needs of this diverse patient population and to potentially limit excessive medical costs associated with fractured and varied care, several outpatient care delivery models have been conceptualized and implemented, including primary care-centered models, consultative or co-management models, and acute episode-based models.[5]

Pediatricians in many primary care settings have expressed concerns about their capacity to serve as a medical home for CMC due to time and cost restraints, among other challenges.[6] Thus, at many large pediatric centers including our institution, complex care centers (CCC) based on the primary care-centered model are being established to address the preventive, acute, and chronic care needs of CMC specifically in the outpatient setting. Our institution's CCC serves a patient-centered care medical home for CMC by providing team-based care and care coordination in partnership with families, subspecialists, and the child's community.

Despite the growing need to provide outpatient primary care to the growing population of CMC, at the current time, there is not a well-defined career track for trainees to gain skills in this area of pediatrics. Although efforts addressing curricular priorities of resident education in caring for CMC are in process,[7] there are currently no Accreditation Council for Graduate Medical Education (ACGME) clinical competencies that guide residents'

instruction in caring for this population. Thus, residency programs may have variability in learning opportunities (e.g. rotations, electives, or formal curricula) designed for interested residents; resident experiences that do exist are not often publicly shared or published. At our institution, residents who are interested in incorporating care of CMC into their future careers previously relied on their experiences caring for a variable number of CMC seen in general pediatrics clinics (e.g. continuity clinic), the inpatient setting (e.g. hospital medicine, intensive care units), or other closely related outpatient sub-specialties (e.g. physical medicine and rehabilitation, developmental behavioral pediatrics, palliative care) to guide their acquisition of skills. Here we report our experience creating and implementing a resident-designed and resident-directed elective in outpatient complex care pediatrics. Our goal was to gain critical, timely, and career-specific experience in caring for CMC in the outpatient setting.

PROGRAM DESCRIPTION: An Outpatient Complex Care Elective

Under the guidance of a CCC faculty advisor (J.L.), interested senior pediatric residents (B.B. & R.S.) created a two-week, multidisciplinary elective at our free-standing, academic pediatric medical center (Table 1). Elective goals and objectives are outlined in Supplement 1. The elective included experiential learning in the hospital-associated multidisciplinary CCC, which operates as a primary care medical home for approximately 500 local CMC. While in the CCC, residents participated in pre-visit planning, observed clinic encounters, and provided supervised care to CMC during health maintenance and acute care visits.

Experience		Goals & Objectives
Day 1	Meet with financial advocates	• Medical funding mechanisms (e.g. waivers, Medicaid, other insurance)
	Review articles and webinars	• Chronic Care Model • Family-centered and team-based models of care • Ethical considerations • Effective communication with patients with cognitive impairment
Day 2	Pulmonary Clinic	• Medical technology: tracheostomies, ventilators, airway clearance
	Physical Medicine & Rehabilitation Clinic	• Medical technology: Baclofen pumps
Day 3	Complex Care Center	• Learn and perform basics of well care and ill care of children with medical complexity • Work with multidisciplinary team • Participate in provider-family shared decision making
Day 4	Shadow Respiratory Therapist	• Medical technology: tracheostomies, ventilators, airway clearance
	Review articles and webinars	
Day 5	Complex Care Center	
	Resident Continuity Clinic	
Day 6	Physical Medicine & Rehabilitation Clinic	
	Complex Care Center	
Day 7	Gastroenterology Clinic	• Medical technology: feeding tubes and nutrition
	Pulmonary Clinic	
Day 8	Complex Care Center	
Day 9	Home Care Visits	• Experience alternate care setting
	Therapy Center	• Medical technology: wheelchairs and other assistive technology
Day 10	Resident Continuity Clinic	
	Complex Care Center	
Day 11	Therapy Center	• Observe Early Intervention and Early Childhood programming
	Complex Care Center	
	Elective Debriefing	• Meet with faculty advisor to reflect on elective experience and advocacy opportunities

Table 1. Outpatient Complex Care Elective sample schedule of experiences with associated goals/objectives.

Given the pace and structure of our clinical setting, residents primarily provided care with faculty present in the exam room, then completed notes independently following the clinical encounter. Residents also observed clinical providers completing electronic and telephone communications such as phone triage, home nursing orders, and medical equipment orders. Residents were able to interact with and learn about the roles of the clinical nurse, nurse care manager, medical assistant, social worker, and registered dietician during clinic visits and through informal discussions between clinical responsibilities.

Given the subspecialty nature of caring for CMC, residents also spent time in various other relevant clinics, such as those for children with cerebral palsy in Physical Medicine and Rehabilitation, with ventilator-dependence in Pulmonology, and with feeding issues in Gastroenterology. Residents were able to observe speech, physical, and occupational therapy sessions during Early Intervention and Early Childhood programming at our on-campus multidisciplinary therapy and support center. One resident (R.S.) had the opportunity to attend scheduled home visits with a palliative care program home care nurse. To better understand the local, state, and national financial resources available to families of CMC, especially in light of the large proportion of health care costs experienced by these families, residents met with financial advocates at our institution. In order to introduce residents to concepts within the evolving national field of complex care pediatrics, residents were directed to read foundational publications by CMC experts (Supplement 2). Core reading topics included defining CMC and other related populations, care model

Complex Care

Clinic	Notes
Complex Care Clinic	In addition to seeing complex care patients, you will spend time with RN, RN Care Manager, SW, and RD.

Subspecialties

Specialty	Clinic/Provider
Pulmonary	Ventilator clinic
	Neuromuscular Clinic
	Aerodigestive Clinic
	Transitional Care Center (ventilator-dependent unit), rounding and/or spending time with RT
Rehab	Cerebral Palsy and Spasticity Clinic
	Cerebral Palsy Clinic
Perlman Center	Early Intervention (EI) and Early Childhood (EC) Programs
	Equipment Evaluations & Speech Language Evaluation
GI	Feeding Team
Palliative Care & Hospice	StarShine Home Visits
Neurology	Various clinics may be applicable

Other Experiences

Group
Financial Advocates
Meeting with Complex Care Families
Complex Care Lectures
Ethics
Self-directed learning (see reference list)

Table 2. Potential Complex Care Outpatient Elective opportunities including subspecialties and other groups.

development, health systems of care, common symptom management, and healthcare spending. Residents met with the faculty advisor once during their elective to discuss one or more resident-selected article(s). A list of additional specialized topic readings were provided by the faculty advisor for resident self-directed learning during the elective time. Finally, residents had the opportunity to meet with families of CMC to discuss the joys and challenges of their journeys; these meetings were informal and held in a public hospital location such as the cafeteria. All experiences outside of time spent in the CCC were scheduled by each resident prior to the start of the elective time. Experiences of value were defined with the support of the CCC faculty advisor, who provided key contact information for scheduling. Table 2 includes a comprehensive list of opportunities available during this elective.

REFLECTIONS & DISCUSSION

This complex care elective is resident-coordinated, resident-implemented, and intentionally tailored to individual resident interests. Two senior residents (B.B. & R.S.) have completed this elective to date. While there was no formal learning assessment at the conclusion of the elective, both residents were able to informally discuss their reflections surrounding the elective with the faculty advisor (J.L.) and felt this elective increased knowledge, skills, and comfort in caring for CMC in their current roles (B.B. is currently a 3rd year resident who will join the CCC after completing residency; R.S. is currently a 2nd year hospital medicine fellow with specific interest in clinical care and research surrounding CMC). Both residents also expressed that meeting with families of CMC was one of the most illuminating and meaningful aspects of the elective, as it provided direct insight into the day-to-day life and the incredible resiliency of these families. Importantly, the elective introduced various models of care and underscored the importance of a patient centered medical home for CMC. The elective allowed for residents to meet and network with a variety of colleagues within our institution who contribute to the care of CMC, including not only physicians, but also subject matter experts such as therapists, dieticians, nursing staff, financial experts, and families. Finally, residents were able to consider various career trajectories related to caring for this population.

Since training opportunities and models of care are evolving, we have created a guide to share with other residents interested in completing a pediatric complex care

elective and who seek learning opportunities around the care of CMC. Our elective was optimized by having a faculty champion in the setting of an established CCC, but could be adapted and replicated in other training settings and models of care (e.g. a community pediatrician who co-manages a CMC's medical issues with multiple sub-specialists in a medical center). In the future, it may be helpful to formalize an elective assessment process in order to continue developing and improving the experience for subsequent participating residents. Opportunities for expansion include integrating aspects of the elective into a residency-wide longitudinal curriculum on caring for CMC, as proposed by Homer, et al.[8] We hope to further develop opportunities for mentorship between residents and CCC providers, as well as longitudinal clinical experiences (e.g. continuity clinic) in the CCC. Finally, we will continue promoting this elective to each class of residents and could consider monitoring the impact of the elective on their future career choices.

CALL TO ACTION

Various models of caring for CMC have been proposed,[5] yet there is not a clear consensus on the best locus of care for these patients. Furthermore, the population of CMC continues to grow, requiring prompt attention to the development of the provider workforce and examination of funding sources. Despite a need to develop a new generation of pediatricians prepared to care for CMC, clear training pathways do not currently exist. Here we have shared one educational model that may serve as an initial step for residents who are interested in caring for CMC, but have little exposure to these patients in outpatient settings. This elective represents one opportunity to increase provider exposure to CMC while in training. The ultimate goal would ideally be that this increased exposure increases the provider work force and access to care for CMC, whether in a dedicated Complex Care Clinic or translated to clinics more remotely located from an academic medical center. Interested pediatric residents must have formalized opportunities to explore and build skill sets in the ever-growing field of complex care pediatrics. Perhaps most importantly though, CMC and their families deserve providers who are well-trained, have a passion for caring for CMC, and are enthusiastic about future expansion of this field.

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Supplement 1. Goals and Objectives

Complex Care Outpatient Elective

Goals & Objectives

Summary

This make-your-own elective is designed for residents interested in caring for children with medical complexity and with career interests in outpatient complex care, primary care, or hospital medicine. While the elective is centered around time in the Complex Care Center (CCC), there are not enough clinic days or staffing availability to make up a full elective. Therefore, you must add in additional experiences; a list of suggested experiences is below.

Goals and Objectives

Knowledge

- Identify the basics of well care for children of medical complexity
- Identify the basics of ill care for children of medical complexity
- Describe and interact with various technological supports: GT, GJ tubes, trachs, central lines, ports, Baclofen pumps, Bipap, Vibratory vests and cough assists, etc.
- Review medical funding mechanisms (waivers, Medicaid and coordination of benefits with commercial insurers)
- Summarize the Chronic Care Model and its benefits to this population
- Understand the unique role of and work with various members of Complex Care Clinic team (e.g. Care Manager, SW, RD)
- Discover information regarding the Medical Home and Medical Neighborhood (school, camp, faith-based supports, funding, counseling, family/sib supports, respite care)
- Discover information regarding ethical concepts which might affect patient care
- Discover and participate in some of the various specialty clinics available to this population
- Review the basics of outpatient medical coding for this population

Clinical Skills

- Perform a complete well child physical exam of a child with medical complexity, with particular focus on commonly-observed pathology of this population
- Understand types of airway clearance and indications for their use
- Understand types of feeding regimens and interventions and indications for their use
- Utilize provider-family shared decision making
- Begin to advocate for children with medical complexity at the local, state, and/or national levels

Professionalism

- Review literature to optimize interactions with people with cognitive impairment
- Use family-centered and team-based models of care, especially around interacting with families and respecting their expertise about their child
- Express insight into the daily struggles a from family members of patients on a personal-social level

Table 1. Outpatient Complex Care Elective sample schedule of experiences with associated goals/objectives.

	Experience	Goals & Objectives
Day 1	Meet with financial advocates	• Medical funding mechanisms (e.g. waivers, Medicaid, other insurance)
	Review articles and webinars	• Chronic Care Model • Family-centered and team-based models of care • Ethical considerations • Effective communication with patients with cognitive impairment
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Day 3	Complex Care Center	• Learn and perform basics of well care and ill care of children with medical complexity • Work with multidisciplinary team • Participate in provider-family shared decision making
Day 4	Shadow Respiratory Therapist	• Medical technology: tracheostomies, ventilators, airway clearance
	Review articles and webinars	
Day 5	Complex Care Center	
	Resident Continuity Clinic	
Day 6	Physical Medicine & Rehabilitation Clinic	
	Complex Care Center	
Day 7	Gastroenterology Clinic	• Medical technology: feeding tubes and nutrition
	Pulmonary Clinic	
Day 8	Complex Care Center	
Day 9	Home Care Visits	• Experience alternate care setting
	Therapy Center	• Medical technology: wheelchairs and other assistive technology
Day 10	Resident Continuity Clinic	

	Complex Care Center	
Day 11	Therapy Center	● Observe Early Intervention and Early Childhood programming
	Complex Care Center	
	Elective Debriefing	● Meet with faculty advisor to reflect on elective experience and advocacy opportunities

Table 2. Potential Complex Care Outpatient Elective opportunities including subspecialties and other groups.

Complex Care

Clinic	Notes
Complex Care Clinic	In addition to seeing complex care patients, you will spend time with RN, RN Care Manager, SW, and RD.

Subspecialties

Specialty	Clinic/Provider
Pulmonary	Ventilator clinic
	Neuromuscular Clinic
	Aerodigestive Clinic
	Transitional Care Center (ventilator-dependent unit), rounding and/or spending time with RT
Rehab	Cerebral Palsy and Spasticity Clinic
	Cerebral Palsy Clinic
Perlman Center	Early Intervention (EI) and Early Childhood (EC) Programs
	Equipment Evaluations & Speech Language Evaluation
GI	Feeding Team
Palliative Care & Hospice	StarShine Home Visits
Neurology	Various clinics may be applicable

Other Experiences

Group
Financial Advocates
Meeting with Complex Care Families
Complex Care Lectures
Ethics
Self-directed learning (see reference list)

Supplement 2. Reading List

Reading List for Complex Care Elective

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PUBLICATION REVIEW

Two Recent Policy Statements About Safe Transportation

By the American Academy of Pediatrics

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The policy statements by the American Academy of Pediatrics suggest that pediatricians make recommendations for safe transportation and provide advocacy. They apply, however, to all physicians and other health care professionals. The more we are knowledgeable about safe transportation and work to maximize passenger safety for individuals with disabilities, the more they will be protected while traveling. In addition to considering transportation by families and on school buses, safety needs to be improved on public buses, paratransit, vehicles that transport individuals to medical appointments, and accessible taxis.

The policy statements reviewed are:

O'Neil J, Hoffman BD; COUNCIL ON INJURY, VIOLENCE, AND POISON PREVENTION. School Bus Transportation of Children With Special Health Care Needs. *Pediatrics.* 2018; 141(5): e20180513

O'Neil J, Hoffman B; AAP COUNCIL ON INJURY, VIOLENCE, AND POISON PREVENTION. Transporting Children With Special Health Care Needs. *Pediatrics.* 2019; 143(5): e20190724

[a]Independent Practice

School Bus Transportation of Children With Special Health Care Needs

This policy statement by the American Academy of Pediatrics discusses school bus transportation safety for children with special needs, including students who use wheelchairs and those with a variety of health and behavioral problems. A special care plan that addresses transportation and medical emergencies while being transported is recommended. The roles of the school system, parents, and pediatricians are described. It is suggested that physicians be aware of appropriate use of restraint systems for children with special needs and that they provide orders and recommendations for transporting these students safely.

The authors propose that the plan for safe transportation be included in the IEP (Individualized Education Program for children ages 3 to 21) and, when needed, the IFSP (Individualized Family Service Plan for children ages 0 to 3). A collaborative process is suggested during which parents work with occupational and physical therapists, school nurses, a school psychologist if there are behavioral concerns, and a certified passenger safety specialist. Specific training in safe transportation for children with special needs is necessary so that appropriate devices can be selected and used correctly. Adequate instruction must be provided for transportation staff so that the plan can be implemented.

Whenever a child can be safely transferred from a wheelchair, the best form of transportation is in child safety restraint systems (CSRSs) including car seats, safety vests and harnesses, and 5-point harnesses integrated into bus seating. Those children of school age who can sit properly on a standard bus seat with a lap and shoulder belt should do so. Children who cannot be reasonably transferred from a wheelchair should use a wheelchair that faces forward in the vehicle. It is important that the wheelchair, the seating, and wheelchair tie downs and occupant restraint systems (WTORSs) meet the standards of the American National Standards Institute and Rehabilitation Engineering Society of North America (WC 18, 19, and 20). Most wheelchair postural supports and harnesses have not been crash-tested. Unless there is a clear indication that they have been successfully crash-tested, the vehicle's occupant restraint system (lap/shoulder belt) should be used.

Among additional recommendations are the following:

- Safe use of car seats is discussed for children weighing up to 80 pounds.
- Three wheeled devices, carts, and strollers should not be used for transportation on a school bus unless they successfully pass impact tests (crash tests, WC 19 standards).
- Four tiedown devices that are attached to the floor of the bus are needed to secure occupied wheelchairs, with additional ones required if the weight of the child and wheelchair combined exceeds 250 pounds.
- Lap boards must be removed from the wheelchair and secured to the bus separately. A foam tray may be used as a substitute if necessary.
- Medical equipment needs to be secured on the bus.
- Children with certain medical conditions need to travel with a nurse or specially trained aide; some children need rescue medications available on the bus.
- Plans and practice for safe emergency evacuations are suggested.
- Bus drivers and substitute drivers should have information about a child's special needs and have emergency medical information available.
- For children who have behavior problems that interfere with riding safely on the bus, psychological intervention is recommended. If these interventions are not successful, use of CSRS for restraint may be suggested.

Transporting Children With Special Health Care Needs

Proper resources are necessary so that children with special health care needs can be transported safely. This policy statement describes strategies to protect children with difficulties such as airway obstruction, gastrointestinal disorders, orthopedic conditions or procedures, developmental delays, abnormalities of muscle tone, and behavioral difficulties. It supplements the following other policy statements by the American Academy of Pediatrics: "Child Passenger Safety"[1] and "School Transportation Safety"[2]. The purpose is to assist parents and professionals to promote safe and comfortable transportation for these children. Recommendations that are reported in the above review of "School Bus Transportation of Children With Special

Health Care Needs" will not necessarily be specified again unless additional important information has been added.

A standard car safety seat (CSS) is said to provide the best protection for many children who have special needs. These seats are available and are regulated by federal standards for children who weigh up to 80 pounds. Other large car seats have been crash-tested and are appropriate for children and adults who weigh up to 115 pounds.

There is a discussion of a policy that hospitals should have a child passenger safety program which provides discharge recommendations for safe transportation. The policy also suggests that hospitals have an inventory of needed restraints and have access to custom medical transportation products. A recommendation is made that pediatricians advocate for transportation safety.

Specific additional guidance follows:

- Standard child restraint devices should be used whenever possible. Children with reduced head and trunk control can ride more safely in rear-facing car seats so long as they meet the weight and height limits. Some convertible rear-facing CSSs accommodate children up to 50 pounds.
- A standard or special needs booster may work for some children, and conventional lap/shoulder belts for others. A reclined seat is not safe.
- Children up to the age of 13 need to be in the rear seat. An exception to this recommendation is children who require frequent observation when there is no additional adult available to sit in the back seat. A switch which can turn off the air bag is suggested if a small child must sit in the front seat.
- Information about transporting premature infants and others of low birth weight is specified in another policy statement by the American Academy of Pediatrics.[3]
- Regulations about air travel are available at the Federal Aviation Administration website.
- Specific evaluations are needed for children with possible airway obstruction, with modifications including a rolled towel to adjust the angle of a car seat, if authorized in manufacturer's instructions, or a car bed. Restraint systems for children

with a tracheotomy should not come in contact with the tube. A trained person is needed to monitor children with significant airway obstruction.

- CSSs should only be used for travel. There is a risk of airway obstruction if a car seat is used outside the car, even for typically developing children.
- For children with abnormalities of muscle tone, consider rear-facing car seats up to the height and weight limit; car seats whose manufacturers allow forward-facing seats to be semi-reclined; crotch rolls between the legs and the crotch strap; rolls under the knees to help control extensor spasticity and opisthotonus; and lateral support with rolled blankets, towels, or foam rolls. It is dangerous to use soft padding between the child and the CSS because the padding compresses and prevents the harness from being secure. Head bands and stiff cervical collars are unsafe.
- Gastrointestinal problems: For children with reflux, suggestions include waiting sufficient time after feeding and using a CSS that permits changing the angle of the car seat. A child with a gastrostomy tube needs a harness that does not rub against the feeding tube.
- Children with a spica cast may require a specialized car seat. A hospital loaner program is suggested. Older children with a spica cast or a body cast may need a specialized travel vest or harness. Some can ride in a seated position. There is a vest that secures a child who lies on the seat of the car and also secures the cast.
- When challenging behaviors interfere with safe transportation, every effort should be made for parents to collaborate with professionals and find triggers for challenging behaviors and strategies to resolve the problem. When needed, specialized restraints that have been approved for safe transportation can be used during travel.
- Children with medical equipment that uses electricity need portable power that will last twice the amount of time of the trip and a charged back-up system.

COMMENTS

Knowledge of the above information is vital for anyone concerned about the safety of individuals with disabilities and/or special healthcare needs. Follow up by reading the full articles which have been reviewed here and relevant references. Important additional information is available at the University of Michigan Wheelchair Transportation Safety website[4] and in a 2011 special issue of *Journal of Pediatric Rehabilitation Medicine, "Transportation Safety for Children with Special Healthcare Needs".* [5]

When a child has behavior problems while being transported, in addition to psychological consultation consider a shorter trip. School transportation can be modified so that the child rides in a smaller bus or is the last one picked up and the first one dropped off. Some children may do better if they travel alone to school or even on a different bus route. Advocacy from outside the school system by parents and professionals may be necessary to achieve these changes. If medical consultations require a long trip, consider telemedicine and/or collaboration with a local pediatrician whenever feasible.

Wheelchairs which are ordered should meet the standards of WC 19, and seating needs to meet WC 20 standards. Beware of chairs that have transportation tie down brackets but are not crash-tested! A sales representative for a major wheelchair company recently informed me that a wheelchair was appropriate for transportation in a vehicle, and the order form indicated that this model has tie down brackets but has not been crash tested.

Based on personal experience, training of transportation staff to manage wheelchairs safely and to properly secure wheelchairs on school buses requires one-to-one practice on a bus with a child in a wheelchair **and** follow-up observation and guidance. Theoretical instruction and demonstration in a are insufficient! Placement of the pelvic belt properly at the pelvis and not over the abdomen requires guidance, as does locating the shoulder belt so it does not press on the neck or slip off the shoulder. Parents who transport their children in wheelchairs also need adequate instruction, demonstrations, and monitoring.

At times it might be discovered that the wheelchair seating system does not permit the crash-tested lap belt to be placed properly at the pelvis (no open area through which the belt can pass). If the person sits in a wheelchair while on a bus or in a van, seating **must** be revised for safety.

Special considerations are needed when there is a VP shunt. The person's seat should be in a position that allows the shoulder strap to be on side of neck that does not have a shunt.

Seizures may be triggered by flashing lights when traveling, as the vehicle passes through sunlight and shade. Tinted windows, on cars and school buses, have been recommended for individuals with this problem.

The policy statements by the American Academy of Pediatrics suggest that pediatricians make recommendations for safe transportation and provide advocacy. They apply, however, to all physicians and other health care professionals. The more we are knowledgeable about safe transportation and work to maximize passenger safety for individuals with disabilities, the more they will be protected while traveling. In addition to considering transportation by families and on school buses, safety needs to be improved on public buses, paratransit, vehicles that transport individuals to medical appointments, and accessible taxis.

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