Children with Medical Complexities, Part Two
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Welcome to the thirty-seventh issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues that involve children with medical complexities (CMC). Because this is such an important subject and one with many dimensions, we have divided the discussion into two parts, the first of which appeared in August as issue #36 of this E-Journal. As an experienced physician in our work group has noted, CMC deserve concurrent palliative care and pediatric palliative care patients are almost exclusively CMC. We appreciate that there may be many additional issues that touch upon these children, their families, and those who provide care to them. Our hope is that the topics addressed in this issue and in the one that preceded it will be useful for and helpful to readers of this E-Journal. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at christytork@gmail.com or Maureen at horgan.maureen@gmail.com.

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Issue #37:
Children with Medical Complexities, Part Two

Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.

Just another Mile  
Scott Newport  
This is a poem that our "resident poet" read at a memorial service following the early death of a child. This was the parents’ first child and the poem was written with the child's Mother especially in mind.

For Life  
Joanne Di Simone  
Benjamin's mother describes life with her son who was diagnosed at four months of age with Lissencephaly, a rare brain malformation. Benjamin is now 15 with constant pain and several medical complications, but his mother says he has a "joyful soul . . . has never gone one day without smiling [and] fills our home with his contagious laughter." She worries now what will happen to Benjamin if he outlives her and her husband. Her conclusion is: "I will regret some of these thoughts if I do one day find myself standing on Benjamin’s grave, but there will be no peace if he is wheeled across mine."

Living as a Young Adult with a Chronic Complex Medical Condition  
Aly Becker and Becky Benson, MD, PhD  
In response to prompts from her palliative care physician a young woman of 22 describes herself and her complex medical challenges. She comments on the many specialists who have been involved in her care, periods of depression and anxiety, some positive experiences in healthcare, and some recent achievements.

Bringing Back the Hope  
Carrie L. Cormack, MSN, RN, CPNP  
The author describes the value of a family-centered approach to the care of a 13-year-old boy who was born with spastic quadriplegia and is now profoundly delayed with multiple health challenges. The article shows the value of palliative services that will assist his medical team with the prevention and relief of suffering and maintain the highest possible quality of life in the home, school, or community setting.

Pediatric Palliative Care Partnerships: Best Practice for Children with Complex Chronic Conditions  
Kathy Davis, PhD  
This article examines four principal topics: (1) the historical and current educational and palliative care services available to children with complex chronic conditions (CCCs); (2) barriers to the full complement of available school services; (3) ways that schools and palliative care providers may partner to best support the needs of this population of student-patients; and (4) important directions for future service provision and collaboration between professionals.

Extreme Measures in the Care of Children with Complex Medical Illness  
Nathan Ionascu, MD  
This article explains why it is difficult for many caring physicians to share with parents the true prognoses of children with complex medical conditions, even when the diagnosis has been established. The author notes that there are major emotional, psychological, and ethical issues involved in these situations, which physicians may lack training and/or experience in knowing how to address.

"You Deserve a Break Today": Making the Case for Needed Respite Care for Families of Children with Chronic Complex Medical Conditions  
Ann Fitzsimons, BA, MBA  
This article identifies the need for and barriers to respite care for families of children with complex medical conditions, offer some potential solutions, and indicates ways individuals can help.
White Paper: A Successful Model for the Provision of Care to Medically Complex and Technology-Dependent Children  p. 24
David M. Steinhorn, M.D., Michael Msall, M.D., and Mary Keen, M.D.
This article identifies children with complex medical conditions or those dependent on medical technology that have specialized healthcare needs that are difficult to meet within acute care hospitals and community-based home health programs. In response, the Almost Home Kids has for the past ten years provided in the Chicago area a successful solution for (1) transitional care for a child with complex health care needs, (2) family training in complex medical technologies, and (3) periodic care for children and the establishment of systems of caring and competence that promote safety, quality assurance, and child and family well-being. The authors argue that this model provides a cost effective solution to a difficult and growing need that can easily be replicated to care for the most fragile children among us.

Managing Complex Medication Regimens  p. 29
Melissa Hunt, PharmD
Because children with medical complexity often have complex medical regimens, this article offers guidance in managing polypharmacy, whether that involves administering a large number of medications, managing complex medication schedules, decreasing risks of medication errors, or evaluating medications for appropriateness on a regular basis, e.g., de-prescribing or tapering, withdrawing, or discontinuing medications to reduce polypharmacy, side effects, and/or ineffective use of medications as the child's health status changes.

Two Reviews of “Digging Deep, a Journal for Young People Facing Health Challenges”  p. 32
Erin Gaab, PhD and Kathy Davis, PhD
We offer two reviews by members of our work group of a publication “Digging Deep,” one by Erin Gaab, PhD, who focuses on the value of diary writing; the other by Kathy Davis, PhD, who seeks to put this publication in the larger context of the literature on journal writing.

Reader’s Corner: Abstracts of Three Articles  p. 36
Suzanne S. Toce, MD
Here, Dr. Toce offers abstracts of three articles that are likely to be of interest to readers:
- Regoaling: A conceptual model of how parents of children with serious illness change medical care goals
- Pediatric Palliative Care for Children with Complex Chronic Medical Conditions
- Supportive and palliative care of children with metabolic and neurological diseases

Items of Interest  p. 41
- In each issue of our ChiPPS E-Journal, we offer additional items of interest.
JUST ANOTHER MILE
(About early loss)

Scott Newport
scottandpenni@hotmail.com

Your tiny heart beat within my essence
within my every thought a gleaming presence
My restless nights were filled with dreams
and of days to come and laughs that would loft, so it seemed
Your precious being was with us for such a short while
each and every day you whispered, “It’s ok mom. Just walk with me this last mile.”
But how did I know your sweet voice
I would never hear
Not a cry or even a smile
till we meet again I’ll
keep loving you all the while
FOR LIFE

Joanne Di Simone
Benjamin's mother

It goes against everything we believe about motherhood, but I’d rather bury my child than leave him behind.

My son Benjamin was born with Lissencephaly, a rare brain malformation. Developmentally he’s like an infant in a fifteen-year-old body. He can’t walk, talk, or use his hands. I bathe, feed, and diaper him every day. In the not so distant past, Benjamin would have been institutionalized. Without an arsenal of seizure medications, he wouldn’t have lived to see his first birthday. By the age of ten, he was taking twenty-six prescribed pills daily.

Many children with Benjamin's disorder suffer with chronic pneumonia, and unstoppable seizures. Medical advances and invasive interventions, like tracheostomies and feeding tubes, have extended their lives but cannot change reality. These children die, young. I have spent Benjamin's entire lifetime mourning the deaths of children I've met on the Internet.

When I dreamt of parenthood, I expected to raise children who would grow strong and healthy. I dreamt of watching them graduate college and launch exciting careers. I hoped they would fall in love, marry and fill my life with grandchildren. I never thought I’d envision my son’s name on a headstone in a peaceful resting place.

It began when Benjamin was diagnosed at four months old. My husband and I were forced to redefine parenthood. We couldn’t protect our son from his physical devastation. Our only goal was to give Benjamin the best quality of life. We knew that the definition of “quality” would be hazy, dependent on Benjamin’s needs and our capabilities. We knew we would always be judged.

The miracle in this situation is the existence of Benjamin’s joyful soul. Although he has constant pain ranging from constipation to his slowly dislocating hip, Benjamin has never gone one day without smiling. He loves when I read, sing and dance for him. He likes to stay up late with company, and sit on his Daddy’s lap for hours. He fills our home with his contagious laughter.

I have looked into Benjamin’s eyes more than I’ve ever looked into anyone’s. I’ll never know his thoughts, but our connection is powerful. He possesses an intangible, indefinable beauty. I love my son in a way I will never love anyone else.

I used to worry about Benjamin dying but now fifteen years in, I worry about him surviving beyond my husband and me. Only we have comforted Benjamin through daily seizures and seven surgeries. We are his one true voice. No one can understand Benjamin the way we do.

A few years ago Benjamin was vomiting for two weeks. The doctors assumed it was a virus, instructed us to wait it out. We watched him grow weak. There was a vacant, lifeless look in his eyes. He was a suffering shadow of himself. I kept pushing the doctors to help him fight to live. I felt selfish. Part of me wanted him to let go and die. That felt selfish too. Because of my persistence, we discovered Benjamin had an atypical presentation of pneumonia. I fear the day my voice is silenced.

If orphaned, Benjamin would need to live in some kind of hospital facility. I’ve seen medical residencies
for children like Benjamin. They are sad places. A hospital setting is a business, not a home. I picture Benjamin alone in a bed, hooked up to tubes, nothing more than an insignificant number on a chart. With that in mind, I’d rather see him dead.

I have learned to embrace motherhood with brutal honesty. I don’t actually want to see my son take his last breath. I don’t want to know life without him. For as long as I live, I will do whatever I can to keep Benjamin healthy and give him the best possible quality of life. His happiness is my happiness. He is no less than anyone else, deserves every right and consideration. As Benjamin’s advocate I can guarantee a strong proactive force. When I’m gone, I can do no more.

I will regret some of these thoughts if I do one day find myself standing on Benjamin’s grave, but there will be no peace if he is wheeled across mine.

Joanne De Simone lives in New Jersey with her husband and two sons. She’s a special educator and writer whose work has appeared in The Huffington Post.

This article has been reprinted by permission. "For Life" was originally published in Brain, Child: The Magazine for Thinking Mothers, www.brainchildmag.com. The Huffington Post changed the title of this article to "Bury My Son Before I Die" when they published it online.
Aly is a 22-year-old young woman whom I have followed for palliative care for the past 3 years. She was generally healthy until she hit her teenage years, when she began developing auto-inflammatory issues, including arthritis and eosinophilic esophagitis. Despite this, she was a valedictorian of her high school and started college as a pre-med student. Over the course of the next two years, her inflammatory disorder continued to defy both diagnosis and treatment strategies. She is followed by multiple specialists, as many organ systems are now involved. She has a central line for parenteral nutrition due to feeding intolerance, and has had several life-threatening infections due to immunosuppression from her disease process and the treatment for it. She has chronic abdominal pain and nausea, and has a G-tube that she uses primarily to vent to mitigate her nausea and vomiting. She has recently had an episode of severe depression and anxiety. She has chronic, complex medical issues that have interrupted her college education and career aspirations, as well as her burgeoning independence from her parents. I asked Aly to share with us what it has been like to struggle with these issues.

Tell us how you would describe yourself.

How I describe myself to others varies greatly upon the situation. In a free response, I would describe myself as someone who is tenacious, responsible, outgoing, thoughtful, and highly independent. I have an ever-growing list of questions that feeds my persistent curiosity that drives me to the act of learning. In a positive light, I am driven to do well, strive for perfection, and ignore limitations. It is just as correct to say I am motivated by success, am an obvious people pleaser, and am stubborn beyond belief. Many of these traits are viewed as positive and essential to thriving, while others, since I do everything 100% all the way, like my fiercely stubborn demeanor, can occasionally stand in my way. Regardless of the downfalls, my personality has mostly been an essential weapon in my fight to gain ahold of my life and to never let it completely go. My most prominent personality traits, answered by others, are my desire to be independent, my stubbornness, and my desire for knowledge. These traits are a big part of why I am where I am today. Why I have convinced myself to keep going. Why I won’t let the other parts of my life (socially and educationally) completely disappear, though a break may be necessary. I hope that when my doctors think of me and my health journey they can see these traits and how much they shape who I am and how I wish to and have fought my disease. With doctors and nurses and other health staffs I spend time with I feel comfort from their understanding of my personality and who I am in the bigger picture. It helps them know what treatments are possible and fitting to my personality. Them having knowledge of me as a whole person helps them set goals and talk and teach me things about my health in a way I can easily relate to and use to succeed. Doctors and health staff that I see frequently learn these things over time like any other casual acquaintance would and many think that this type of relationship is only possible in long term personal or professional relationships. While this does make it easier, it is in no way the only way it is possible. Too often I feel (as a chronic patient even) not much more than a name (full name granted…I won’t belittle the system), birthdate, MRN hospital number (8 whole characters long), and occasionally an allergy list. I am not totally blind and ignorant. I understand that many people are involved in care and this number multiplies exponentially in a teaching hospital, but regardless making me or any other patient feel like a whole person is attainable. Clearly the important patient information questions are warranted and needed, but it doesn’t need to stop there. An extra 5 minutes at the first appointment even, remembering one fact out of many (I like school, I’m a perfectionist, I like music, I like questions explained… virtually any trait or desire) goes a long way. I am more likely to
open up and share things about the whole me if I feel like the provider views me as a whole person. **Tell us about the specialties you see, and how they each are a part of your story.**

I have a complex health history with multiple diagnoses and much to my dislike, multiple question mark symptoms and disorders. The first specialty I began seeing was pediatric rheumatology where I was diagnosed with polyarticular juvenile idiopathic arthritis and Reynaud's phenomenon. Currently my joints are in remission though I have had frequent flares throughout the years and continue to experience discoloration of my extremities in the cold. I then began seeing pediatric gastroenterology where I was diagnosed with GERD, eosinophilic esophagitis, and later GI dysmotility. I see pediatric (now switching to adult) pulmonology for chronic asthma and interstitial lung disease w/ decreased DLCO. I have seen nephrology on many occasions for follow-up after acute tubular necrosis secondary to severe dehydration and troubles regulating electrolytes. I see infectious disease frequently, any time that I have a fever or unexplained symptoms that could relate to an infection. I see psychiatry for depression and anxiety and to control these medications. Finally, I see palliative care which helps me to have an outlet to discuss treatment and quality of life questions and treatment decisions. Palliative care also works closely with me to work on symptom management and balancing controlling my pain and nausea and other debilitating symptoms with being able to live as much as possible without unnecessary medical intervention. I would not be where I am today, still fighting for my health and my life in other areas like school and social areas without palliative care. It is in many ways more important than the physical specialties. I try much harder to feel better and make sure treatments can work best and try to stay active in other areas of my life when I know I have a team in place to catch me if I stumble and cheer me on to the finish line.

**What was it like to go through a period where you had depression and anxiety as major impacting forces on your life?**

Depression and anxiety are common amongst those with chronic health conditions and I was no exception. Before becoming ill and struggling and learning myself how these conditions make you feel, I had no understanding of how encompassing they can be. With very little time and range, these symptoms become entirely debilitating. Often, these diagnoses are more traumatizing, threatening, and overwhelming than physical symptoms and conditions. It is no secret in our society that mental health conditions are often regarded as taboo and as a personal problem, rather than a health concern that can be helped and treated and that is a true tragedy. However, contrary to much discussion, I do not believe the patient is at all to blame or is unreasonable to feel ashamed or less of a person for struggling with these issues, especially when they come simultaneously with physical health concerns. Even in the year 2014, science is vastly changing and much is unknown. Despite all the incredible breakthroughs and massive understanding, there is still much that is not explained. Unfortunately, it is common for doctors to take the “blame the patient” route when medical tests or information don’t immediately make sense. First, I need to say that I agree 100% that all scenarios need to be addressed and assessed when treating a patient which includes psychological disorders. It would be remiss of a provider or hospital not to pursue all options and guarantee that mental health is stable as well. However, once this is established and second opinions are sought and answers are still at large, providers need to be careful to not belittle the patient or make the patient feel at fault. I carry with myself a very large amount of guilt every day. I am frustrated that I can’t do the things I want to do and that I am not better. While it is frustrating for a doctor personally when the treatment a doctor prescribes is not successful, it is much more frustrating and depressing for the patient. Believe it or not, patients want just as badly to reach a happy ending. This can’t happen if a patient feels untrusted or at blame. While trust is essential, the biggest risk and problem that can result from this thinking is potentially missing a major health issue. If a patient doesn’t feel like they are taken seriously or believed, they are much less likely to seek help and share new symptoms and therefore remain untreated. This was a problem for me. For several years it was obvious something was wrong but tests unfortunately continually neglected to shed light on the issue. As this continued, more and more I was questioned, felt blamed, and many times was sent home with an unconfirmed psychiatric diagnosis that wasn’t correct and with no curative treatment. As things progressed and we realized more was going on, I began treatment. Several years into my chronic illness, however, I began to develop severe depression and anxiety that slowly overtook my life. I had been through stressful, painful, and challenging situations with my physical illness, but had never felt so bad as I did with the added...
depression and anxiety. Unfortunately, my diagnosis and treatment was delayed as I was afraid to mention my new symptoms, fearing being judged and blamed for my physical issues again if I also admitted I had psychological struggles as well. It is important to look at the whole patient and all possibilities. Once this has occurred, however, pushing the subject and making the patient feel uncomfortable and not trustworthy is quite damaging. My treatment of my depression and anxiety was delayed as a result of my previous experiences. In my case I was lucky. This delay resulted in a couple months of mental and physical torture until I felt comfortable seeking help and acknowledging the concerns of providers I was close with regarding my mental health. However, the results could have easily been much worse. Trust is essential to a good patient and doctor relationship and to good treatment outcomes.

Can you describe some positive experiences in healthcare?

Positives in healthcare would be the relationships I have built with those providers who took the extra step and the extra time, who listened to me, who got to know all of me beyond the chart, and who encouraged me in all aspects of my life. These relationships are major contributors to the success and management I have achieved. Healthcare has also given me an invaluable appreciation of life in general. Things are so temporary. What is here today is easily gone tomorrow. Nothing is guaranteed. Everything is a gift. These statements all seem cliché and honestly are, but they are also all completely true. Many people do not realize the truth in these statements until later in life or after they have lost something big. I am lucky and incredibly blessed. I live my life now completely aware of every positive and every gift and I wouldn’t change that for the world.

Tell us about some of your recent achievements.

Things I am proud of achieving may seem small to others but are big to me, but that’s life, everything is relative. Big accomplishments have included getting to go on an overnight trip with friends again out of state and riding roller-coasters at Six Flags. This was my first vacation in 4 years. I’m eager to drive again when I am well enough to not take sedative medications. Other achievements have included speaking to medical students about my experiences in healthcare, promoting local blood drives, and providing support to other patients with chronic conditions in the hospital. Recently, I was invited to speak at a Pain and Palliative Care Summit at the state capitol and I attended the Governor’s Pain Awareness Proclamation, which gave me a chance to advocate at the state level. I am now working on continuing my education. Many complain about homework and work load and classes… and I dream of getting to do those things every day. Sometimes the losses I have experienced seem so great, but that makes the achievements all the more meaningful to me.
His smile lights up a room. Last year, his peers, with the assistance of teachers, voted him class president. Max* is loved by everyone, and when he left school this past December, everyone felt the void. Not only is he one of the largest children in the school—his large frame takes at least two adults to transfer—but also his loud boisterous laugh easily fills the school’s hallways. Those who know him love him, and there is no doubt he loves them back. Aside from his exceptional charisma, Max is the same as many kids his age. At 13, he loves coming to school to see his friends, and he constantly laughs at his teacher’s funny jokes. He likes watching videos made of him and his friends and loves listening to music. There are differences too, and these differences have kept him away from the school—and his friends—for the past six months.

Max is one of approximately 12.6 million children in the US with chronic disabilities (The National Survey of Children with Special Health Care Needs, 2012). Barriers to healthcare are abundant for this population, and quality of life for children with disability is often limited. These barriers become progressively worse as their illness or disability increases in severity. Max is considered profoundly delayed. Born with spastic quadriplegia, he has very little purposeful movement of his body. Max is wheelchair bound and unable to complete any activities of daily living independently. He is diapered and fed via a gastrostomy tube. He is non-verbal and communicates with sounds and eye gaze only. Max has a long complicated medical history, and last December, his seizure disorder began to worsen. His medical team was unable to get his seizures under control, and the hospital became home for him and his mother for weeks at a time. Their quality of life declined rapidly and Max’s contagious laughter was rarely heard.

Pediatric palliative care is a method of care delivery that focuses on reducing suffering; it helps children and adolescents living with complex chronic conditions, as well as life-threatening or terminal conditions, improve quality of life and live full and meaningful lives (American Academy of Pediatrics, 2000). This type of care offers holistic, compassionate and interdisciplinary care directed at relieving physical, psychological, social, and spiritual suffering.

Children with complex chronic conditions, or severe and multiple disabilities, often require modifications to the healthcare delivery models that are in place for children with typical development. A review of literature demonstrates that a family-centered approach is widely supported as the ideal model of healthcare delivery for children with complex chronic conditions and their families (Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011; Lawson, Bloom, Sadof, Stille, & Perrin, 2011; Palfrey et al., 2010; Wei & Yu, 2012). Palliative care offers this holistic, comprehensive, collaborative care in the context of coordinated services. This method of care delivery provides the care coordination that is necessary to support these children and their families as they navigate the often confusing and overwhelming medical needs and systems. It also helps children and their families consider goals to improve and sustain their quality of life (Flint, 2014).

Over the past decade there has been a shift in care delivery models for children born with complex chronic conditions. With the advancing technology and broadened services, traditional custodial care has been replaced with innovative rehabilitation and goal-oriented programs focused on progress and potential. The importance of early intervention and implementation of services has been recognized by professionals and families caring for children with complex chronic conditions. Medical providers are encouraged to recognize the need for and initiate intervention services as early as possible; and outcomes related to these physical activity interventions are promising (Dodds, et al. 2011). Max attends
Pattison’s Academy for Comprehensive Education. Pattison’s Academy is an example of this type of program. It is a place where the needs of the whole child are considered and individualized potential is maximized through integrating therapy, early intervention, education, and community involvement (Pattison’s Academy, n.d.). While these efforts and attention to rehabilitative services have enabled children with disabilities to meet goals that many never thought possible, it is imperative that professionals continue to recognize the importance of providing concurrent supportive services to children and families especially during more difficult times as Max and his family are currently experiencing.

Reserving palliative care services for children who are actively dying or near death may exclude patients and families who could benefit. The American Academy of Pediatrics (AAP) recommends an integrated model for providing palliative care for all children living with a life threatening or terminal illness (2000). In March of 2014, Dr. Brian Carter, the Chair of the AAP’s Section on Hospice and Palliative Care Medicine, charged the pediatric community with further contemplating the role of palliative care services within medical homes providing care for all children with special health care needs and their families.

Max and his mother are ideal candidates for a referral to a palliative care team. Hands of Hope, a child-centered and family-focused organization in South Carolina, has recently partnered with Pattison’s Academy, and thanks to this collaboration, this method of care is now available for children like Max and their families. Hands of Hope’s unique model of care can provide Max and his mother palliative services, in their home, school, or community setting, that will assist his medical team with the prevention and relief of suffering and maintain the highest possible quality of life. Providers will work together to meet the needs of the family and the patient and work together towards goals set collaboratively. With this service in place, hope can be restored for Max and his mom…hope for that laughter to return to Max, to his mom, and maybe even to his friends.

*name changed

References

PEDIATRIC PALLIATIVE CARE PARTNERSHIPS: BEST PRACTICE FOR CHILDREN WITH COMPLEX CHRONIC CONDITIONS

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Children with complex chronic conditions (CCC) live at the crossroads of medicine and childhood. A child’s self-concept is threatened by growing up with a serious diagnosis or by the knowledge that they may die as a result of their diagnosis. Children with CCCs require exquisite case management and effective collaboration between the professionals who care for them in various environments. Good communication between the child and family, healthcare providers, and education professionals can ensure the best possible opportunity for the child to thrive despite their health circumstances.

This article will examine: (1) the historical and current educational and palliative care services available to children with complex chronic conditions (CCCs); (2) identify barriers to the full complement of available school services; (3) suggest ways that schools and palliative care providers may partner to best support the needs of this population of student-patients; and (4) highlight important directions for future service provision and collaboration between professionals.

Historically, there has not been a clear definition of chronic complex conditions. As a result, there has been confusion regarding exactly what conditions and which children should be included in the category of children with CCCs in both healthcare and educational environments. CCCs have been described by Feudtner and colleagues (2000) as, “Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center.” There are nine ICD-10-CM diagnostic categories of CCCs including cardiovascular, respiratory, neuromuscular, renal, gastrointestinal, hematologic or immunologic, metabolic, other congenital or genetic, malignancy and neonatal. Children with CCCs may be technology dependent or have post-transplant (organ or bone marrow) related conditions. Forty one percent of patients discharged from a single children’s hospital in 2000 were dependent upon medical technology including 20% with medical devices, 32% taking medicines and 11% using both technology and medicine. In light of the significant health conditions experienced by children with CCCs, it is not surprising that they may also face challenges within their social and educational environments. Children with CCCs do not typically live in a medical environment. Rather, they are engaged with family and friends, attend school, participate in activities outside of school, and may be a member of a faith community. Like all children, opportunities to grow, develop, and achieve are paramount to becoming a functional adult. Unlike most children, however, children with CCCs must navigate the diverse world of a child while being tethered to a ventilator hose or a gastrostomy tube or a central venous catheter. They may have concomitant behavioral, cognitive, or mobility challenges. Pediatric palliative care providers may cast a wide net to include educators, coaches, faith leaders, and others in the development of optimal goals of care across all environments in which the child is involved.

Since 2008, the pediatric palliative care program at The University of Kansas Medical Center has been providing palliative care for children with CCCs, either from the time of birth or from the time of diagnosis. The focus is on quality of life issues and ensuring that all environments, in which the child lives, include adults who have been educated about the physical, psychological, emotional, and spiritual needs of the child. Children do not spend most of their waking hours at the hospital but, rather, in school or in activities. Thus, the goal is to train caring adults such as educators, clergy, athletic coaches, dance teachers, and others to provide “palliative care” while the child is with them.
Two generations ago, children with CCCs often lived in institutions and received minimal medical care and no educational services. Children with CCCs are now living long and well enough to attend school and engage in favorite activities. Over the past 50 years, the definition of CCCs has changed to reflect the changes observed in the prognoses of many serious conditions of infancy and childhood. Children with a wide array of diagnoses have begun to survive long enough to gain entry into the category of CCCs. For example, children with cystic fibrosis (Dodge, Lewis, et al, 2007) and spina bifida (Wong & Paulozzi, 2001) lived only into adolescence in the early part of the 20th century, while those with cerebral palsy or other developmental disabilities were often placed in institutional care where educational goals were nonexistent (Wise, 2004). At the same time, care in neonatal intensive care units (NICUs) has improved survival of premature infants (Lorenz 2000) and infants with chronic heart or lung conditions, genetic disorders or birth defects (Feudtner, Hays, et al, 2001). Medicines, ventriculoperitoneal (VP) shunts, central venous access lines, gastrostomy tubes, and ventilator support have increased the life expectancy of children with neuromuscular disorders (Eagle, Baudouin et al 2002).

It is, obviously, good news that more children are surviving. An unavoidable consequence, however, is that many of these children are living with significant disability and challenging needs: medically, educationally, and socially. Services and programming must provide coordinated, efficient, and cost-effective care (Feudtner et al 2014). Perhaps the central “hub” of palliative care for a child should be the school. Partnerships between families, healthcare providers, and schools may result in services which address the holistic needs of the child with CCC, and carrying out goals of care which optimize the child’s potential.

Prior to 1975, public schools were not required to provide educational services for any child with a disability. The enactment of Public Law 94-142, later renamed the Individuals with Disabilities Education Act, or IDEA, entitled all children, regardless of disability or special needs, to a free and appropriate public education (FAPE) at no cost to parents. IDEA now includes 13 specific categories of special needs, and children with one or more of those diagnoses, and who qualify for special education services, have an Individualized Education Program (IEP) developed to address their specific learning needs. In addition, an Individualized Health Plan (IHP) is developed to address the child’s health needs at school. The IHP can address daily healthcare needs at school, emergency procedures related to the child’s care (i.e., what to do if the power fails in the school of a child on a ventilator), and address strategies for normalizing the child’s environment at school, to the greatest extent possible.

If the child’s condition does not adversely affect academic performance but he/she still needs accommodations to the learning environment to ensure optimal learning opportunities, Section 504 of the Rehabilitation Act of 1973 may help. A “504 Plan,” developed by educators, parents, and child, identifies accommodations needed by that learner. Accommodations may include rest periods during the day, appropriate seating to ensure the child is engaged along with classmates and a social group to help foster friendships with peers. Although Section 504 is actually civil rights legislation denying discrimination against persons with disabilities, it has served to effectively address the need for accommodations of children with CCCs who do not have learning disabilities.

It is not surprising that the healthcare and educational needs of children with CCCs are more expensive than for their healthy peers. Ghose (2003) found that .5% of a population of children with serious health needs incurred 15% of total health care charges. Children with CCCs use greater amounts of outpatient, inpatient, and emergency room care. If children with CCCs are in school, healthcare costs may be reduced by providing services such as OT, PT, and SLP at school, as long as there is an educational need for such services. Often, educational need and medical need for therapies are similar.

In addition, the needs of family caregivers of children with CCCs are extraordinary and diverse, and include many services traditionally provided by palliative or hospice care such as care coordination, respite care, and direct home care (Kuo et al 2011). Kuo and colleagues report that one parent often must quit work to care for the ill child and that out-of-pocket healthcare costs are greater for parents of children with CCCs. Highly coordinated and efficient care, emanating from the community school setting and partnering with palliative care providers, may ensure that parents, healthcare organizations, and schools...
equally share the cost and service provision burden of caring for the child with CCCs.

Not surprisingly, educators have concerns when students with CCCs are in their classrooms. A student with a ventilator, a youngster who has seizures, or a child who is post-transplant remind a teacher that they do not have training to care for possible medical needs of the child. Educators can receive education about their student’s needs and, most importantly, be reminded that their role is to teach the student, not treat the patient. There are certain safeguards that enable teachers to enjoy the student and reduce their worries. One helpful strategy is ensuring that every school employs a full-time school nurse and trains other school personnel in nursing duties in the event that the nurse is absent (AFT, *The Medically Fragile Child*, 2009).

Educators may need to be reminded that the student has learning needs that may be complicated by frequent absences. The high level of healthcare needs may place the child at risk of not receiving the same level of educational services, due either to the teacher/paraprofessional being the nurse’s designee to provide healthcare, or the child being removed from the room for care by the nurse. Ideally, there will be a full-time nurse in the school, who can attend to the child’s healthcare needs (i.e., tube feeds, ventilator care, breathing treatments, suctioning of the trach, medication administration, etc.) and at a time that will be the least disruptive to the child’s learning.

Kuo and colleagues (2011) also found that children with CCCs use more early intervention, special education and related services, child care, vocational education, rehabilitation, and community programs. In addition, these children typically miss more days of school. Thirty-three percent of families reported difficulties when they attempted to access non-medical services for their child.

Although the legal requirements exist in IDEA and Section 504 for individual children’s unique needs to be met at school, barriers remain that make the school environment challenging to navigate. For example, the IEP may identify only a few educational goals, such as one for reading, one for math, and one for spelling, when the child has deficits in all subject areas. Or, the child may be absent for 3 weeks due to an infection that requires hospitalization, and receive a huge stack of school work when he or she returns to school. If there is not a plan in place to help the child catch up on school work, frustration (for child and parents) is likely to ensue. Or, when a high school student is out of school for a bone marrow transplant, friends may stay in touch initially, but lose interest after a while. The hospitalized child feels alone and abandoned.

These findings and challenges further illustrate the importance of children with CCCs being considered early for pediatric palliative and/or hospice services. The greatest benefit of palliative services occurs when provided not just in a healthcare setting or home, but when incorporated into the school setting and other environments of importance to the particular child such as sports, dance, chess club, youth group, activities with cousins, etc. By teaching other caring adults and children to “do” palliative care, the young person with CCCs may be enveloped in love and compassion rather than left behind as teachers and peers get busy with day-to-day demands.

Future directions should focus on the broadening definition of palliative care in regard to children with CCCs. Whether the child is educated in a self-contained special education classroom, a general education classroom, or changes classes throughout the day, educators and peers can be taught to provide palliative supports. The psychological and social needs of the child may be better addressed in an environment where he/she is with friends and trusted teachers. The motivation for the child with CCCs to connect with peers is likely to be strongest in the school setting, where peers are present. Healthcare providers should be included as an integral part of the child’s IEP or 504 team. Along with parents and school professionals, healthcare providers may provide significant ideas to help develop a portion of the child’s IEP or 504 Plan that focuses on the psychological and social components of the child’s care.

When teachers and peers understand the loss and grief that many children with CCCs have experienced, compassion often flourishes. And, if the child with a CCC feels welcomed and missed after an absence, he or she is far more likely to want to get back to school. Similar relationships and interactions may be forged with worship leaders, athletic coaches, or activity leaders.
The zeitgeist is right for a child with a CCC to find his or her place, fully, in the world. The limits are being lifted, and the possibilities are richer than at any time in the recent past. And, regardless of how the child’s illness progresses, the opportunity to be a functioning, involved member of school, place of worship, and activities will enhance the child’s life and ensure that quality of life is at the forefront.

References

For the families and the children born with life-limiting congenital syndromes, or those who develop complex disease entities early in life, the choices for medical interventions are often difficult to make.

Inasmuch as it is difficult for any loving parent to cope with the fact that their baby or child might not survive them, it is as hard for many caring physicians to share with these parents the true prognosis—once they have established the child's diagnosis. So for much of the duration of the illness, physicians will use their skills and the latest medical technology in order to support life and enable the little patient to grow and develop. By doing this, they not only abide by the parents' wishes, but contribute to crystallizing the family's belief that their sick child's condition is amenable to a cure.

As a result, after months and sometimes years of costly medical interventions, involving the patients suffering through medical and surgical procedures, repeated hospitalizations, separation from their siblings, grandparents, and other loved ones—and most often only one parent can spend the whole time in the hospital with the sick child—it comes as a shock for the family to be told that the child will die!

The first reaction is that of disbelief: how come this can happen? They might then start questioning why they had to go through all these sacrifices, psychological ups and downs, and the suffering inflicted to their child over this lengthy period of medical treatments? Even the quasi-neglect of their other children, while their whole life centered on the sick one. Was it all in vain?

Why did the physicians not tell them from the start the truth about the dismal prognosis? Why did they give the family "False Hopes?"

For many physicians, there are major emotional and psychological issues involved when being faced with a child with life-limiting diagnoses, or facing death. They oftentimes lack training in how to approach the discussion with the families of such children, beyond suggesting treatments—which is what parents expect. Communication at the bedside of a child with complex medical conditions, and all it entails—cultural sensitivity, translating medical terminology into everyday language, making choices, setting goals, and drawing up treatment plans—is as much a science as an art, and might take years of practice to develop.

Although giant steps have taken place in medical technology, pharmacology, and clinical developments since the 1970s, these advances have outpaced pediatricians' development of the skills needed to deal with life-limiting conditions and premature death, since all terminal conditions cannot be eradicated.

Consider the creation of NICU, CPAP, performance of tracheostomies and gastrostomies on very young children, to support and maintain life. Yet comforting a parent or a child faced with a life-limiting condition, along with families who are understandably upset, anxious, and trying to understand what has happened and why, should not lead to giving them false hopes.

While no physician intends to give the parents and family "False Hopes," it is not ethically permissible to take away all HOPE. Therefore it is understandable why some medical professionals will not share a dismal prognosis right out at the start. Yet, during the course and trajectory of the illness, it behooves the medical staff to share, slowly over time, the true nature of the prognosis. It gives the family time to digest and integrate the bad news in their outlook of their child's life and untimely death. Anticipatory
bereavement might also help the parents cope.

Case in point: a newborn was diagnosed with anencephaly, he only had a thin layer of white cerebral tissue surrounding a cystic mass that occupied most of the cranial cavity, yet looked otherwise perfectly normal, with a cherubic face. In this circumstance, the pediatrician waited to share the prognosis with the child's parents.

Those young parents concentrated on feeding and nurturing their newborn, despite the dismal prognosis. When the baby's sucking reflex diminished, the parents felt desperate as the baby started losing weight. A gastrostomy was performed and the baby was started on tube feedings, which the mother religiously administered. The main purpose of the gastrostomy, besides feeding the baby, was to alleviate the parents' guilt feelings and give them time to adjust to their baby's premature and untimely death. After a few bouts of aspiration pneumonia and subsequent hospitalizations, the baby stopped gaining any weight, the tube feedings became harder to accomplish, and eventually the baby died. The tube feedings through the gastrostomy enhanced the parents' feeling of self-worth, assured them that they did everything for their baby, eased their deep grief, and softened the subsequent bereavement.

From this clinical vignette we can see that the ethical principle of Beneficence has to address both the young patient and the extended family. And in maintaining Hope, even though as the disease advances and the patient's condition deteriorates, the Goal should change from Hope to improve, to Hope for an enhanced quality of life, minimizing suffering (both physical and existential), and discontinuing treatments that appear futile. The same holds true for the ethical principle of Maleficence: “to do no harm.” It refers both for the patient: no treatments that increase suffering, as well as for the parents by being truthful about the prognosis while maintaining their Hope for a peaceful death. No "extraordinary" treatments should be instituted, where the burden of suffering is disproportionately higher than any benefit to the patient.

As far as the ethical principle of Utility comes into consideration, in these cases it has no place as no one should consider the cost of treatment if it can alleviate the child's suffering and the parents' angst. By discontinuing futile treatments as the illness progresses, with the parents' approval, one is implementing the Utility principle by default. Also by discussing the benefits of Palliative care and making an early referral for Hospice care, physicians can enhance the quality of life for the whole family by the child being treated at home, surrounded by his loved ones, if conditions permit.

In every language, there is a word for a spouse whose life-partner dies: a widow, if the husband died or a widower if the wife died. There is also a word for a child who loses a parent: she or he is an orphan. But there is no word in any language that I am aware of for a parent whose child dies.
“YOU DESERVE A BREAK TODAY”:  
MAKING THE CASE FOR NEEDED RESPITE CARE FOR FAMILIES OF CHILDREN  
WITH CHRONIC COMPLEX MEDICAL CONDITIONS  

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The Family Impact of Caring for a Child with a Chronic Complex Condition

As the McDonald commercials so aptly tell us, “We all deserve a break today” and we’ll get it by just eating in or picking up their drive-through food at any of their Golden Arches. If only it were that easy. While we all deserve some time away from the day-to-day activities that drain our energy and/or physical/mental/spiritual resources, no one may deserve this more than the families who live with and love a child with a chronic complex medical condition. For them, there are no breaks in the action, no breathers, relief, reprieves. They live with the constant weight of caring for a child who often can’t care for him or herself…who may be dependent on medical technology to eat, breathe, live…and on their parents to keep everything working the way it needs to in order to sustain their life. But what does this constant round-the-clock care of a medically fragile child do to these parents and the rest of the family?

In a focus group I recently moderated with Moms of a child/children who were medically fragile or who were living with a chronic complex condition, these Moms identified many issues which hamper their ability to be the caregivers they need and/or want to be for their medically fragile child. Given what they deal with, both inside and outside of the hospital, it’s no wonder these Moms would need a respite from all they juggle for their medically fragile child, as well as the rest of the family. Some of their biggest caregiving issues include:

- Difficulties navigating the insurance/available health benefit/reimbursement “jungle”
- Lack of access to and/or no insurance coverage for needed benefits like respite care, certain therapies, some medications and medical supplies, etc.
- Problems getting the needed home modifications done required to accommodate the healthcare/technology needs of their medically fragile child
- Dealing with physicians within/across select health systems who are untrained in their child’s specific healthcare needs (e.g., during ER visits, for example)
- Physicians not being supportive of their care plan goals for their child, resulting in denial of some surgeries/interventions desired by the parents, but vetoed by the physician and/or health care team
- Not being made aware of and/or offered interventions that would have helped their child in some way
- Not being able to have a child/other children in the family visit with the medically fragile child when hospitalized (due to H1N1 flu season, for example)

re·spite

noun\ ˌres-pət  also ri-ˈspit, British usually ˈres-,pīt\  
: a short period of time when you are able to stop doing something that is difficult or unpleasant or when something difficult or unpleasant stops or is delayed  

-Webster’s Dictionary
Dealing with all the “paperwork,” including insurance reimbursement, orders for services/meds/tests and scheduling appointments with multiple specialists and therapists (often potentially across multiple health systems)

These Moms are very clear that caring for a child with a chronic complex condition has an impact on the entire family. Perhaps the most telltale sign of how this caregiving has affected these Moms was in their response to the question of how and what they do to care for themselves through all this. The room went silent and they simply said, “We don’t.” They then went on to state that while they wouldn’t change their life or wouldn’t wish their child not be here, they certainly don’t have the life that they used to. They’re exhausted most days, they don’t shop, they don’t do their nails or make themselves up like they used to. Some days, they don’t even get out of the house or get a shower. Their lives get small and closed-in, sometimes for many days at a time, depending on the child’s condition. Isolation was a recurring theme for some of these Moms when living with a medically complex child.

These Moms also cited many ways that the other children in the family (and/or the entire family) are impacted when they have a sibling who requires constant/a significant amount of at-home medical care. The family can’t/doesn’t go out as often or do things together as a family. Siblings’ playmates/friends may not be able to come into the house on some days, depending on how immune-compromised the medically fragile child may be. Family vacations can be difficult to impossible, depending on the trip/outing, often requiring the family to “divide and conquer,” with one parent taking the healthy kids on the trip while the other (often Mom) staying home with the medically fragile child. The siblings may also become more versed in medical terminology and jargon than any child their age should and may also be able to operate and help with the medically fragile child’s medical interventions or health issues more than they should. One Mom shared that her 15-year-old stepdaughter can change a feeding tube and also knows what to do when her brother has a seizure. However, the Mom also expressed concern because a 15-year-old shouldn’t have to worry about these things with her brother. This Mom finds it difficult to watch her stepdaughter grow up too quickly in things that are not her stepdaughter’s responsibility or worry.

And what happens when Mom gets sick and can’t care for the child with a chronic or medically fragile condition? Or another child gets sick or requires a hospitalization for something minor? Of if Mom has to work, as she is the primary wage earner for the household? What then? Does Dad stay home from work? If yes, does it endanger his job (as in some households, he may be the only provider and carrier of the health insurance for the family)? Some families may have an in-home nursing benefit, others not, but an illness on Mom’s part, for example, and the need for 24/7 care of the child could burn through any insurance benefits the child has quickly. And if no skilled nursing benefits for home care, then what? It’s easy to see how complicated this all is for these families of medically fragile children.

The Need for and Barriers to Respite

It’s also no surprise, then, that some of these children often end up presenting at the hospital (maybe through an ER visit) because the family needs a break from the burden of care. Healthcare colleagues tell me of numerous hospital admits that are very likely “respite” admittances for the family, but not necessarily for the medically fragile child. That is, situations where the child requires medical care, but not an in-patient sub-acute or acute hospital admittance. The child does not need to be in the hospital for his own benefit/care, but instead, the family needs him/her to be there, even for a day or two, until they can get some much needed rest (or a “respite”) or just a weekend away as a family. With no respite insurance benefit, or not enough of a skilled nursing benefit, or no appropriate place to take the child for a respite visit, they are left with nowhere else to turn but to take the child to the hospital and pray they can make a case that his/her symptoms require the child be admitted for as long a respite stay as needed. As good palliative physicians caring for the entire family, the child is often admitted, but changes in the insurance landscape may make this more difficult over time. Then what?

Several factors presumably help to perpetuate this vicious cycle of parents taking their children to the hospital for what is very likely respite care, including:
• Respite not being a covered insurance benefit for their child/the family (but in-patient admits are)
• No funds to pay for this type of care for their child if it has to be private pay
• Limited, if any, community resources to help fund this type of care
• Limited and/or no specifically designated hospital beds specifically for respite care
• A shortage of skilled care nurses trained in pediatrics and/or on the medical technologies (e.g., trachs and vents) that some of these children may be dependent on
• Bad experiences with some skilled nursing staff for their medically fragile child in the home (Note: Many of the Moms from our focus group claimed that they have gone through numerous at-home nurses to get to ones that they feel are competent and whom they can trust leaving their child in their care.)
• A lack of parental trust in leaving their child with anyone (even trained medical professionals) at-home if they were to go away for a few days
• The absence of any facilities, besides the hospital, that offer and are staffed by trained medical professionals who can adequately care for these medically fragile children

A White Paper entitled, “A Successful Model for the Provision of Care to Medically-Complex and Technology-dependent Children,” authored by Dr. David Steinhorn, Dr. Michael Msall, and Dr. Mary Keen, and reprinted elsewhere in this issue, also cites the following obstacles to caring for children with special health needs:

• Limited funding for the wide range of services required by medically complex children
• The time commitment required by families to do the necessary care coordination for children who are often cared for by multiple specialists across multiple healthcare systems
• Enough adequately trained parents/caregivers who are able to operate and oversee any needed medical technology and problem-solve to correct it when it malfunctions, as well as administer the correct and appropriate amount of medications needed with these types of interventions 24/7
• Caregiver fatigue or “burnout” and isolation
• Financial hardships (as one parent may have to stop working to care for the medically complex child)

Starting Thoughts on Some Potential Respite Solutions

So when a family has reached the end of their proverbial rope in terms of needing respite care for whatever reason—a family issue, a medical emergency, an out-of-town funeral, a family vacation, they're just exhausted—but is not able to access it for their child, what are they to do? The current continuum of care seems to have missed respite care as part of the continuum for many, many families.

There's no doubt that further lobbying is needed to get a respite benefit added to more of the health insurance plans and waivers for these children, regardless of whether the child is dependent on medical technology, or not. One of the Moms in our focus group has a son who would be classified as medically complex, but who is not vent-dependent, and as such, she does not get a respite care benefit for him, despite his multiple chronic complex conditions. She is his 24/7 Mom, Nurse, Care Coordinator, Case Manager, Billing Administrator, Cheerleader, and so much more. Her days and nights are filled with caring for her son whom she loves to bits, but it takes its toll on her and the rest of the family. She acknowledges that respite care would most certainly help her, and the rest of the family, get that breathing space they sometimes need when the burden gets too great or when they have something they'd like the rest of the family to be able to do together.

In addition to lobbying, some cities are seeing efforts emerging from outside the healthcare system whereby individuals and/or community groups are spearheading the creation of pediatric facilities which would offer respite care for these medically fragile children and their families. These have/are taking on several different business model formats, including:

• A stand-alone pediatric palliative care facility like George Mark House which offers hospice as
well as respite care

- A pediatric transitional care facility which offers transitional and respite care as in the Almost Home Kids facilities in Illinois (Editor's note: see the article on this program elsewhere in this issue.)
- Ryan’s House, a pediatric facility which provides respite and palliative/hospice care in partnership with a care partner, Hospice of the Valley

While there may be other models out there, the good news for the families of children with chronic complex conditions is that this gap in their child’s care continuum has been identified and is being filled by a (very) few pediatric facilities around the country. Beyond the nation’s children’s hospitals, there are currently at least two pediatric-specific palliative care facilities in the US which offer pediatric respite care, including:

- George Mark House, Oakland, CA (http://www.georgemark.org)
- Ryan’s House, Phoenix, AZ (http://ryanhouse.org)

Importantly, there are several more in various stages of visioning and/or development (or on hold at the present time), including:

- Children’s Lighthouse of Minnesota (currently being renamed as Crescent Cove) in Minneapolis, MN (http://www.childrenslighthousemn.org/)
- Ladybug House in Seattle, WA (http://www.ladybughouse.org)
- Sarah’s House, Cincinnati, OH (http://www.sarahhousecincy.org/)
- here4U House, Southeast Michigan (http://www.here4U.net)

The founders of Connor’s House in New Jersey actually have gone so far as to get a Bill written (A3558) and approved through both the Assembly and Senate which was signed into law by Governor Christie in 2014. This bill establishes licensure requirements for that state for a pediatric respite care program. This may be the first specific bill of its kind to lobby for a specific pediatric respite care facility licensure across the US.

Beyond the obvious benefit to the family (i.e., they all get a needed break), the Steinhorn et al. White Paper lists these other benefits to providing respite care to these children in a pediatric-specific facility:

- It fills a need for a reliable and trusted care provider when needed by the family for emergencies, for family vacations so the other siblings can get away, for when there are family issues like other hospitalizations, funerals, school functions, etc.
- It facilitates the family learning to trust and develop relationships with providers and others outside of the immediate family, yet still in their community
- It provides a more home-like environment in which to care for the child vs. a more institutional hospital
- It is a cost-effective alternative to having the children admitted to an acute or sub-acute care setting for respite
- It also frees up potentially needed hospital beds for children with more serious illnesses/conditions than respite care
- It also provides the medically complex child with a change of environment and some independence away from mom and dad (under the watchful eye of skilled nursing staff) so that he/she can also get some relief from the same setting and caregiver(s) day-in and day-out

Lengths of respite stays at these facilities do and will vary from a single overnight stay to up to two weeks, when needed by the family, and as the beds are available. Additionally, whether the respite stay is billable, or something that has to be funded by philanthropic donations, will also vary contingent on each child’s insurance coverage. So while there are still some issues to be worked out, these transitional care/respite/hospice homes for children do seem to be filling a needed gap in the continuum of care for these kids with chronic complex conditions, and their families in a cost-effective, “medically-strong,” and
compassionate way, and therefore presumably warrant our support. With a changing legislative and insurance landscape, a need to contain medical costs and penalties for hospital re-admits within specific periods of time, the time to think about creating quality pediatric facilities or programs which can help to offer respite may never have been greater. I think the case for the need for respite is clear; now we just need to get creative about how we solve this need for the families of children with complex chronic conditions or who are medically fragile.

How You Can Help

One way is by “Innovation through Collaboration.” If your community is one of those listed as having a pediatric respite program (or transitional care or hospice house which would offer respite) in a visioning and/or developmental stage, reach out to see how you can help them move it forward. And if your city isn’t one that is looking at developing one of these, then maybe gather a group of like-minded healthcare colleagues and some parent/family advisors and start the conversation. A business case done for the George Mark House recently by the Haas Business School goes so far as to suggest that insurers should consider partnering with George Mark House to “roll out this economically advantageous model of care” throughout California. The report speaks to the great need for pediatric palliative care facilities (of which respite would be a part); unfortunately, the resources (i.e., facilities/programs) are few.

So as pediatric palliative care gains momentum in the US, houses like these, while already important, will presumably become more relevant as viable, reliable, medically-competent, and compassionate and caring alternatives to acute and sub-acute care facilities when these kids and/or their families need (to quote the McDonald’s jingle), “a break today.”

Author’s Note: If anyone is interested in joining a group of individuals who want to collaboratively work together to form a consortium of pediatric transitional care, respite care, and/or hospice houses (at various visioning/developmental stages) from across the US, please email me, Ann Fitzsimons, at ann@here4U.net and we’ll add you to our email distribution list as we try to get this consortium off the ground. There are multiple groups wanting to start efforts like this and we can all learn from one another to help our individual respective efforts.

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WHITE PAPER:
A SUCCESSFUL MODEL FOR THE PROVISION OF CARE TO MEDICALLY COMPLEX AND TECHNOLOGY-DEPENDENT CHILDREN

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Introduction & Summary

Children with complex medical conditions or those dependent on medical technology have specialized healthcare needs. These needs are difficult to provide with the current system of acute care hospitals and community-based healthcare providers. As a result, these children and their families are often stressed and isolated, and the children are at risk of re-hospitalization.

The model of care developed and practiced at Almost Home Kids for the past ten years represents a successful solution for 1) transitional care for a child with complex health care needs, 2) family training in complex medical technologies, and 3) periodic care for children and the establishment of systems of caring and competence that promote the safety, quality assurance as well as child and family well-being. Almost Home Kids provides a cost effective solution to a difficult and growing need. Almost Home Kids can easily be replicated to care for the most fragile children among us.

Who are Medically Complex and Technology Dependent Children?

The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) define children with special health care needs (CSHCN) as:

“…those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” 1, 2

While this definition is very broad, it reflects the presence of a group of children with health care needs that differ from conventional pediatric health care.

Across the nation, there are an estimated 10.2 million children with special health care needs. Advances in modern medicine save more infants and children with life threatening illnesses, premature births and major trauma. A number of these surviving children are left with complex medical conditions that require medical technology and skilled nursing support.

Technology-dependent children “use some form of medical technology, including medications and devices. If the technology were to fail or its use be discontinued, they would likely suffer a sufficiently adverse health consequence that hospitalization would be required” or death would occur.

While it is difficult to find reliable data regarding the incidence of technology-dependence, a study by the Federal Office of Technology estimated that there are at least 50,000 children nationally who are technology dependent or about 1 per 1,000 population. 3 In addition, 85% of all children with medically complex conditions have more than one life-altering medical condition and 28% have multiple difficulties. 4 Although children with special health care needs represent only 14% of the general pediatric population, they account for more than 40% of the medical expenditures for children overall. 5

Children’s Project on Palliative/Hospice Services
ChiPPS serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization.
Learn more at www.nhpco.org/pediatrics
In the State of Illinois there are an estimated 6,000 technology-dependent children out of an estimated 451,000 children with special health care needs. Of these patients, 23% have conditions that “usually or always” affect their activities, and therefore affect the activities of their parents and siblings.

**Who Cares for the Medically Complex Child?**

The life of a medically fragile child does not proceed along traditional pathways. It is usually assumed that a child will fairly rapidly gain competence, will become an independent individual, and not require continual support and assistance.

Generally, by the time they enter school they will achieve independence and ultimately contribute in meaningful ways to society. For children with complex medical needs, this assumption may not hold true. They will not be able to care for themselves.

The parents and families of children who are medically complex or technology dependent face formidable ongoing challenges. For example, in one calendar year, 26% of patients discharged from a major children’s hospital required some form of technological assistance. While 91% were discharged to home, 15% required home nursing care or other services following discharge. Additionally, 24% of families with medically complex children report that family members had to cut back or stop working due the child’s medical needs.

Meanwhile, there is a trend towards sicker patients with more complex medical conditions being treated and discharged from all pediatric hospitals throughout North America.

The challenge for children with special health needs and their families remains invisible to most of society. The families are often isolated, fatigued by lack of sleep and burdened with worry and financial difficulties.

**What are the Obstacles to Caring for Children with Special Health Needs?**

On any given day in Chicago there are several dozen hospitalized children who are medically ready to go home but cannot due to various obstacles such as the shortage of nurses, limited family resources, and limited alternatives to hospital care.

One significant obstacle is limited funding for the wide range of services required by medically complex children including home modifications, equipment and supplies, technological support, transportation, and nursing and therapy services. In addition, care coordination for these children requires time commitment, skills across systems of care and communication with multiple specialties.

Another obstacle to getting medically complex children out of the hospital safely and home is the teaching and family preparation necessary to accomplish this task. Respiratory therapists, for instance are not provided for outpatient and home management of these children. Transitional care refers to the period of time following stabilization of a child’s medical condition and their going home. Typically, patients are medically stable during the transitional period and the primary focus is on family teaching, equipping the home to care for a medically complex child, and a variety of rehabilitation or developmental goals for the child.

Many children who are medically complex and especially those who are technology-dependent require care that entails specialized training. Parents and other family members must learn not only how to administer the correct and appropriate amount of medication at the appropriate times, but also to operate ventilators, place and replace various tubes and medical devices, and provide monitoring and oversight for their child 24 hours a day and 7 days a week. Weeks of training may be necessary for family “caregivers” to achieve the necessary competence for safe discharge home. While hospitals do provide some training, it is often insufficient for the complexity of the technology involved. Unfortunately, the
training is usually on equipment that is different than what parents will use at home.

Once families acquire the skills and resources to care for their child with special health care needs at home, they are often faced with months and years of isolation, interrupted sleep or sleepless nights. In two-parent families, one parent generally stays home full time. However, this can create a financial hardship. Other children may feel neglected when a sibling requires continual one-on-one care. Single parent families may be subjected to even more difficulties. Caregiver fatigue or “burnout” is a well-recognized phenomenon in such circumstances. The falloff in performing these difficult duties can be remedied by a periodic sabbatical that includes retraining and the opportunity for independent medical review of equipment and protocols. Regularly scheduled visits can even reduce the risk of “burn-out” and the re-hospitalization that may arise. In addition, because there are serious gaps in human power, management and skills across multiple systems, there is a lack of sustainable commitments to families over time.

**Almost Home Kids – Meeting the Patient's and Family's Needs**

Almost Home Kids, formerly known as CoACH Care Center, was a concept of two mothers of medically fragile children who recognized the need for a community-based program to assist in the care of technology-dependent medically fragile children. Originally, CoACH Care Center was a home-away-from-home providing transition and periodic care.

The Almost Home Kids model has a demonstrated ability to provide the medical care that medically-complex children need, as well as the teaching and preparation that families need to feel comfortable taking their child home. Providing this training in an intermediate care facility such as Almost Home Kids is a better use of resources and facilities and can reassure parents that they can care for their child at home without having the resources of a hospital constantly present. The home-like environment of Almost Home Kids is more child-friendly and developmentally appropriate than a prolonged stay in an acute care hospital. Involvement of the local community members in the Almost Home Kids model further attests to the importance of each community taking responsibility for the care of its children rather than relegating them to distant, impersonal institutions.

The care provided at Almost Home Kids does not duplicate that provided in a children’s hospital. Rather, Almost Home Kids serves those children who no longer require hospital care but cannot go home yet due to obstacles to home care.

Almost Home Kids has since developed relationships with all of the pediatric medical centers in the Chicago region and cares for children from across the state. Almost Home Kids has a 10–year track record of providing high quality care to medically complex children and their families.

As a single, freestanding facility in suburban Naperville, IL, Almost Home Kids is just that – almost home. Today, Almost Home Kids can house a total of 10 children. It is situated on a wooded lot where siblings can play and mothers and fathers learn to care for their medically fragile children. This home-away-from-home provides these families the comfort and reassurance that their children are cared for in a medically strong and loving environment.

The burden of care giving 24/7 can have negative consequences not only for the family but for the patient as well. The need for a reliable alternate care provider like Almost Home Kids is important for families, siblings, and for the affected child themselves to develop relationships and trust outside the nuclear family. Almost Home Kids provides the opportunity for re-education, equipment maintenance and upgrade, and independent review of medicine and protocols. In addition, family emergencies, medical needs of parents of siblings or even the need to give the other siblings a vacation from their daily routines may make such alternate care indispensable.

**Almost Home Kids – A Cost Effective Solution that Works Now**
Almost Home Kids is a cost effective solution to a difficult and growing problem. The cost of care at Almost Home Kids is substantially less than conventional hospital-based care. Daily costs at Almost Home Kids are about one-third of the cost of acute hospital care. In 2008, the Almost Home Kids approach to care saved the State of Illinois and the federal government approximately $5 million.

Almost Home Kids is the only facility in the Chicago area that is designed to provide for transitional and periodic care. Unfortunately, the current site has a limited number of beds and staff and cannot meet the needs of all children and families who might benefit. Unfortunately, it is not readily accessible to many families in the Chicago-land area. If all 10 children at Almost Home Kids were re-admitted to a pediatric ICU for 2 days per week and for eight weeks per year for medical furlough, the additional cost would be an additional $3 million.

Fortunately, the Almost Home Kids can be replicated in additional sites throughout the region with a relatively small investment compared to an acute care hospital. In a preliminary analysis and assuming only 10% of patient days in six acute care hospitals in Chicago might be suitably cared for in a home with lower intensity care, this approach would save over $23 million in combined neonatal and pediatric ICU costs.

A Vision for the Future – Almost Home Kids in Every Community

Almost Home Kids has dedicated itself to developing a successful model of care that provides expert medical care, excellent family teaching, and cost-effective, community-based care. It has demonstrated the ability to work with a diverse group of referring hospitals and governmental agencies. Almost Home Kids is poised to be a leader in the field of care for medically-complex children and to share its expertise with other institutions in order to increase the capabilities and capacity of the region to care for such children. To this end, we envision other facilities throughout the region adopting the Almost Home Kids concept in providing care for medically complex children. Central to this evolution is assuring that children will receive the same high quality care regardless of where they live. Additionally, it is our goal to see children cared for as close to their homes as possible with strong local community support and commitment to each center’s success. Almost Home Kids must remain independent of the existing medical institutions and draw from them to optimally reach its vision.

Chicagoland has thousands of children with special health-care needs including technology-dependent children who are best served by care in a home setting. Currently, the Almost Home Kids model provides a highly successful program for transitional and sabbatical care. It is a model that can be replicated in other settings with modest outlay of capital, providing care that cannot currently be delivered appropriately in acute care hospitals. The model can be a rallying cry for each community as it shares in the responsibility of caring for its own children. What each community does in caring for the frailest and most needy of its residents is a reflection of how highly it values human life.

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5 – Newacheck, PW & Kim, SE. A national profile of health care utilization and expenditures for

This White Paper is reprinted here by permission of *Almost Home Kids*, who would like you to know that this is an early version of the document; a new version is currently in preparation. For additional information on these documents and on the *Almost Home Kids* program, please contact Judith A. McLean, Director of Marketing & Communications for *Almost Home Kids* at jmclean@AlmostHomeKids.org
As a pharmacist, the first thing I think of when I hear the term “medically complex patient” is “extensive medication list.” Obviously medically complex children have complex medication regimens; but, what are the risks associated with polypharmacy?

In simple terms, polypharmacy is the use of multiple medications (typically considered five or more regular medications). Most pediatric hospice patients meet that qualification, especially medically complex or fragile patients. With increased medications comes increased risk of adverse reactions and drug interactions. Some medications may work synergistically, allowing for lower doses and favorable effects (e.g., opioids and adjuvant agents for pain management). But, some interactions may decrease effectiveness of medications or increase risk of adverse effects. Additionally, a prescribing cascade may develop where medications are added to treat side effects of other medications (e.g., an antihypertensive agent is started in a patient receiving a corticosteroid). Obviously, medications cost money, therefore, the more medications a patient is receiving the higher the medication costs. Additionally, expenses may be increased if laboratory monitoring is necessary, dose adjustments are needed due to interactions, or medication side effects must be managed.

Children with complex medical conditions often have many healthcare practitioners involved in their care. Unlike the hospice interdisciplinary team, these practitioners may be from different disciplines, offices, or organizations and may not collaborate with one another. These specialists often prescribe medications for specific problems in their field of expertise along single disease guidelines. They may be unaware of the medications started by other physicians or the reasoning for initiating new medications, which increases the risk of drug interactions. Additionally, patients may be discharged from the hospital on medications that may not be necessary to continue (e.g., proton pump inhibitor started for ulcer prophylaxis while inpatient).

Polypharmacy may be associated with decreased quality of life. Caregivers often have difficulty administering a large number of medications and managing complex medication schedules. A large pill burden leads to decreased compliance, increased risk of hospitalization, increased risk of medication errors, and increased costs.

With all of the possible risks associated with polypharmacy, what steps can be taken to manage medication profiles and decrease risks?

Although polypharmacy can be necessary, all medications should be evaluated for appropriateness on a regular basis. As diseases progress, patients may not be able to effectively use certain medications, such as inhalers. Other medications may have been appropriate to use earlier in the disease course, but may have limited, if any, benefit in late-stage disease.

Involving a pharmacist on your interdisciplinary team. Pharmacists can perform medication therapy management (MTM) reviews evaluating:

- Appropriateness of medications, doses, and routes
- Therapeutic response to medication
- Risk of drug interactions
- Options to minimize risks
- Potential adverse drug reactions
• Laboratory monitoring (including serum drug levels)
• Duplication of therapy
• Opportunities for de-prescribing (especially at end-of-life)

De-prescribing is the process of tapering, withdrawing, or discontinuing medications to reduce polypharmacy, side effects, and/or ineffective use of medications. Medications should be re-evaluated regularly to ensure they are still indicated and effective. Assess risks and benefits when considering whether to continue a medication. When discontinuing medications, drugs without a clear indication should be considered first. Next, evaluate drugs with a current indication but that may, given patient circumstances, provide limited or no benefit. Consider patient prognosis and onset of effect. Benefit from some medications may not be seen for weeks; therefore, these particular medications may not be appropriate in a patient with a prognosis of weeks to days. Finally, certain drugs may have benefits, but an unfavorable risk profile and should be substituted for others with a more favorable risk versus benefit ratio. Medications must be discontinued carefully to prevent worsening of disease or withdrawal effects. Some drugs may need to be tapered (to prevent withdrawal symptoms), while others can be safely stopped abruptly. Limited evidence is available regarding the best ways to stop medications, especially in children, although in clinical practice many follow a sequential, step-wise approach to discontinuing drugs, evaluating patient-specific factors and response throughout the process.

When evaluating appropriateness of medications, consider these key elements:

1. Indication
2. Effectiveness
3. Correct dose for patient (including age and weight) and condition
4. Appropriate & practical directions
5. Clinically significant drug-drug or drug-disease interactions
6. Unnecessary duplication of therapy
7. Acceptable duration
8. Least expensive alternative compared to others of equal usefulness
9. Appropriate with patient’s goals of care

Prioritize medications. Help caregivers determine which symptoms are the most disturbing and if medications are providing benefit and contributing to quality of life. Avoid situations where the caregiver spends so much time and energy attempting to get the patient to take their multivitamin that the caregiver is stressed and the patient is too tired to take their pain medication. In those situations, we can also evaluate other routes of administration to simplify the process as much as possible. Conversely, clinicians must be alert to medications that may be contributing to problematic symptoms, causing adverse effects, or simply no longer have a beneficial role at end of life.

Reduce complexity of medication schedules. Decrease pill burden by choosing medications that treat a variety of symptoms (e.g., opioids for pain or dyspnea) and/or are given less frequently (e.g., once daily rather than three times a day). Adjust administration times so compatible medications are given together, decreasing the frequency of medication administration. Avoid giving medications during the night if possible. Also consider medications available in numerous routes of administration (e.g., lorazepam can be given PO, SL, PR, IN, IV, IM, or SQ).

Evaluate doses regularly. As children grow, doses may need to be increased (or conversely, if the patient has significant weight loss, the dose may need to be decreased). When new medications are added to a patient’s regimen, dose adjustments may be necessary due to drug-drug interactions. As doses change, ensure the dose is measurable in the available dosage forms. Consider other medications that provide similar benefit that may be available in easier to administer forms, provide less frequent dosing, or are more cost effective.

Clinician awareness of pharmacologic profiles and potential drug interactions among medications commonly used in hospice and palliative care will aid in using medications safely and effectively.
Successfully managing complex medication regimens depends on using a careful, stepwise process that merges key principles of pharmacologic care with the clinical reality, social situation, and goals of care for the patient. Ongoing monitoring for toxicity and effectiveness of drug therapy is critical to providing quality care and improving outcomes. Proactively evaluating medications can improve quality of life, minimize side effects, simplify dosage schedules, decrease the risk of interactions, and minimize costs.2,7-9

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When asked what they do in order to minimize the effects of work-related stress, healthcare providers sometimes mention a need for catharsis, an emotional release. When it comes to compassion fatigue (an intense stress of care giving that can lead to burnout), there is a need to “let it go,” as the recently popularized Disney song suggests. Experts recommend participating in social and physical activities for the purpose of self-care and focusing on something external, such as the breath. It has also been suggested that healthcare workers manage stress through releasing their feelings either by talking to others or writing in diaries.

Although people have been writing in diaries for years, the first well-known research study was conducted in the area in the 1980s. James Pennebaker and colleagues measured participants’ stress hormones and antibodies reacting to infection. He found that those who wrote about traumatic experiences in journals improved immune functioning, decreased hospital visits, and less stress and depression. Since then, several studies have been conducted, supporting the use of diaries as therapeutic tools.

As a 16-year-old volunteer at a small facility that provided palliative care to children, I found journaling to be the most effective way to manage my stress. Although volunteering was the most intrinsically rewarding part of my life, seeing other children in less fortunate situations was stressful at times. Since the names and ages of children were to be kept confidential, my diary allowed me to express everything I wanted to about them without having to worry about holding back private information or embarrassing feelings. As a sometimes insecure teenager, I was grateful for the nonjudgmental container my diary provided.

A few years later, I gave 16 patients and their siblings (aged 9-18) diaries to collect data for my Ph.D. dissertation entitled “Perceptions of life and death in pediatric palliative care: Family communication about the end of life.” The diaries contained two prompts inside the front cover: (1) What emotions did you feel today?; and (2) What is it like to be a young person who is unwell (or his/her sibling)? This project served as a platform for children to express their feelings and express their opinion to a researcher who assured them that their information would be used to help others and their names would not be used. Patients expressed their frustrations over receiving special treatment as patients, wanting to spend as much time with family as possible, feeling judged, being understood, and their limited mortality. Although their diaries were not used for clinical purposes, some reported therapeutic benefits of participating in my research.

As a therapeutic tool, “Digging Deep: A Journal for Young People Facing Health Challenges” is a journal for children living with chronic or life-threatening diseases. It was recently published by Resonance House, a subsidiary of the Silicon Valley Community Foundation. The journal provides themes with prompts to get children started and indirect advice such as, “Missing Out: When we feel we’re missing out, it’s a great opportunity to try something new. Write a paragraph about what you are missing out on, and then make a list of activities, hobbies, and experiences that you could enjoy.” It is my hope that someday, an audio version of this tool will be made available for children who cannot write (as is often the case in the PPC population).
Since a non-judgmental, open approach is recommended for consulting with patients and siblings, diaries such as “Digging Deep” might be a good way for children to manage stress and assess which of their concerns should be passed on to healthcare providers.
Digging Deep—A Journal for Young People Facing Health Challenges (Rose Offner & Sheri Brisson; Resonance House, 2013) provides kids and adolescents an opportunity to express their personal feelings about their illness and how it has affected them emotionally. The co-authors’ intent is to provide young readers with serious and chronic conditions a chance to build their own emotional skill set to better cope with their diagnoses and treatments.

Brisson was hospitalized, for eye surgeries, several times during childhood and was diagnosed and treated for a brain tumor at the age of 24. In addition, her biography states that her passion is doing creative art with children in hospitals and at special camps. Offner has authored a series of journals for other populations. The authors suggest using the journal with chronically ill children between the ages of 10 and 16 to proactively manage the emotional issues that their illnesses have wrought, and to provide a chance to improve their own physical health (Delamare, 2014).

There are strengths and potential useful applications to Digging Deep, and it offers a contribution to the field of working with seriously ill children. The pages are engaging with bright, interesting art serving as the background. Although the artwork appears appropriate for a younger audience than the 10-16 year olds that the journal targets, it is cheerful and bright. The journal topics reflect common issues that are often expressed as concerns by some young people with serious illness. The Afterword includes a paragraph for professionals in which it is suggested that topics in the book may be utilized when working with a young person with a serious illness.

Journaling is defined as keeping a diary that explores the thoughts and feelings surrounding the events of one’s life including personal reflections, accounts of events, and descriptions of experiences by an individual (Chabon & Lee-Wilkerson, 2006). A review of the literature on journaling does not produce any studies that examine the use of this medium with children or adolescents (from this point referred to as “children”) with chronic illness, and the research with adults is limited. Both the authors and Jennifer Delamare, a marketing consultant for the publisher of the journal, suggest that using the journal will have significant benefit to children. However, there is no research that supports that assumption. Delamare, in a review article written for the publishing company of Digging Deep, suggests that direct correlations can be made between experiences of adults with journaling and experiences of children with journaling. Adults have a significantly more mature and developed ability to write about and understand their feelings and experiences related to illness, whereas it is unknown if journaling will benefit children or cause greater trauma as they attempt to understand their feelings without support in doing so.

Thus, working in conjunction with a trained professional may be the most appropriate and beneficial use of the journal. Giving a child or adolescent the entire journal and allowing them to work on topics alone could be very difficult for a child. However, working on the topics with a professional could open the door for discussion and result in benefit to the child. Topics may be introduced by a trusted professional, and either discussed at that time or written about and discussed later. In that manner of use, discussion and support may take place around the issues and concerns that children experience related to the very direct topics in the journal. For example, the page entitled Talking Too Loud asks what the child thinks “people are not telling you that you want to know.” Perhaps the child did not have that concern, but does now that he read that question. Or, she may be overwhelmingly upset by what people are not telling her. A concern is that, without the support of a trained professional, children may be overwhelmed by feelings that are
associated with the poignant topics in the journal. Although the topics may warrant exploration, children may not have the experience or understanding to handle their feelings alone.

Journal writing in K-12 schools has been a common practice for many years. Educators have had the opportunity to observe the evolution of journaling during that time, as well as developing a body of research related to children and journaling. The recommendation is to allow children to write about topics of their choosing. Teachers may offer suggested topics for when children are “stuck” and cannot think of their own topic, but do not force children to write on a specific topic. Again, the exposure to topics that have been associated with difficult situations for children, may prove to cause renewed stress for the child. Journaling only about one’s negative feelings without incorporating thoughts or plans may actually cause more stress (Ullrich & Lutgendorf, 2002).

Educators require that children share their journals with them, as a means of gaining knowledge about what the child understands, if the child has situations with which they need adult support, or what the child’s needs are, in order to better help and support the child. If the child wants to keep a particular journal entry private, they are instructed to fold the page in half and write “private” on the outside. The teacher pledges that he/she will honor that request. The teacher does tell students, however, that they will have to act on any open entry that suggests the child may be at risk of harm. Similarly, if a child had, for example, suicidal thoughts due to an issue brought up in the journal, it would be imperative that an adult had awareness and could help.

Journaling may not be the best option for seriously children due to a variety of reasons. For example, children with chronic illness and concurrent diagnoses of autism spectrum disorders, learning disabilities, or cognitive challenges may not be able to engage in journaling. Similarly, other children who may not be able to benefit from journaling are those with brain tumors, those with cognitive deficits resulting from intrathecal chemotherapy for leukemia, or those with cognitive decline due to sickle cell disease. Fatigue, weakness, and general poor health are side effects of chronic illness in childhood that reduce a young person’s ability to engage in activities like journaling. However, all of these groups of youngsters could benefit from discussions around the topics included in *Digging Deep*, if introduced in discussion by a trusted professional.

I applaud the authors for creating this journal, and will certainly use pages with the young people with serious illness with whom I work. Certain topics will be relevant with certain children. However, I would not provide a child with the entire journal to work through alone. In addition, I look forward to the coming issues for siblings and parents. When used in the proper manner, *Digging Deep* can be an effective tool to help children explore some of the aspects of having a chronic illness.

**References**


READER'S CORNER: ABSTRACT #1 OF 3

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Regoaling: A conceptual model of how parents of children with serious illness change medical care goals

BMC Palliative Care 2014, 13:9  http://www.biomedcentral.com/1472-684X/13/9 (this article is “open access”)

Abstract
Background: Parents of seriously ill children participate in making difficult medical decisions for their child. In some cases, parents face situations where their initial goals, such as curing the condition, may have become exceedingly unlikely. While some parents continue to pursue these goals, others relinquish their initial goals and generate new goals such as maintaining the child’s quality of life. We call this process of transitioning from one set of goals to another regoaling.

Discussion: Regoaling involves factors that either promote or inhibit the regoaling process, including disengagement from goals, reengagement in new goals, positive and negative affect, and hopeful thinking. We examine these factors in the context of parental decision making for a seriously ill child, presenting a dynamic conceptual model of regoaling. This model highlights four research questions that will be empirically tested in an ongoing longitudinal study of medical decision-making among parents of children with serious illness. Additionally, we consider potential clinical implications of regoaling for the practice of pediatric palliative care.

Summary: The psychosocial model of regoaling by parents of children with a serious illness predicts that parents who experience both positive and negative affect and hopeful patterns of thought will be more likely to relinquish one set of goals and pursue a new set of goals. A greater understanding of how parents undergo this transition may enable clinicians to better support them through this difficult process.

Who is the audience for this information? Both home and hospital based providers of care for children with medical complexity will benefit from understanding the process by which goals of care may change and how to support these transitions.

What is special about this article? The authors provide a model for regoaling, and factors involved including barriers and facilitators. The authors emphasize that regoaling is neither always possible nor appropriate. However, those parents for whom regoaling is successful may have an improved outcome. Regoaling involves disengaging from previous goals, reengaging in new goals, positive and negative affect, and hopeful thinking. Disengagement is facilitated if there is a high degree of certainty that the original goal(s) is unattainable and that there is a feasible alternative goal(s). I particularly like the guidance in supporting parental hopeful thinking. Hopeful thinking may help parents adopt new goals. Providers can facilitate this process by prompting parents to think about new hopes and goals, gently suggesting some realistic achievable possibilities, and providing support in achieving the new goals. If understanding the regoaling process can help providers guide parents in decision making on behalf of the child, we should anticipate improved outcomes for the child and the family.

Where and how can I apply this information? For anyone involved in the care of children with medical complexity, it is likely that goals may change over time as the disease/condition changes. Having discussions about goals should be integrated into routine care. As degree of certainty is central to
disengagement, it is necessary for providers to be able to sensitively communicate complicated prognostic information including degree of certainty. This information gives providers tools to guide families when there are discussions about transitions in goals.
READER’S CORNER: ABSTRACT #2 OF 3

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Pediatric Palliative Care for Children with Complex Chronic Medical Conditions
Scott Schwantes, MD, Helen Wells O’Brien, MDiv, MEd, BCC

Abstract
KEYWORDS
Children with complex chronic conditions; Dysautonomia; Neuroirritability; feeding intolerance; Spiritual care

KEY POINTS
- Children with complex chronic conditions and life-threatening conditions benefit from a dynamic pediatric palliative care team to adapt to the child and family’s evolving needs throughout their illness trajectory.
- Children with complex chronic conditions and life-threatening conditions have a subset of distressing symptoms that can be managed through careful diagnosis and treatment.
- Ongoing dialogue with families of children with complex chronic conditions can prepare for anticipated forks in the road throughout the child’s disease trajectory.
- The spiritual and psychosocial care of children with complex chronic conditions and their families takes on special dimensions given the lifelong nature of the child’s life-threatening condition.

Who is the audience for this information? While this is published in a mainstream publication for pediatric providers, this is also appropriate for pediatric palliative care and hospice providers caring for children with medical complexity (CMC). The article is strongly supportive of using the model of palliative care in the management of CMC.

What is special about this article? This is a review article that covers a wide range of topics: “one stop shopping.” Symptom management, nutritional support, decisional support, spiritual and psychosocial assessment and care, and unique aspects of bereavement are reviewed.

Where and how can I apply this information? Providers can utilize the information to better manage the complex symptoms of CMC. This information strongly supports instigators amongst us who are interested in broadening the reach of pediatric palliative care and including it soon after diagnosis of a potentially life-limiting complex condition in a child.
Supportive and palliative care of children with metabolic and neurological diseases
Julie M. Hauer and Joanne Wolfe
Curr Opin Support Palliat Care 2014, 8:296–302

Purpose of review
To review the role of pediatric palliative care (PPC) for children with metabolic and neurological diseases.

Recent findings
There is a growing body of literature in PPC, though it remains limited for children with metabolic and neurological diseases. Evidence indicates the benefit of PPC. Utilization of PPC programs can facilitate communication, ensure that families are better informed, improve certainty with decisions, enhance positive emotions, result in fewer invasive interventions at the end of life, and have an impact on location of death. Barriers to utilization of PPC include concern about taking away hope and uncertainty about prognosis. Challenging areas for children with metabolic and neurological diseases include the identification of distressing symptoms and prognostic uncertainty. This article aims to review literature relevant to this group of children, as well as provide a framework when considering specific palliative care needs.

Summary
PPC for children with metabolic and neurological diseases can lessen a child’s physical discomfort and enhance parental certainty with decision-making. These areas along with other needs throughout the illness trajectory and bereavement are being increasingly met by the growing availability of PPC programs.

Who is the audience for this information? The information provided is useful to inpatient and outpatient providers for children with complex metabolic and neurologic diseases.

What is special about this article? The authors provide compelling data supporting the benefit of early introduction of pediatric palliative care in the treatment of these children with significant prognostic uncertainty. It reminded me of what Betty Davies so eloquently wrote:

“We think that clinicians need to realize that uncertainty is not something to be avoided but rather is an inherent dimension of care. An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it, even when it is not yet appropriate to begin end of life care.”


By helping the family focus on goals of care in the context of prognostic uncertainty during times of stability, attention can center on comfort, optimizing health, and minimizing painful treatments that aren’t consistent with the goals of care. As symptom management is a significant challenge in these frequently nonverbal children, palliative care provides an additional aid to meeting the goals of care. Hope and preparation are supported.

Where and how can I apply this information? There is a great table that is of practical help to health care providers. Markers of high risk for such things as life-threatening events, intractable physical
suffering, intractable gastrointestinal symptoms, central nervous system decline, etc., are reviewed including hopes and benefits vs. potential harms. Some valuable suggested opening statements will help begin the conversation. The strategy of early introduction of pediatric palliative care is appropriate soon after diagnosis of a potentially-life limiting metabolic or neurologic disease.
ITEMS OF INTEREST:
In each issue of our ChiPPS E-Journal, we offer additional items of interest.

1. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL. For upcoming E-Journal issues, we plan to address issues related to: advance care planning tools and their use; a starter kit or "how to" tools for new programs in pediatric palliative/hospice care; another look at concurrent care; and respite care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; Maureen Horgan at horgan.maureen@gmail.com or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

2. READER'S CORNER. Our Reader's Corner columns, like those in this issue, provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

3. A ONE-DAY CONFERENCE ON CHALLENGES IN PEDIATRIC PALLIATIVE CARE will be held at the Holiday Inn Convention Center in Coralville, Iowa on Wednesday, November 19, 2014. The focus on this conference will be on issues in adolescent care. This is the 5th annual conference sponsored by The University of Iowa Children’s Hospital Pediatric Palliative Care Program. Sessions at this conference will address subjects, such as: palliative care across care settings, and fatigue as a distressing symptom in children with life-threatening illness; unique challenges in establishing goals of care in young adults with advanced heart failure; recognizing and responding to moral problems; expressing wishes through creative arts and play-based interventions; and a moderated panel of adolescents with life-threatening illnesses and their families. The program has been developed for nurses, social workers, child life specialists, music therapists, chaplains, physicians, and other ancillary providers caring for pediatric patients with life-limiting conditions. Download the brochure and registration form.

4. 7th CARDIFF INTERNATIONAL CONFERENCE on PEDIATRIC PALLIATIVE CARE is planned for July 8-10, 2015, in Cardiff, Wales, UK. The conference, "Medicine and Compassion: Tool for the Task… Or Dangerous Distraction?,” is sponsored by the International Children's Palliative Care Network (ICPCN) and by Cardiff University. More information is available at www.icpcn.org.

5. PedPalASCNET is the interprofessional and multi-site Canadian Network for Accessible, Sustainable, and Collaborative Research in pediatric palliative and end-of-life care. It continues the pioneering work of PedPalNET and offers links to current research and publications by members of the network, tips and advice on doing research in this field, highlights from current research, and information about the researchers in the network. Contact this network at www.pediatricpalliative.com.

6. A LEXICON OF TERMS IN PEDIATRIC PALLIATIVE CARE (2014). A publication of PedPalASCNET reflects the use of 18 key words in Canada in this field and is available at www.pediatricpalliative.com/publications.

7. THE MONTREAL DECLARATION. At the recent 20th International Conference on Palliative Care in Montreal, Canada, Stephen Lewis noted in his opening plenary presentation that the new draft of the United Nations Sustainable Development Goals for 2015-2030 makes NO mention of palliative/hospice care. Including palliative/hospice care in those Goals does not guarantee that they will be given substantial attention in countries around the globe, but failing even to mention palliative/hospice care among the Goals may mean that they will NOT be given appropriate attention in countries around the world.

Accordingly, one result of the Montreal conference was to develop the "Montreal Declaration," a petition that palliative/hospice care should be included as part of the new United Nations Sustainable
Development Goals. Individuals can read and decide whether or not to sign the Montreal Declaration by going to http://www.palliativecare.ca/ Those who wish to support this initiative can also circulate this petition to colleagues and friends.

8. FAMILY COMPANION DOCUMENT. The UK charity, Together for Short Lives, has recently published its new Family Companion, a document developed to help children with a life-limiting or life-threatening condition and their families get the care and support that they are entitled to. The new document is designed as a companion to The Together for Short Lives Core Care Pathway – a tool for professionals to help them to maintain the best standards and provide a framework and practical guidance for all professionals at key stages of a child’s care journey.

The Family Companion is split into six sections that reflect the six key standards of the Core Care Pathway. The six standards are: The prognosis – sharing significant news; Transfer and liaison between hospital and community services; Multi-disciplinary assessment of a family’s needs; A child and family care plan; An end of life care plan; and Bereavement support. For each stage, The Family Companion looks at implications for families – what it means for them, what to expect, who can help and useful checklists. Families might not want to read the whole document at once, but having the information there to read when they do feel ready, can make facing these difficult issues a little less stressful.

Together for Short Lives has also developed a range of Family Factsheets to be used alongside this Companion, which offer more detailed information about specific topics, e.g., Understanding Siblings’ needs, Children’s Hospice services, and Transport.

The Family Companion can be downloaded for free at http://www.togetherforshortlives.org.uk/companion.

9. PEDIATRIC GRIEF SONG NOW AVAILABLE. Grammy award winning song writer, Joanne Shenandoah, was inspired by what she experienced at a children’s grief camp her daughter was attending after the death of a dear friend. She wrote the song, ‘I Feel Your Love,” to help others heal. Watch the video on YouTube – and consider sharing it with those you are working with and are supporting.

10. CNN ARTICLE HIGHLIGHTS INFANT LOSS. Article provides stories of infant loss and features the work of photographer Todd Hochberg, a pioneer in the field of perinatal bereavement photography.

11. CURESEARCH WEBSITE NOW IN SPANISH. CureSearch for Children’s Cancer has translated the Foundation’s website, www.curesearch.org, in Spanish, making medical content about children’s cancer available to parents and families whose children have cancer. Users will find that the entire site has been translated, while maintaining easy-to-use navigation and simple illustrations that depict medical tests and procedures.

12. “KEEP IT ON” CAMPAIGN. To help hospitals join the campaign, the Physician-Patient Alliance posted an article, ”Keep It On” Campaign: 8 Tips for Ensuring Children are Monitored Safely, on its website. Developed by Physician-Patient Alliance Clinical Nurse Consultant Lynn Razzano, RN, MSN, ONCC, the article offers guidance to nurses and clinicians about how to correctly use pediatric pulse oximetry when monitoring children receiving post-surgical opioids.

13. NEW MOMENTS OF LIFE VIDEO ON CAMP ALOHA. A new video, “Grief through a Child’s Eyes” has been added to the website of the national, awareness campaign Moments of Life: Made Possible by Hospice. Take a journey with courageous young people who participated in Hospice of Savannah’s annual Camp Aloha.

14. CALENDAR OF EVENTS. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed.
Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to pediatrics@nhpco.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the NHPCO/ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.