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Pediatric Palliative Care for Children with Severe Neurological Impairment and Their Families

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Introduction

Up to 40% of patients cared for by pediatric palliative care teams have severe neurologic impairment (SNI). Children with SNI have congenital/chromosomal, central nervous system static or progressive conditions that result in lifelong cognitive disabilities and developmental delay.[1] These children often have complex care coordination and symptom management needs. Many children with SNI receive care from multiple subspecialists at tertiary pediatric hospitals, home nursing care, and developmental services through school or community programs. Palliative care teams can have a large impact through the ways they support these patients and families psychosocially, symptomatically, spiritually, and emotionally.[1]

Case Description

Jennifer was her parents' first child and was born prematurely. Within the first few weeks of life she was diagnosed with a progressive neurometabolic disease hallmarked by developmental regression and early death. She spent the first few months of her life in the

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Neonatal Intensive Care Unit feeding and growing before discharge home with her parents. During Jennifer's NICU stay, doctors talked to her parents about her life-limiting condition and shared the devastating information that her diagnosis meant that she would likely die within the first year of life. Her parents were heartbroken by this news. They coped with their grief by focusing on their faith and maintaining hope that their child would be healthy with minimal developmental delays. Jennifer was discharged to home with hospice supports.

Upon returning home, Jennifer's parents declined their planned hospice visit. They felt that welcoming hospice would mean that they were accepting their child's death. Instead, Jennifer's parents did all they could to provide the care they felt was best for their daughter. They spent hours feeding her slowly by mouth, playing with her on the floor, and suctioning her secretions. They tried to provide all the developmental stimulation they could to help Jennifer to grow and maintain her skills. Her parents visited with her pediatrician and subspecialists infrequently and tried not to focus on the concerns these providers shared about Jennifer's uncoordinated suck and swallow, her increased muscle tone, and her loss of developmental milestones.

At 15-months of age, Jennifer was referred by genetics to outpatient palliative care. On exam, Jennifer was unable to fix and follow objects with her eyes nor move her body on her own. She would grimace and cry when upset, but otherwise seemed comfortable. Her breathing was calm and unlabored, but she coughed and gagged occasionally with secretions. The outpatient palliative care team tried to open discussions with Jennifer's parents about her symptoms, their thoughts on medical technology such as a gastrostomy tube for feeding, and how they were coping as a family. Jennifer's parents shared only that things were going as well as possible and that Jennifer was making progress.

At 2-years of age, Jennifer was admitted to the pediatric intensive care unit (PICU) after developing breathing problems at home. After arriving in the PICU, she was intubated and stabilized. Concerns were raised about whether Jennifer would be able to be extubated because of the severity of her neurologic disease. The inpatient palliative care team was asked to help better understand the family's goals, to support them psychosocially, and to assist with advance care planning. At the time of consultation, the team found Jennifer's parents to be emotionally shaken. Jennifer's parents declined or redirected discussions about how the disease was affecting their daughter and her quality of life. Both parents described how their strong religious faiths guided their treatment decisions and informed their decision to focus on cure despite her life-limiting diagnosis.

As Jennifer's health worsened, she developed periods of severe agitation and apnea. Her parents' goals continued to focus on life-prolongation and giving Jennifer time to recover to the fullest extent possible. After two months in the PICU, her parents and the clinical team decided to move forward with surgical placement of a tracheostomy and gastrostomy tube to ease Jennifer's cares, allow her to receive more developmental therapies, and enable her parents to more easily see her face. After her surgery, Jennifer developed multiple respiratory infections. Her agitation and tone issues worsened necessitating continuous intravenous infusions of medications to keep her as comfortable. She remained hospitalized for another 9 months. Jennifer's agitation was highly concerning for staff at the bedside,

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who worried that Jennifer was suffering without any benefit to her quality of life. Moral distress among staff fueled conflict between the parents and the staff. This conflict resulted in Jennifer's parents feeling an even stronger need to advocate for what they saw as their child's best interest. Ethics was consulted to help the teams process moral distress and achieve consensus about how to best care for Jennifer.

During these months, the palliative care team was able to build a relationship with Jennifer and her family. Her parents slowly felt comfortable sharing some of their joys as parents and the important details about Jennifer that made her unique and special. Her parents shared that she loved music— and the palliative care team consulted with music therapy and provided a music box for Jennifer to listen to at the bedside with her parents. The palliative care team also visited with the hospital chaplain to facilitate a deeper understanding of the parents' perspectives regarding their faith and to build a stronger relationship with Jennifer's family. Together they celebrated many holidays in the hospital. During that time, Jennifer's family was able to carry out many important milestones and family celebrations. Slowly, Jennifer's parents openly discussed some of their own worries and the changes they saw in their daughter as her disease progressed.

Comments

Epidemiology

The majority of pediatric deaths in the United States occur in infants less than 1 year old with congenital or chromosomal conditions. Many of these children have SNI as part of their condition leading to increased fragility and morbidity.[1] Although they make up <1% of the pediatric population, children with SNI account for 14% of the total bed days at pediatric hospitals, and around 50% of PICU admissions.[2,3] Over three-quarters of children with SNI use medical technology to sustain their basic needs. Over half of these children die in the PICU after withdrawal or withholding of life-sustaining interventions.[3,4] Prognostic uncertainty and limited empirical evidence to guide treatment decisions heighten the need to understand parents' values and goals for how best to care for the child.[1,5–7]

Pain and Non-Pain Symptoms

Increasingly it is recognized that children with SNI have regular and severe symptoms that require multimodal treatment.[8] Up to 40% of children with SNI that experience pain are thought to have pain symptoms on a daily basis.[9] Many of these children have pain from musculoskeletal issues including hypertonicity and muscle spasm. Commonly, children with SNI also have gastrointestinal issues including constipation, diarrhea, and dysmotility. These issues can result in visceral hyperalgesia, when pain fibers from the gastrointestinal tract are constantly signaling painful stimuli and triggering pain episodes.[8] Similarly, some children with SNI have disrupted areas of the brain that help modulate and dampen pain signals from the rest of the body. Pain symptoms are complicated by frequent non-pain symptoms including sleep disturbances, seizures, and breathing difficulty.[1] Symptoms can overlap and layer upon one another to make symptoms more pronounced. Children with SNI are at risk for a cascade of symptoms; for example, gastrointestinal issues may lead to pain symptoms, which may exacerbate issues with sleep and muscle tone.

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Assessing symptoms in children with SNI is challenging. Many scales that assess pain in children rely on behavioral cues like facial expression, movements, or crying. Children with SNI often have underlying conditions that influence their ability to vocalize, move, or grimace. Increasingly there are tools designed for use with children with SNI. The Individualized Numeric Rating Scale can help parents to relay the signs and symptoms they see most commonly in their child so that other caregivers can similarly understand the child's unique behaviors and needs.[10] Typically, an approach to symptom management for patients with SNI should aim to 1) exclude treatable causes for pain and non-pain symptoms,[11] 2) limit ineffective testing, and 3) focus on non-pharmacologic and pharmacologic symptom management strategies. This approach should involve supports from child life, music therapy, and developmental specialists when possible. Patients with SNI are at risk of polypharmacy; medications should be initiated at the lowest dose and maximized prior to being deemed ineffective. Table 1 shows common symptoms in children with SNI along with approaches to symptom management. Parents will often know the best ways to optimize their child's symptom management and the unique things that bring their child comfort. As in this case, it can be difficult to witness symptoms that are amplified in neurologic illness. Palliative care teams can support parents and staff in treating symptoms whenever possible through pharmacologic and non-pharmacologic approaches and providing psychosocial support for refractory symptoms.

Care Coordination and Home Supports

Children with SNI have an average of 5 or more subspecialists.[12] Complex care medical homes can help to provide wraparound services and connections to community resources. Home nursing is often necessary, and staff must be trained to meet the child's unique needs. Pediatric home nursing is limited or absent in many locations. Parents provide care during any unfilled nursing shifts and sometimes have to provide 24/7 care for their child at home.[13,14] Home-based pediatric palliative care and hospice teams can provide quality of life supports, symptom assessments, and help with care coordination and access to community resources.[15] Early introduction of home-based palliative care can result in a smoother transition to hospice care if and when it is needed.

Family Caregivers, Ongoing Loss, and the New Normal

Parents of children with SNI have extraordinary caregiver demands throughout their child's lifetime.[16,17] On average, parents spend >20 hours per week providing direct care for their child. This time does not include the advocacy and care coordination necessary for parents to navigate the health care system, school system, and community.[18–20] Approximately 50% of SNI families have financial hardships related to their child's illness. Many parents must stop working due to their child's care needs.[20] Families face additional care expenses including electricity to power medical technology at home and durable medical equipment as the child grows.[21]

Parents report ongoing losses as they adjust to changes in their child's health, especially during times of critical illness and/or when decisions need to be made about new technology use for their child..[22–24] Some parents also report stigma related to their child's neurologic disabilities, both in the health care system and in their communities.[25] Parents have shared

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they do all they can to fulfill their role as ‘good parents’ to their child which often means making sure their child feels loved, focusing on their child’s health, and making informed medical decisions.[26,27]

Despite these hardships, parents often demonstrate tremendous resilience and strength as they adjust to ‘new normals’ in their child’s life and the lives of their family.[28] Parents have shared the deep meaning they derive from being a parent of a child with substantial special needs and supporting their quality of life.[29] Parents also express joy and celebrate seeing their child change and do things they never thought were possible. Similarly, parents have shared that caring for their child has helped them to focus on what matters most in their own lives.

Bereavement

With all of these positive adjustments, also comes parents’ sense of loss and grief. Parents often experience grief when they first learn of their child’s diagnosis or expected prognosis. Along the way, health setbacks including prolonged ICU admissions or the need to make decisions about new technology supports can feel like additional losses. Parents and siblings will readjust to these changes over time, but they can feel difficult emotionally in the moment. Similarly, when a child with SNI dies there is loss not only of a child who is deeply loved[30] but also the additional losses of being a special needs parent. These losses include parents’ identity as caregivers and their relationships with those within the health care system that previously were such a prominent part of their lives. Staying connected through bereavement supports offered by palliative care teams can be helpful to parents.[31]

Palliative Care Opportunities

Children with SNI and their families benefit from early ongoing comprehensive palliative care to address goals of care and advance care planning, multimodal symptom management, care coordination, as well as spiritual and emotional support. Palliative care teams serve patients, families, and staff best when they are involved early in a child’s illness trajectory and work together as a multidisciplinary team. The upfront and continuous focus on understanding parents’ concerns, listening to the values that drive decision-making, and understanding what quality of life means for each unique child are essential.[32] Partnering between home-based community palliative care, outpatient palliative care, inpatient palliative care, and hospice teams can provide longitudinal, comprehensive support. Whether children die in the hospital or at home, palliative care teams can help to honor family’s wishes and to support staff.[33]

Case Resolution

As Jennifer’s disease worsened, hours of her day were spent with persistent myoclonus and spasm. After nearly a year in the hospital, getting Jennifer home became paramount to her family. Her parents agreed to home hospice support and the use of scheduled benzodiazepines and opioids for comfort, even though the doses required to manage her symptoms made Jennifer much less alert. She was able to transfer home with hospice care, a tracheostomy/ventilator, and a feeding tube. At home she was celebrated with her family.

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After a few weeks at home, Jennifer returned to the hospital for fever and worsening respiratory status. Despite her continuous feeds, she was losing weight and she was very weak. After another few weeks in the hospital, her parents and the clinical team agreed it was time to stop her ventilator and Jennifer died in her parents' arms. They were surrounded by staff that knew them well after the many months Jennifer had been in the hospital. Her parents expressed their gratitude for all the teams that fought for Jennifer throughout her life and helped them celebrate the many milestones she reached.

Summary

Children with SNI and their families have unique needs that are well-served by pediatric palliative care teams. Whenever possible, early and ongoing palliative care helps in building trust with the medical team and partnering with the family to support their goals. Comprehensive palliative care for children with SNI also includes symptom management and spiritual/psychosocial support. Palliative care teams can journey alongside families impacted by SNI, support them in the ways that are possible, and learn from them about loss and love.

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Table 1:

Common Symptoms Among Children with SNI and Treatment Approaches

Symptom	Pharmacologic Treatment Approach	Non-pharmacologic Treatment Approach
Nociceptive Pain	Mild • Acetaminophen 10–15 mg/kg PO q 4–6 hours, maximum 3 g/day • Ibuprofen 10 mg/kg PO q 6 hours • Naproxen 5–7mg/kg PO q 12 hours Moderate to Severe • Morphine 0.2–0.3 mg/kg PO q 3–4 hours • Oxycodone 0.1–0.2 mg/kg PO q 4–6 hours Hydromorphone 0.04–0.08 mg/kg PO q 3–4 hours	• Positioning for comfort • Holding/Rocking/ Movement • Warm/Cold Compress • Massage • Acupressure/ Acupuncture • Vibration • Physical Therapy • Music Therapy • Light/Dark Environment • Familiar Blankets/Toys
Neuropathic Pain • Visceral hyperalgesia • Central pain	• Gabapentin 2 mg/kg TID or 5 mg/kg PO QHS, titrate by increasing by 2 mg/kg/dose every 2–4 days, maximum dose 3600 mg/day • Pregabalin 1 mg/kg/dose PO QHS on days 1–3, increase to 1 mg/kg/dose PO q 12 hours on day 4–6, maximum 6 mg/kg/dose	
Agitation	• Lorazepam 0.05 mg/kg PO q 6 hours, maximum 2 mg • Diazepam 0.03–0.05 mg/kg PO q 6–8 hours, maximum 2 mg	
Myoclonus	• Clonazepam 0.005–0.01 mg/kg PO q 8–12 hours, maximum 0.2 mg/kg/day	
Autonomic Dysfunction	• Clonidine 0.002 mg/kg PO TID on days 1–4, then 0.004 mg/kg PO TID on days 5–8	
Secretions	• Hyoscyamine 0.125 mg/ml solution 3–4 kg: 4 drops PO q 4 hours prn 10 kg: 8 drops PO q 4 hours prn 50 kg: 1 ml PO q 4 hours prn • Glycopyrrolate 40–100 mcg/kg/dose PO q 4–8 hours • Atropine 1% ophthalmic drops, 1–2 drops PO q 2–4 hours prn	
Sleep Disturbance	• Melatonin 1–3 mg PO QHS, titration to higher doses of 6–10 mg may be beneficial for children with SNI	