

Serious Illness Care for Children and Adolescents in North Carolina

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Patient Scenario: Jane is a 10-year-old who was involved in a motor vehicle accident and sustained a serious neurological injury. She is now technology dependent (tracheostomy with nighttime ventilation and gastrostomy) and has mobility limitations. She is unable to independently perform her own care. She and her family face a host of challenges as they adapt to her ongoing medical fragility and personal care needs.

Hospital Supports

Jane requires specialty medical care, rehabilitative services, and psychosocial support. In the hospital setting, children and adolescents may receive care through a structured program for children with medical complexity [1]. These programs often work collaboratively with pediatric palliative care teams made up of interdisciplinary staff including physicians, advance practice providers, nurses, social workers, chaplains, child life specialists, and occupational, physical, and speech therapists.

Advance Care Planning

During Jane's initial hospitalization, health care providers ideally will explore Jane and her family's goals, values, strengths, and worries. This conversation, also known as pediatric advance care planning (pACP), is the gold standard for serious illness care [2]. Traditionally, advance care planning has focused on adults, therefore most health care providers do not have a consistent approach to pACP. Barriers to pACP include a lack of legal forms, prognostic uncertainty, time, and complex social situations [3-5]. Despite these barriers, innovative approaches to pACP exist and are highlighted by use of resources like Voicing My Choices, Courageous Parents Network, and Seattle Children's Decision-Making Tool. Notably, pACP is not a one-time conversation and should recur regularly with Jane's primary medical team.

Home and Community Supports

After hospitalization, Jane's family must decide how to meet her care needs. Jane needs continuous monitoring to ensure her equipment is working correctly. A nurse with experience in pediatric respiratory and skin care (or a

trained family member) will monitor her equipment, provide respiratory care, administer tube feeds and medications, and help Jane turn every two hours. Jane qualifies for up to 20 hours per day of private-duty nursing services. Private-duty nursing agencies serve all counties in North Carolina, but frequently experience a shortage of skilled pediatric nursing providers [6]. The hospital and community agencies train family members to provide care for Jane when nursing staff is not available due to nursing shortages (vacation, illness, lack of qualified staff) or limits on nursing coverage. In North Carolina, the Community Alternatives Program for Children (CAP-C) provides additional resources, including equipment, home modifications, and respite nursing hours [8]. Jane is eligible for the CAP-C program because she requires the same level of care as a child in a long-term care facility or hospital.

Another option for ongoing care is a residential care facility. Families of children with medical complexity have very limited options for care outside the home. There are two residential facilities in North Carolina that can care for a patient with ventilator dependence. As of April 2020, one facility has 22 beds and capacity to care for one child with ventilator dependence, while the other facility has 30 beds and capacity to care for up to 12 patients with ventilatory needs (telephone correspondences, Diane Van Husen, executive director, Hilltop Home and Director of Nursing Christine Jackson, RHA Howell Center—Tar River, Greenville, NC, April 7, 2020). The aforementioned facilities are not designed to provide respite, a short-term break for parents, or coverage for family or provider's vacation [7]. Respite hours in the home may not be sufficient in the event of caregiver illness, travel, or caregiver responsibilities for other family members.

Family and Caregiver Perspective

Caring for a child with serious illness can be difficult emotionally and financially. The emotional impact of this care affects parents, siblings, and extended family. The change in routine and lack of attention from parents can impact the sibling by making them feel isolated, ignored, or not worthy of their parents' attention because they are

healthy. Grandparents watch the suffering not only of their grandchild, but of their own children as they struggle to navigate this serious illness. Financially, a parent may have to work in order to maintain medical insurance, which can increase burden in a one-parent household. Jane and her family may experience social isolation due to changes in school, religious activities, and work responsibilities.

Palliative and Hospice Care

While Jane may have received palliative care when in the hospital, unfortunately pediatric palliative care services are scarce in the community setting. The lack of community palliative care increases hospital readmissions, affects symptom management, and limits psychosocial support to the family system [9]. If Jane were expected to be in the last six months of her life, home hospice care may be more readily available. For Jane, whose family is experiencing social isolation, remaining home in a familiar environment at end of life is crucial. Other families may choose to return to the hospital for end of life or may not have a choice due to lack of home or inpatient hospice providers in geographic areas throughout the state.

Recommendations

Caring for children with life-limiting illness requires a team-based approach across the spectrum of care. The current system leaves the caregivers of children with serious illness with significant unmet needs. Given these unmet needs, we recommend increased funding for home health nursing and pediatric palliative care programs providing team-based care in both hospital and community settings (see North Carolina Institute of Medicine Task Force on Serious Illness Care Recommendations 2.1, 2.4, 3.14) [10]. Additionally, caregivers of seriously ill children should be engaged in planning for their child's care through pACP, offered family support services, and be able to access non-hospital respite facilities (see NCIOM Task Force Recommendations 3.2, 3.11) [10]. **NCMJ**

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