Pediatric Palliative Care in the Medical Home

Shivani S. Tripathi, MD; G. Patricia Cantwell, MD; Audrey Ofir, MD; Dolores Serrecchia, RN, BSN; and Samantha Peck, RN, BSN, CHPN

Pediatric palliative care, a comprehensive, family-centered approach, is now widely recognized as an essential component of care. A crucial element of this approach is to provide consistent, seamless care, regardless of where the child is being treated.1,2

Having a medically fragile child on a medical home patient panel may be potentially overwhelming, stretching the limits of the primary care office practice; however, with preparation, networking with other providers, and staff education and coaching, primary care providers have the potential to experience the unique and rewarding opportunity that comes with helping to maximize quality-of-life for such patients and their families.

ROLE OF MEDICAL HOME IN PPC

The scope and benefits of pediatric palliative care (PPC) overall are misunderstood by the medical community, as well as the lay public.3 Too often, palliative care is thought of as “brink-of-death care;” thus, when palliative care is suggested for a child, it is common for the family and medical provider to say, “We are not there yet.” But PPC can and should be implemented near the time of diagnosis of a medically complex child. The primary care pediatrician who works to ameliorate the physical, emotional, social, and spiritual impact of illness is already providing PPC where the child most needs it.
— in the home community, where he or she spends the most time.

The personal knowledge and longitudinal relationship that characterizes the medical home puts the primary care physician in an optimal position to ensure the best long-term outcome for the child and family. This is done by proactively coordinating care; facilitating consistent communication for better decision-making; providing anticipatory guidance; and helping to manage symptoms and social distress; and helping with medical decision-making. Specialists in hospice and palliative medicine are available in some settings to address unusual problems and to advance the field, but for these children to have access to the care they need, the majority of basic PPC falls to general pediatric providers.

The American Academy of Pediatrics (AAP) supports this concept of PPC, affirming that “components of palliative care should be offered at diagnosis and continued through the course of illness, whether the outcome ends in cure or death.” While pediatricians in general always have been advocates for family-centered care, the importance of the pediatrician’s involvement with the patient and family at every level of care (hospital, office, home, and community) was highlighted recently in the January 2012 AAP policy statement by the Hospital Care Committee.6

**COORDINATED CARE**

Fragmentation of medical care typically leads to loss of information; medication errors; unnecessary testing; and even contradictory goals and processes of care. A palliative care team led by the patient’s medical home can facilitate care coordination.7,8

For example, technologic treatments such as home ventilators, tracheostomy care, continuous enteral feeds and/or hyperalimentation, stoma care, monitors, and devices transform family homes into small hospitals. Such machinery also complicates the capacity of the family to attend medical appointments. A care coordinator can minimize the number of trips the family must make to see the various subspecialists by coordinating as many appointments as possible on the same day and in the same location. Doing so takes diligence, patience, and determination because care delivery is most often

---

**Having to make a decision in times of crisis can paralyze families and lead to poor decision-making and regrets.**

---

In addition, medically complex children usually have medication lists that are long and constantly changing, a situation fraught with the potential for medical errors. The primary care pediatrician with a good electronic medical record (EMR) system and communication plan can help prevent these errors, in addition to ensuring consistent decision-making. The reality is that such communication systems are rare. Office-based and hospital EMRs are just coming online and may not be mutually compatible; the primary care physician may lose track of the child when the hospital stay is especially prolonged; and hospital-based providers may not do their part to maintain communication. A medical home provider who understands the “big picture” and can appreciate subtle clinical changes in a medically complex child, optimizes the care for the patient. This can also lead to the primary care provider creating a strong and rewarding bond with the family.

Hospitals can make a profound impact on a PPC patient’s care by using existing resources to create an interdisciplinary team9,10 that includes the community-based primary care physician; this is more likely to happen when the medical provider expresses interest in being part of the care team and indicates the best means to facilitate contact. Being proactive and innovative can result in seamless, comprehensive care, despite a “lack of resources.” Interdisciplinary care teams addressing the needs of children with complex conditions may include representatives from the services listed in the Table (see page 114).

Before receiving a medically complex child into your care after a hospital discharge, it is ideal to have established contact with all care team members and to have access to all the patient’s relevant information (see Sidebar 1, page 114). It is also helpful to discuss the child over the phone with the discharging physician. It may also be beneficial to have a meeting with the parents to discuss their hopes and concerns and to clarify the goals of care once the child is discharged home.11

**ANTICIPATORY GUIDANCE**

Anticipatory guidance should include discussions about each possible scenario, primary goals of care, and the path to achieve those goals. Having to make a decision in times of crisis without foreknowledge and time to think can paralyze families and lead to poor decision-making and regrets. The medical team’s recommendations regarding aggressive technological support, and whether that support relates to the family’s goals of care, can prove invaluable to a distraught
family. Too often, parents are faced with the burden of choosing to prolong their child’s life in the face of profound suffering or to allow death to come with meticulous symptom control.

Conversely, improved survival rates after neonatal and pediatric intensive care experiences have had the unintended consequence of creating false parental and societal expectations that death can most often be averted.1

Accurate prognostication, always more of an art than a science, has been complicated further by the availability of technologic support, such as home ventilation, parenteral nutrition, and gastrostomy tubes, that can result in long-term survival.12,13 Such measures can sacrifice quality of life for the child and family.

A decision made in the hospital to not attempt resuscitation of a child may need to be reconsidered if the child survives and is discharged. The primary care provider has the challenge of discussing the goals of care at a time when the family has restored hope because their child has survived, sometimes leading parents to conclude the “doctors in the hospital were wrong” about their child’s prognosis. If indeed the prognosis is correct, then it is important to help the family understand their child’s likely future and to make a realistic care plan that honors the family’s hopes and values. When discussing these plans, it is vital to be aware of respective state laws governing the implementation of prehospital Do Not Resuscitate (DNR) orders. A potential obstacle to the consistent application of these orders is that for them to be considered valid, parents are required to sign the DNR prehospital form covering facilities outside of the acute care setting. Many parents are afraid that their signature implies that they have given up hope.14

The primary care physician can assist parents by considering such “worst case scenarios” of medical decompensation. In some cases, the primary subspecialist is in a better position to address such potential declining clinical trajectories; the primary care physician can then serve as a sounding board for the family to better understand all their options. Such difficult discussions are often neglected, in part due to a prevailing sense that a discussion of death will negate hope.

Another challenge is when the family is reluctant to allow health care providers to speak to the child about death and dying.15 Depending on their developmental stage, children may know that they are dying, and merely need “permission” to share their feelings.16-19 In the absence of such permission, the child frequently becomes the parents’ protector, fiercely fighting for life despite severe suffering, knowing that the parents are struggling with his or her impending death.20-22

**ILLNESS TIMELINE**

The most important factor for families is to have a provider who knows and understands them and whom they can trust to guide them in supporting their child and family and in making difficult choices when called to do so.

Technological intervention should not be offered if it does not support the goals of care; the “big picture” should always guide the treatment plan. Personal recommendations may be welcomed by grief-stricken families.22,23 For example, “In my medical judgment, dialysis would not be expected to change Juan’s illness or its outcome, so I do not recommend its use” (see Sidebar 2, page 115). It is especially important for older children and adolescents who have the capacity and desire to do so to participate in the conversation about their condition.

It is impossible to predict an exact time of death, yet one can outline a likely disease trajectory, as well as a range of life expectancy (hours to days, days to weeks, weeks

---

**TABLE.**

The Interdisciplinary Pediatric Palliative Care Team

| Patient, parents, and siblings | Child life specialist |
| Primary care physician | Pastoral care |
| Registered nurse/home health nurse | Case manager |
| Social worker | School tutor |
| Child psychologist | Physical/speech/occupational therapist |
| Psychiatrist | Subspecialty physicians |


**SIDEBAR 1.**

Essential Clinical Information for Medical Home of PPC Patient

- Discharge summary, including the social network, pastoral care, and child life assessment
- Ongoing durable medical equipment and nursing needs and instructions
- Reconciled current medication list, and any new adverse medication reactions or allergies
- Home care providers contact information and schedule
- Names and contact numbers of consulting subspecialists, planned follow-up appointments
- Any limitations of medical interventions, copies of any out of hospital “DNR” orders

to months, months to years), and probable mechanisms of death can be outlined. When families are considering the use of “high-tech” medical intervention, the associated medical, social, practical, and financial risks of such treatments should be discussed openly, such as the increased risk for infection/pneumonia/aspiration in the neurologically devastated child.

Compassionate discussion of an anticipated medical decline is an essential component of anticipatory guidance, the hallmark of pediatric primary care. Families may be aware of a very poor prognosis, yet time and time again, they will ask, “When did this happen to him?” or state, “I never thought that she was this sick.”

Agreeing to “not attempt to resuscitate” may render a sense that they did not seek every possible therapeutic plan or that some aspect of therapy will be neglected; an explanation of the likely outcome of CPR for their child often allays such fears. Other underlying reasons for parents to request their child be put on the intensive care unit or receive CPR may be summed up by the statement, “I was afraid if I agreed to ‘do not resuscitate’ that nothing would be done.”

Primary care providers who are knowledgeable about relevant state laws and who are willing to work with local emergency services, and medical examiners or coroners, are a huge source of support for families of technology-dependent children who may desire a peaceful death at home. Such circumstances can result in the primary care provider being asked to sign a death certificate for their patient; hospices are a good source of information for more about this process.

Documentation of such conversations can be shared with members of the entire care team. A thorough review of the hoped-for benefits and the expected burdens of the medical treatment plan is vital to assist all team members in honoring the patient and family values. Documentation will also help keep the family abreast of the prognostic changes that often occur.

**SIDEBAR 2.**

**Scripting Examples for Conversations with PPC Families**

- How do you think things are going?
- Tell me how you think you are/your child is doing.
- What do you/your child’s best days look like?
- What gives you/your child joy and pleasure?
- What are your greatest concerns, hopes, and fears for yourself, your child, and your family?
- What have the other doctors told you to expect?
- I have reviewed the medical data and the issues seem to be __________.
- Has anyone in your family experienced a situation like this?
- What is your understanding of what might happen in the future?
- This is what is likely to happen …
- I am very concerned about __________.
- Based on your goals for care, I would recommend the following treatment plan …
- What would you like to do to make these days special?
- How can we be helpful?
- What matters most to you now?


**CAREGIVER SUPPORT**

Parents frequently become experts on their child’s disease and are always experts on the illness experience. However, they look to the health care team to assist them with arranging ancillary care, symptom distress management, and decision-making.

The hectic schedule of a general practice office can make having the time for such discussions difficult. There are innovative strategies to overcome such barriers, however. For example, discussions can occur between family, the primary care provider, and subspecialists via conference calls or even Skype. Creating a written summary of such planning meetings and keeping them on file can prevent frenetic reaction to a clinical decompensation.

**OTHER IMPORTANT PPC TEAM MEMBERS**

**Pharmacist**

Some medications commonly used in PPC require compounding, which is only done by certain pharmacies. Any discrepancies between the hospital formulary and the outpatient pharmacy may result in lack of medication reconciliation and frustration for both the provider and family. Establishing an alliance with a local pharmacist experienced in medication regimens and compounding can be helpful for understanding medication delivery options. Working together with the pharmacist on options for ongoing treatment in advance of the actual discharge can prevent lapses in the child’s care regimen and will decrease anxiety for the family.

**Skilled Home Nursing**

Each state and community has unique resources to support family through the challenges of caring for a medically fragile child. There are several PPC care delivery models: hospital-based teams; home-based teams aligned with hospice or home health agencies; and outpatient palliative care clinics.

Home nursing coverage is often essential to the family’s quality of life. Redundancy in the schedule can prevent emergencies; care coordinators can work with the home health provider to create nursing backup plans. Because it is rare to have 24-hour nursing cov-
verage, parents must also be trained to provide competent care. Unplanned lapses in coverage can also occur, so parents must have confidence that they can care for the child. Insisting that the training is done before and after discharge can help parents be more capable of caring for the child.

Schools and Camps

It is important to prepare the patient’s school for expectations for care while maintaining confidentiality. Most often, this orientation for the school nurse, teachers, and classmates is done by hospital-based personnel, such as an advance practice nurse or child-life specialist. This is done after the child’s hospital discharge in anticipation of returning to school. School attendance may enhance much needed socialization and allow the formation or continuation of age-appropriate relationships.

Some states have prescribed pediatric extended-care programs. These are structured day care-like facilities that function with the expertise of skilled nurses and therapists. Such programs are invaluable in enhancing a smooth transition from home or hospital into the mainstream school environment. They also serve as integrated care programs to ensure skilled care and socialization for more medically complex children who would otherwise be incapable of transitioning to school.

Camps for children with terminal illness are also wonderful resources for medically complex patients and their families. Providing the child with some “normal” experiences can give both the child and family an enormous sense of comfort. The PCP is invaluable in emphasizing the focus on care of the “whole patient,” for which the family will be forever grateful.

CONCLUSION

Integration of PPC into the primary care practice can enhance the quality and completeness of the family-centered medical home. Palliative care incorporates informed decision-making, coordination of care, patient comfort, and family-centered care.

Pediatricians have been advocates of such empathic, comprehensive, and continuous care for years; the challenge to provide this has escalated with the increasing complexity of home-based medical technology and therapies. The fragmentation associated with subspecialty care can sometimes distract from a focus on comprehensive care of the patient. The primary care provider can be a powerful force in creating seamless care for this special group of children and their families.

REFERENCES