Introducing Families to Palliative Care

Learning Objectives

After reviewing this Guide you will be able to:

- Distinguish between palliative care and hospice care in a family conversation
- Illustrate the value of palliative care for a patient family
- Formulate a personal approach to introducing palliative care and corresponding CPN resources

Educating Yourself

Many, many families ultimately regard their child's palliative care provider(s) as a lifeline—whether they had initially resisted a consult, or welcomed it, or had agreed to a meeting with some degree of skepticism (or fear). And that fear is understandable, as palliative care is frequently confused or conflated with end of life or hospice care. A lot of emotion can be generated when the topic is raised, so a clinician may hesitate to suggest palliative care. They may anticipate that the family will believe that they are being abandoned; that all treatment options have been exhausted; that the team has given up. It can therefore be important to explain the differences between palliative care and hospice care.

Families may find it reassuring to learn that palliative care is a resource for anyone living with a serious illness and is not related to prognosis. It can be delivered as early as diagnosis and at almost any point during the illness. The primary goal of palliative care is to relieve pain—physical, emotional and/or spiritual. Practitioners do not displace the primary medical team; they work as consultants to the family and the team. The term refers to a wide range of treatments and interventions that complement disease-directed care. In pediatric palliative care the interventions may include therapies (physical, occupational, play, etc.) for the sick child and other family members.

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(Practitioners, however, sometimes say that the most important intervention they provide is listening: listening to the family's story, and finding opportunities to create, or restore, a sense of medical, psycho-social and spiritual equilibrium as they accompany a family during the illness journey and even beyond.)

Caregivers also appreciate that pediatric palliative care providers typically follow the family through changes in the child's health status, addressing caregivers' hopes and worries, and helping them understand and choose treatment options consistent with their goals of care.

The Courageous Parents Network guide "Understanding Palliative Care and Hospice Care" carefully explains the differences between the two modes of care.

How Palliative Care Helps

Early integration of palliative care has been shown to improve symptom management, improve decision-making, and decrease the caregiver burden. Providers and families find that palliative care specialists can help to

- Clarify the family's values and care goals for their child
- Facilitate communication and decision-making among the family members, primary providers and subspecialists. This is especially important, as fragmentation in the patient's care can be difficult and bewildering for everyone involved
- Provide a space to think through medical decisions in the context of what is important to the family
- Focus attention on symptom (especially pain) management, quality of life and comfort in all situations

When to Introduce Palliative Care

Examples of appropriate times to suggest palliative care include:

- When the family has recently received a difficult, life-threatening diagnosis
- If the child has intractable symptoms (e.g., pain, nausea, breathlessness) that are beyond the primary team's ability to optimally manage
- If the child is experiencing a decline in a chronic condition or has had a lengthy or complicated medical course
- If the child has had repeated hospitalizations and setbacks with declining baseline
- If the caregiving partnership or family unit is experiencing difficulty with functioning at a customary level

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- If the child has had a medical course filled with many uncertainties, where the outcome is not certain
- If the focus of care has shifted from treatment to comfort-only

The Family Perspective

Hearing from families can inform your understanding of the value of pediatric palliative care. When you have viewed CPN family videos, you will be better positioned to say, “I have learned from other families how helpful it has been to include palliative care on their child’s team.”

Scripts

In your own voice you might use language like this for describing palliative care and suggesting a consult:

“May I talk with you about something I have been thinking about for (your child)? I have been seeing how they are having a hard time with X. There is a specialist at the hospital who helps families whose child has a serious medical diagnosis involving difficult decisions that include a lot of uncertainty. It may be a good time to have a consultation with this specialist.”

“Have you heard the term palliative care? Many people have not, and some who have believe that it is just for end of life. They think it is hospice. But that’s not what it is. Palliative care is not related to prognosis. The specialist spends time learning about your child and family, and thinks with you about your goals. They listen carefully and then help coordinate your child’s care. And, if things change, they can help you think through what you want to do.”

“Some palliative specialists stay with the family through the whole illness journey. Their goal is to help maintain and enhance quality of life. Your child’s life—and your life, too.”

“Would you like me to arrange a palliative care consult?”

Many, many families greatly value the experience of others who have traveled a similar path. In many cases, especially in the case of rare disease, it is difficult for families to connect to much-needed peer perspectives. Some join disease groups and participate in their programs; others prefer to be anonymous or private—but need support, nevertheless.

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Courageous Parents Network supports connection to other families' experience through a wealth of resources: video, audio stories, downloadable guides, events and more. You might use language like this to introduce a patient family to CPN resources:

"You might like to hear from other parents whose child and family were helped by palliative care. Courageous Parents Network offers videos, audio stories, downloadable guides and events featuring parents and professionals, to help you see and feel that you are not alone. Most of the featured families have partnered with and benefited from palliative care, and these families have helped me consider when palliative care could be helpful for my families. I think their words may help you understand why I think it's a good idea to suggest palliative care at any time a child has a serious medical condition, and especially when the future looks uncertain. As one of the physicians in the videos says, pediatric palliative care is not the end of hope, it can be the beginning of the family finding their way. You may find that the CPN resources are really helpful. Here is a card to remind you of their website."

You might also be in a position to suggest a consult for a colleague's patient family, using language like this:

"There are so many times when I want to consider how a family would think about something I want to discuss: what they would want to know, how they would react. Courageous Parents Network offers access to the perspectives of families and other clinicians dealing with the very same issues we do. They are a nonprofit organization with a website that includes videos, audio stories, events, downloadable guides and other tools. These resources are reviewed by medical professionals and can be used to educate ourselves as well as families."

"Palliative-Aware"

Not all hospitals and health centers employ palliative care specialists. If yours does not, it still is possible for a team of physicians, nurses, advance practice partitioners, social workers, chaplains and others, working together, to offer care based on PPC principles. These include:

- Pain and other symptom relief and management
- Active involvement of caregivers in understanding treatment options and decision-making
- Practical support for family members (including help with coordinating insurance coverage and claims)
- Counseling and spiritual comfort for the patient, parents, siblings and extended family

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Resources for Families

These resources are appropriate to use at bedside, in family meetings, or as a follow-on to offer additional support.

Guides

"Introduction to Pediatric Palliative Care"
https://courageousparentsnetwork.org/guides/introduction-to-pediatric-palliative-care

"Understanding Palliative Care and Hospice Care"
https://courageousparentsnetwork.org/guides/understanding-palliative-care-and-hospice-care

Blog

"We Hope: A Letter to Parents from Your Palliative Care Provider"
https://courageousparentsnetwork.org/blog/we-hope-a-letter-to-parents-from-your-palliative-care-provider/

In Navigating Medical Complexity

Palliative Care section explains PPC with complementary videos and other resources
https://courageousparentsnetwork.org/medical-complexity/journey-topics/working-with-the-care-team/palliative-care/

Conclusion

Families caring for a very sick child face very difficult, often heart-wrenching, decisions. The stress on the entire family unit can be almost unthinkable. Pediatric palliative care offers a layer of support to complement disease-directed treatment, especially as the illness progresses and yet more difficult choices must be made. The PPC team can help with many of the most prevalent stressors: pain and symptoms management; relationship and sibling support; values clarification and communication; advance care and end-of-life planning. While caregivers may initially balk at the suggestion of a consult, most will ultimately find that their relationship with a palliative care team helps them have a sense of control and greater confidence in their ability to care for their child.

Find more pediatric palliative care resources in the Clinician-Educator section:
https://courageousparentsnetwork.org/clinicians-and-educators/sections/pediatric-palliative-care/?post_type=clinician-topic