

Primary Pediatric Palliative Care: Psychological and Social Support for Children and Families

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Educational Gap

Families of children with complex, chronic, and/or life-limiting conditions experience unmet psychological, emotional, practical, and spiritual needs. Primary care pediatricians may lack sufficient knowledge, training, and/or resources to address these needs; pediatric palliative care teams can offer additional support services to families.

Objectives After completing this article, readers should be able to:

1. Recognize when a pediatric palliative care consultation would be appropriate to help the patient and family deal with psychosocial stressors related to diagnosis or illness.
2. Describe the roles of the various members of the palliative care interdisciplinary team in providing psychosocial and social support to a patient or family with a child who has a complex, chronic, or potentially life-limiting condition.
3. Understand the role overlap among various clinicians on a palliative care interdisciplinary team.

Imagine 2 parents, Amy and Todd, sitting in a room in the pediatric intensive care unit. Their formerly healthy 2-month-old son, Jack, was recently diagnosed as having spinal muscular atrophy (SMA) type 1 during an admission for respiratory failure secondary to respiratory syncytial virus. He is now extubated and pain free, and his parents have met with the intensivist, neurologist, and pulmonologist regarding what SMA is and how Jack's life will be affected. For the parents, many questions remain: How will we cope with the changes that are happening in our life? How will we afford the specialized care Jack will require? How will we be able to juggle work and other responsibilities to go to multiple medical appointments? Will this affect our marriage? Will this exacerbate our own medical conditions? How will we obtain the supplies we need to care for all of Jack's complex needs at home? Whom do we call when we have a medical question that doesn't seem to be appropriate to ask the general pediatrician or subspecialist? Why would God allow this to happen to us? Will our 6-year-old daughter, Anna, understand Jack's condition? How will she act? How will we cope with the changes that are happening in our life? How can we accept the thought, let alone the reality, of losing our son?

AUTHOR DISCLOSURE Drs. Hirsh and Friebert have disclosed no financial relationships relevant to this article. This commentary does not contain a discussion of an unapproved/investigative use of a commercial product/device.

Quite possibly one of the most frightening things for parents to hear is that their child has a medical diagnosis that can be potentially life-threatening. The uncertainty, or at times certainty, of such diagnoses can profoundly affect the lives of the child, the parents, and the extended family members and bring about numerous challenges (Table).

In addition to facing physical, emotional, and psychological struggles, families will have to juggle practical needs with the needs of their ill child. These needs include attending to the day-to-day functioning of their household, including caring for their healthy children. Children with serious illness often require much more assistance and time than a healthy, developmentally appropriate child to complete their activities of daily living. Chronically and/or seriously ill children usually receive multiple doses of medications during the day and often overnight. Feedings may be lengthy and off-schedule with the rest of the family. If the ill child has impaired mobility or is completely immobile, transportation can be more difficult. To coordinate everything a child with serious illness requires and to advocate effectively, parents often feel they have become full-time care coordinators, leaving little time to enjoy being parents. Besides having many scheduled appointments with subspecialists, therapists, and community agency staff, the family must also coordinate multiple visits by school, home health, case management, rehabilitation therapy, and social service personnel. On top of scheduled visits and appointments, an unexpected bout with another illness can result in additional medical appointments, a possible prolonged hospital stay, and further disruption in parent and sibling routines. Over time, caring for the seriously ill child can become physically exhausting.

Financially, medical illness can be burdensome, even for families that are financially secure at the time of diagnosis. Prolonged or repeated hospitalizations or physician appointments may result in decreased income or lost jobs. Families may also incur additional expenses related to travel, parking, lodging (especially if their treating facility is far from home), home and/or vehicle modifications, and expensive co-pays for visits and medications. Often parents need to secure childcare for their other children. One parent or caregiver may need to stay at home to oversee the ill child's care, which is particularly daunting for single parents. Lost income or other financial stressors can result in an inability to pay bills, contributing to stress and anxiety.

Families can also become emotionally exhausted. As stresses persist over time, and parents see their child's health decline or perceive that their child is suffering because of pain or other symptoms, they may feel conflicted. They may wish for their child not to suffer, yet hope that their child will continue to survive and do as well as possible. They

TABLE. Challenges For Families With a Child With a Complex, Chronic, and Potentially Life-Threatening Condition

- Diagnosis often unexpected
- Care will require multiple subspecialists
- Prognosis can be uncertain
- Potentially long-lasting effects on family's finances, time, relationships, and faith base
- May affect family members' mental or physical health
- Siblings may have difficulty with coping and understanding the changes taking place
- Families must begin to acknowledge that their child may die and begin the anticipatory mourning process

may feel resentful about the effect of the illness on their lives. They may worry about how the illness is affecting the lives of their other children, their extended family, or their marriage. Many other complex emotions may arise, including anxiety, uncertainty, loneliness, guilt, anger, anticipatory mourning for a shortened life, and grief over the loss of their well child and the hopes that they had for him/her.

Spiritually, families may question their faith and struggle to find new meaning in life. They may ask why this has happened to them or their child. They may wonder why God or another higher power would allow their child to suffer. They may question whether they did something to cause their child's fate. They may also struggle to answer the ill child's questions or those of their other children.

In contrast to families coping with acute or self-limited injuries or medical conditions, families of children with serious illness often struggle with stressors for prolonged periods. External support may wax and wane, and the outside community may unrealistically expect the family to return to their former routine. The frequent, rapid changes in care and demand are almost the norm in a chronic illness. Families may be caught off-guard by new issues or the reappearance of old problems thought to be resolved.

Fortunately for an increasing number of families facing such challenges, a pediatric palliative care (PPC) team of specially trained professionals can offer support. Key staff are social workers, case managers, child life specialists (CLSs), chaplains, psychologists, and bereavement specialists.

Jack's case offers examples of how the PPC team can help. Jack's diagnosis of SMA type I will result in a shortened lifespan, with survival likely limited to a few years at most. The various roles of the interdisciplinary team are highlighted as each question in the case example is deconstructed.

How will we afford the specialized care Jack will require? How will we be able to juggle work and other responsibilities to go to multiple medical appointments?

During the initial days after diagnosis, the social worker generally performs a needs assessment, asking such questions as the following:

What is the family structure, and how are decisions handled? Are there any cultural, language, contextual, or environmental issues that need to be incorporated into the child's care plan?

Who is the family breadwinner?

How will the patient's diagnosis affect the breadwinner's employment?

What are the family's current financial and insurance issues?

What assets and resources have the family already accessed?

Who or what has been a source of support to the family in the past?

How has the family coped with crisis in the past?

The social worker is the team member who has in-depth training and knowledge on how to quickly get families linked to government-sponsored insurance programs and services, as well as to local and regional sources of support, financial or otherwise. The social worker can also guide the family through possible citizenship, custody, or guardianship issues, especially for families in nontraditional relationships (such as fostering or adopting their children). If school concerns are an issue, the social worker can work with the teachers, the principal, and the school district to put an appropriate Individualized Education Plan in place that gives the child access to necessary services, helps the child transition between schools or districts, and accounts for missed school days because of illness. In Jack's case, school is not an imminent concern but access to specialized early intervention and home support services will be helpful for this family.

Will this affect our marriage? Will this exacerbate our own medical conditions?

In addition to addressing concrete resource needs, the social worker can counsel families on empowerment, resilience, and the ability to cope with difficult or changing situations. With proper training and licensure, social workers are able to screen for undiagnosed mental illness in the patient's parents and/or caregivers (or the patient, if old enough) and can provide assessment and even short-term treatment, as often social workers have additional expertise in specific counseling techniques. Their background in family systems also enables them to facilitate relationships among stressed family members. In situations where more in-depth counseling or treatment is required, the social worker can work together with the PPC

team psychologist to best address a family's needs (see section on Psychology below).

How will we obtain the supplies we need to care for all of Jack's complex needs at home? Whom do we call when we have a medical question that isn't an appropriate question for the general pediatrician or subspecialist?

The case manager, who is often a nurse (but could be a social worker), plays an integral role in the care of a patient and family of a child with a complex, chronic illness. A crucial part of the management of these patients is coordination of care. This coordination includes formulating a care plan with patients and their families; providing education on the illness, available resources, and the health care system or environment; and assisting with transitions in care. Case managers generally work closely with social workers and other clinicians to help coordinate outpatient appointments, tests, and treatments. The case manager is trained to work with pharmacies and infusion and durable medical equipment companies to help ensure that the family has the supplies necessary for keeping their child comfortable at home. Duties include communicating with home nursing and/or hospice staff, securing nursing services for children who qualify for in-home nursing hours, and working with insurance companies to obtain prior authorization and timely access to appropriate therapy and medications. On many PPC teams, the case manager is often the first person called on by the family when a question about care arises, and after expedient and thorough assessment, the case manager either handles or triages the question to the appropriate team member. The case manager typically comes to know the family well over time and thoroughly handles specific health care questions and personal needs.

Why would God allow this to happen to us?

The chaplain cares for the spiritual needs of the patient and the family, is trained to understand and relate to people and their diverse faiths, and can help the patient and family make meaning of complex, chaotic, overwhelming, and devastating circumstances. Chaplains perform rituals and provide support and answers that are appropriate no matter what faith (if any) the family practices. The chaplain may help the family sort through tough questions about their God's existence and why devastating events happen to "good" people. By sitting with families in silence, listening to their struggles, or praying with them, the chaplain provides comfort. The chaplain can serve as the link to the family's faith community outside the hospital, helping their faith leaders and the community understand the family's situation and how to best support them. If a child progresses toward end of life, the PPC team chaplain can continue to give spiritual guidance while involving the family's own faith leaders or

hospice spiritual care staff. For families who spend most of their child's illness in the hospital, the chaplain may become a trusted part of the family's inner circle. Many families ask the PPC chaplain to participate in, or even lead, the memorial service for their child if death occurs.

Will our 6-year-old daughter, Anna, understand Jack's condition? How will she act?

The CLS is trained to interact with the child and the child's siblings. Depending on the affected child's developmental level, the CLS can explain the current situation and upcoming procedures in terms that the child can understand. Siblings of the ill child may not understand why the family routine has changed and why their brother or sister is ill. In many families, because of difficult circumstances, siblings unintentionally end up shunted to other family members or friends for care, with their needs forgotten or put on hold. The CLS distills complex information into child-friendly lingo to help ill children and siblings understand a world that is far more complex than it should be for any child. Involvement of the CLS with the patient's siblings helps to reduce the exclusion many siblings experience by allowing them access to someone who is specifically available for their needs.

As an integral member of the care team, the CLS can share appropriate information gleaned from the child(ren) with their parents and other care professionals to help convey what the child and siblings understand and feel; this, in turn, helps families and clinicians tailor their interactions with the child and siblings in a more meaningful way. CLSs use a variety of techniques to enable children to exhibit mastery and control over their circumstances, thereby decreasing their fear of the unknown.

Many PPC teams also have expressive therapists (art, music, or other modalities, such as movement) who can facilitate coping for the ill child, siblings, and parents. Working in coordination with a CLS, these professionals bring an extra dimension to the care of children with life-threatening conditions, particularly for those whose verbal expression is not possible or desirable. For Jack's sister Anna, working with a music or art therapist may offer her a nonjudgmental, safe place to express her fears, as well as her normal feelings of jealousy and anger since her life has been "turned upside down." Mastery and control over personal experiences are just as important for siblings such as Anna as they are for the ill child.

How will we cope with the changes that are happening in our life?

The psychologist is also a crucial part of any PPC team. This team member is trained to listen to and help with the spoken and unspoken concerns of the family and/or patient. Psychologists are experts in uncovering whether the family or patient truly understands the implications of the

diagnosis and the possible future decisions on treatment and management. Psychologists can also help families that already have behavioral health challenges to better cope and make decisions. For example, if formal competency or decision-making capacity assessment appears necessary or psychological issues are more prominent or problematic than a trained social worker can address (as above), the PPC team psychologist can provide expertise. If medications are indicated to treat a particular mental or behavioral health issue, the psychologist can help facilitate consultation with a psychiatrist for initial prescribing and can participate in ongoing counseling and monitoring of the affected child or family member. In some cases, a pediatric psychologist may have limitations in terms of training or ability to work with adult clients (such as parents); however, PPC teams can usually provide direct service or educated referral for families and their children with life-threatening conditions.

How can we cope with the thought, let alone the reality, of losing our son?

In cases where a patient's diagnosis is expected to result in a shortened life expectancy, the services of a bereavement specialist are invaluable. This individual can meet with the family before the patient's death and assess the situation. The bereavement specialist can build rapport and help the patient and family deal with anticipatory grief regarding the loss of the child's *expected* life or the very real possibility of the child's actual death. Questions regarding funeral arrangements and end-of-life planning are often most easily addressed by this member of the team. Before or after the patient's death, the bereavement specialist can help with memory making and legacy creation. After the patient has died, the bereavement specialist might attend funeral services to provide the family with continued support, followed by scheduled telephone calls and visits at the home, the office, or a neutral location to assist with the mourning process. The bereavement specialist watches for the development of pathologic grief and can intervene when signs and symptoms of this condition present. The bereavement specialist also serves as a resource for support groups and grief groups that families can attend locally and may, in fact, facilitate forming these groups, depending on available resources. The bereavement specialist can offer further support through mailings, telephone contact, individual and family sessions, community and group outreach efforts, and regular memorial service events.

THE PPC TEAM

Each member of a PPC team has a separate role, yet their roles naturally overlap. It is common for one member to hear a family's new concern that might be more appropriately addressed by another member of the team. For

example, in Jack's case, when speaking to the psychologist, Amy and Todd might discuss their religious beliefs and spirituality. Although Amy receives support from their religious community, Todd may feel abandoned in their time of need. Their faith, once a shared source of strength and support, is no longer a source of solace for both of them. The psychologist can and should address this conflict but should also refer Amy and Todd to the team chaplain. Although each PPC team member has distinctly different subspecialized expertise, each can perform the initial assessment of a new concern with appropriate triage to the most suited team member.

Even when a fully resourced PPC team is present, nothing can replace the relationship that the patient and family has with their primary pediatrician. This is especially true when the family has been going to the same physician for many years and when the ill child's siblings receive care in the same office. The primary pediatrician is often the trusted person the family turns to when the child's condition is first diagnosed for reassurance, support, and direction. The primary pediatrician may even be the physician who originally diagnosed the life-threatening condition. Similarly, the family often returns to the primary pediatrician if and when the ill child's life ends, especially if the pediatrician continues to provide primary care to the siblings. Even (and sometimes particularly) when families encounter multiple clinicians during their child's illness, the primary pediatrician commonly remains the most trusted clinician who knows the child, the family, and the child's course through life. This relationship offers a sense of comfort, safety, and familiarity for most families.

As the medical climate changes and physicians are pushed to see patients with more complex conditions more quickly, addressing all psychosocial issues is becoming increasingly difficult. Most pediatricians' offices do not have dedicated psychosocial support staff, which further compromises access to needed resources for families. Advocating for a palliative care team's services at the time of diagnosis can benefit both the pediatrician and the family. Palliative care teams can help the pediatrician access multiple health care professionals who can address the many psychosocial needs or concerns that arise during inpatient and/or outpatient care. Care coordination is enhanced by the PPC team's core value of ongoing communication with the pediatrician, relieving some of the burden faced by the general pediatrician and practice staff. Individual chaplains, psychologists, expressive therapists, case managers, and CLSs are not widely available in the outpatient arena and in the community; consultation with a palliative care team permits easy access to these services.

A palliative care consultation endorsed by the general pediatrician can also help the family feel more comfortable with the suggestion of palliative care. Because of widespread misunderstanding of the term and confusion with the model of care available to most adults, children and families often have the perception that the ill child is dying or going to die soon when they hear the words "palliative care." Although death may be imminent for some patients for whom palliative care is consulted, for most this is not the case, especially as PPC is integrated closer to the time of diagnosis of a life-threatening condition and before end of life. Reassurance from the general pediatrician as to why the referral occurred will often set patients' and families' minds at ease and helps prepare them to work directly with the team.

Palliative care resources vary across the country. Many children's hospitals have a palliative care team—69% according to a recent national cross-sectional survey. However, not all PPC teams have the breadth of service described in this article. Even if available teams do not encompass each discipline discussed above, those who make up the team are trained in such a way that they can assess patients' and families' needs and make referrals as appropriate. If professionals or families are unable to find a local PPC team through the local children's hospital or medical center, the American Academy of Hospice and Palliative Medicine (www.aahpm.org). In addition, the National Hospice and Palliative Care Organization (www.nhpco.org) also maintains a state-by-state listing of hospice and palliative care programs, located by clicking on the "Find a Hospice" link <https://netforum.nhpco.org/eWeb/DynamicPage.aspx?Site=NHPCO&WebKey=a9338cdd-546a-42f5-9061-6b91dbdb31da>. Another excellent resource is the American Academy of Pediatrics Section on Hospice and Palliative Medicine (<http://www2.aap.org/sections/palliative/default.html>), which offers additional information about pediatric palliative care.

CONCLUSION

Caring for children with complex, chronic, and potentially life-limiting conditions is a rewarding and challenging endeavor. The psychological and social support needs of the patient and family can be overwhelming, especially if there are few resources available to address these needs. Care can be enhanced by consulting a PPC team so that the psychosocial, practical, emotional, and spiritual needs of the child and family can be met in the best ways possible; a PPC team offers comfort and guidance by caring clinicians of many different disciplines at all times.

Summary

- The families of children with complex, chronic, and potentially life-limiting conditions encounter difficult situations as they navigate through the medical system and adjust their lives to caring for a child with a serious condition.
- Challenges include the child's physical needs and the child's and family's psychosocial, financial, spiritual, social, and emotional needs.
- Psychosocial interdisciplinary team members can help address these concerns, with ongoing follow-up, either directly or through referral.
- A palliative care referral can effortlessly expand the breadth of services available to families in overwhelming situations, helping to ease their burden.

The case, continued: *Amy and Todd met with the physician and social worker from the hospital's PPC team later that day. By identifying Amy's and Todd's foremost concerns and goals for Jack's care, the team was able to help formulate a plan that the family could feel comfortable implementing. Amy and Todd expressed their desire to bring Jack home and focus on his comfort; this prompted the team to initiate a discussion about hospice care and additional supportive services. During the next few days, Amy and Todd met with all the members of the PPC team. Each team member completed an assessment and offered expertise and services as appropriate. Jack was soon discharged to home hospice in collaboration with the PPC team and Jack's pediatrician. Team members made home visits during the following few months, addressing concerns as they arose and continually ensuring that care decisions were consistent with Amy and Todd's wishes. The CLS met with Anna several times to help her process Jack's condition, her parents' emotions, and her role in his life. Jack continued to follow up with his subspecialists but had no further hospital admissions. His SMA progressed, and at 11 months of age he developed pneumonia. His parents wished to keep him comfortable at home, and his life ended peacefully in his mother's arms with his father*

and sister at his side. The PPC bereavement specialist continues to work with the family and provide bereavement support.

Suggested Reading

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Parent Resources from the AAP at HealthyChildren.org

- English: <http://www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/What-is-a-Hospice-and-Palliative-Medicine-Pediatrician.aspx>

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Pediatrics in Review 2014;35;390

DOI: 10.1542/pir.35-9-390

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Pediatrics in Review

An Official Journal of the American Academy of Pediatrics

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