

Partners in Pediatric Palliative Care: A Program to Enhance Collaboration Between Hospital and Community Palliative Care Services

Jean M. Carroll, BSN, Gina Santucci, MSN, Tammy I. Kang, MD,
and Chris Feudtner, MD, PhD, MPH

The provision of high-quality palliative care services to dying children and their families often requires extensive collaboration between hospital-based and community-based care teams. This article describes the origins and development of the Partners in Pediatric Palliative Care program, which has provided pediatric-specific educational offerings and fostered joint endeavors between a palliative care service located in a tertiary care children's hospital and a wide range of hospice and home care agencies in 5 states. The Partners in Pediatric Palliative Care program is evaluated in terms of the favorable ratings

that attendees have given the educational components, the relatively modest direct costs of mounting the regional meetings, and the expanded capacity to provide home-based palliative services to children and families who desire them. The Partners in Pediatric Palliative Care program provides another feasible means for hospitals and community agencies to work together to improve pediatric palliative care.

Keywords: palliative care; pediatric; children; home; hospital; community; hospice

To provide high-quality palliative and end-of-life care, care teams located in hospitals and in the community often must collaborate closely, which requires clear communication and joint coordination of treatments and services. Several experts have endorsed the importance of this integration of care across the sites of care that range from hospital to home. In 2001, the National Hospice and Palliative Care Organization and the Center to Advance Palliative Care studied various hospital-hospice partnerships around the country and noted that regarding palliative care, "new approaches are built on partnerships between the hospitals and hospice programs, tapping the expertise of both partners, emphasizing an

interdisciplinary approach to care and extending patient- and family-centered, supportive palliative care to seriously ill hospitalized patients earlier in their illnesses."¹

When the palliative care patient is a child, the importance of hospital-community integration is perhaps even greater. Most children who die from complex chronic conditions, which is to say, not due to trauma or sudden unexpected medical illness, are hospitalized in the months or weeks leading up to their deaths, underscoring the significance of hospital-based teams.² But these teams are not sufficient, as a greater proportion of these children are returning home to die.³

Most community-based hospice/home care agencies that provide palliative or end-of-life services are oriented toward the care of adult patients. The Institute of Medicine report, *When Children Die*, observed that, "when the child and family return home, they may have to rely on professionals and providers with limited experience in caring for children with advanced illnesses or providing palliative and end-of-life care. The coordination, continuity, and quality of a child's care may suffer as a result"⁴

From Pediatric Advanced Care Team, The Children's Hospital of Philadelphia (JMC, GS, TIK, CF); Department of Pediatrics, University of Pennsylvania School of Medicine (TIK, CF); and The Leonard Davis Institute and the Center for Bioethics, University of Pennsylvania (CF), Philadelphia, Pennsylvania.

Address correspondence to: Chris Feudtner, MD, PhD, MPH, The Children's Hospital of Philadelphia, General Pediatrics, 3535 Market Street, Rm 1523, 34th & Civic Center Boulevard, Philadelphia, PA 19104; e-mail: feudtner@email.chop.edu.

In this report, we describe the origins and implementation of a program designed to improve the collaboration and quality of hospital-community palliative care services, so that other sites wishing to replicate this type of partnership program could do so.

Formation and Limitations of the Hospital-Based Pediatric Advanced Care Team

Established in 2003 at The Children's Hospital of Philadelphia (CHOP), the Pediatric Advanced Care Team (PACT) is dedicated to the mission of relieving suffering and improving the quality of life for children living with life-shortening conditions and for their families. The PACT is multidisciplinary, consisting of 8 physicians from diverse pediatric subspecialties, 2 nurse coordinators, a social worker, 2 child life specialists, a bereavement counselor, a psychologist, and a chaplain. This team functions as a consult service that is always available for patients and families at the request of the patient, family, or any member of the health care team.

From the outset, the PACT members realized that they needed to "think outside the hospital." One of the PACT's main goals is to honor the wishes of the child or family about whether to remain in the hospital or go home. A key task, consequently, is to facilitate high-quality care during transitions from hospital to home, or vice-versa. If the decision is made to provide care in the home, then the PACT nurse coordinators must collaborate with the patient's principal speciality care team and the hospital case managers and also with hospice/home care agencies so that optimal services are planned for and provided.

The PACT's experiences over the past few years with caring for patients during the course of their illness trajectory supports the importance of hospital-based palliative care programs becoming engaged with the community providers. From 2003 to 2005, the PACT consulted on the care of 212 infants, children, and adolescents. Of the 142 patients who have died (67%), 50% of the children or families had engaged hospice services, and among those who received home-based hospice service, 78% died at home.

Rationale for Partners in Pediatric Palliative Care Program

The Partners in Pediatric Palliative Care (PPPC) program evolved at the intersection of 2 sets of needs.

On the one hand, as already mentioned, the PACT realized the necessity of linking its hospital-based services to the services offered by community agencies to provide continuity and quality of care for dying children and their families as they journeyed between the in-patient hospital world and the home community.

On the other hand, most hospice/home care agencies in the Pennsylvania, New Jersey, and Delaware Tri-state area provided end-of-life care almost exclusively to the adult population and had minimal-to-no experience caring for dying children. As a consequence, many community-based providers were reluctant to assume the responsibility of caring for pediatric patients at the end of life.

Across the nation, this situation is not uncommon. "Adult-focused programs and staff are typically unprepared to respond to the infrequent pediatric referrals and also lack connections to pediatric providers to assist them in providing safe, appropriate hospice care."⁵ Furthermore, because "hospice services vary in the amount of experience their staff has had with dying children[,] some medical teams have to rely on [pediatric-focused] home care nursing agencies that are not primarily hospice organizations."⁶

With these 2 sets of needs in the background, the impetus for developing a partnership program between PACT and community hospice/home care agencies was a particular patient experience:

In the fall of 2003, the PACT was consulted by a neonatal intensive care physician about a newborn girl diagnosed with Trisomy 18 and multiple congenital anomalies that, when taken together, were not compatible with more than a few months of life. When asked, the parents clearly expressed their hopes that their daughter be comfortable and not suffer, and that they therefore were focused on her quality of life and wanted to take her home. With these priorities in mind, the multidisciplinary team's goals of care were to (1) transition the baby to a hospice home care program, (2) provide comfort and support measures as needed for the baby, and (3) provide the family system with bereavement resources as they progressed through their anticipatory grief and eventual loss.

A formidable challenge quickly emerged, however; namely, locating a hospice/home care agency in northwestern Pennsylvania that could support the goals of care for this infant and her family. Although the PACT found an agency, its staff had little or no experience with pediatric patients, especially not one weighing less than five pounds. Focused on the



Figure 1. Location of hospice/home care agencies that have attended a Partners in Pediatric Palliative Care program.

immediate needs of this infant and her family, PACT and the local hospice worked together to coordinate and support the necessary services. Six weeks after discharge, the infant died peacefully at home with hospice present.

The experience of working with the baby and her family underscored the need to establish a strong working relationship with hospice/home care agencies, providing 24/7 consultative support and meeting any self-identified educational needs for these agencies. From this specific case, the idea of a broader program offering started to take shape.

Many of the agencies PACT contacted for referrals were seeking guidance and support on a range of issues, including understanding how a child is likely to progress in his or her illness and what symptoms to expect before death; managing medications and dosages for pediatric pain; addressing respiratory symptoms, seizures, and gastrointestinal disturbances; engaging in difficult conversations with children, parents, siblings, and other family members; and responding to the myriad of bereavement-related issues associated with a child's death. How could these broader sets of common concerns be aired and addressed in an on-going collaborative manner across the hospital-community divide?

The PACT was aware of the multidisciplinary program run by San Diego Hospice, which was developed

by a free-standing hospice agency that partnered with pediatric hospitals in its region. The PACT approached the issue in reverse: as a hospital-based service, we sought to create a relationship with community-based hospice/home care agencies, developing a network among multidisciplinary health care providers with a common vision for pediatric palliative care.

Development and Growth of the Partners' Program

The PPPC program was launched with the purpose of sharing information, providing education and networking opportunities, and discussing issues of mutual concern for hospice and hospital staff. The PPPC programs, which have been held at CHOP 3 times a year, are offered to hospice/home care agency directors, medical staff, clinical nurse coordinators, social workers, bereavement specialists, pharmacists, respiratory therapists, and clergy. Since the first meeting in January 2004, the PPPC program has grown from 5 agencies and 10 participants to more than 32 agencies and more than 40 community-based providers attending each meeting. The program has drawn attendees from agencies in the 5-county region of Philadelphia as well as more distant parts of Pennsylvania, Delaware, and throughout New Jersey (Figure 1).

Each of the PPPC 4-hour programs has included educational presentations by the PACT staff, members of the CHOP staff, or community-based care providers on a range of topics that have included:

- Pain and symptom management
- Communication: talking with children and families about death and dying
- Caregiver burn out and techniques for self-care
- Hope and hopelessness in caring for children and families at the end of life
- Stories from the field: hospice/home-care providers sharing their experiences
- Pharmacology for pediatric end of life management

In addition to learning from didactic and participatory sessions that address these subjects, attendees have an opportunity to discuss cases from their practices, network with each other, and to pursue specific projects, which are facilitated by breakout sessions into more focused groups addressing either medical-nursing or psychosocial-bereavement issues.

The cost of mounting the PPPC program involved both PACT and hospice/home care agency staff time, of which we do not have any accurate measure, but chiefly involves organizing the meetings, preparing to lead sessions, and travel to and attendance at the meeting. More direct costs were meeting-associated meals, photocopying of educational materials, and rental of room space and audiovisual equipment, which has never exceeded a total cost of more than \$450 for a given meeting.

In a recent set of evaluations of the PPPC program, 19 community-based respondents, who on average had cared for 3 pediatric palliative care patients during the past year, rated the programs on a scale that ranged from strongly disagree (1) to strongly agree (7). They agreed (mean \pm SD) that attendance at the PPPC programs had enabled them to gain knowledge about caring for children with complex chronic conditions (5.8 ± 1.7), providing pain and symptom management (5.5 ± 1.8), talking with pediatric patients and their families about death or dying (6.2 ± 1.5), providing grief and bereavement services (6.2 ± 1.4), and that overall, the PPPC program had helped them feel more comfortable and confident working with dying pediatric patients and their families (6.2 ± 1.4) and improved the way they care for pediatric patients at the end of life (6.2 ± 1.4).

Anecdotally, participants have informed us that the PPPC program has fostered closer working relationships between hospice/home care agencies and

the PACT, and has provided beneficial networking opportunities for the participants.

Five Observations Regarding the Partners' Program

Through involvement in the PPPC program during the past 2 years, the PACT has learned—and had reinforced—several important lessons:

First, dying children and their families are often better able to identify their hopes and wishes if they are informed of the possibility of being cared for at home or in the hospital and are given choices about alternative means for providing palliative or end-of-life care. To present an array of possible choices, a hospital-based palliative care service must know not only the intricacies of the third-party payer reimbursement structure and how to optimize the utilization of benefits but also the range of community-based services and, conceivably, work in partnership with the existing hospice/home care agencies to expand the range of available high-quality services.

Second, most community agencies that previously were focused exclusively on the care of adults have welcomed the opportunity to expand their services to the pediatric population if they know they will be supported by PACT hospital staff. The round-the-clock availability of the PACT physician and nurse clinical team through a long-range pager to respond to any hospice staff's questions and concerns has (we hope!) not only improved the quality end-of-life care for children but has also made hospice/home care agencies more willing to accept pediatric cases.

Third, time spent by the PACT staff visiting hospice/home care agencies in their home communities has been invaluable, an experience that has built relationships, facilitated communication, identified issues for improving the partnership, and provided a first-hand understanding of the challenges facing hospice home care agencies.

Fourth, the community-based hospice/home care providers often have insights into the management of particular patients or certain clinical problems that the PACT members do not have. In one instance, the hospice nurse suggested a method of treating an adolescent patient hospitalized with a bowel obstruction that was so effective that the patient was discharged home where she was far more comfortable and, in her final days, able to eat with enjoyment her favorite foods (including nacho-flavored chips and peanut butter and jelly sandwiches). At

Table 1. Collaborative Hospital-Community Projects Spawned by the Partners in Pediatric Palliative Care Program

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- Creation of a pediatric-specific comfort kit to standardize emergency medications available in the home to hospice and family members
 - Identification of a set of tools and techniques for social workers to help improve support for children at the end of life and their families and to reduce caregivers' stress
 - Joint planning of programs that meet the educational needs identified by the group
 - Development of an advocacy and policy network to address issues specifically related to optimizing benefits and services for pediatric patients at the end of life
 - Conduct of an education series in which PACT team members visited hospice/home care agencies to provide education and on-going support
 - Offering a 2-day End-of-Life Nursing Education Consortium (ELNEC) training program, a curriculum specifically developed for nurses working in end-of-life care developed by the City of Hope and the American Association of Colleges of Nursing through a Robert Wood Johnson Foundation grant
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the PPPC program meetings, sharing of stories from the field by hospice/home care workers enables some powerful learning to occur, not only regarding techniques in the care of patients but also fostering participant awareness that they are not alone with their concerns and anxieties about caring for children at the end of life.

Finally, and in sum, the PPPC program has been able to provide more than a forum for education and networking. It has evolved into a framework for a hospice-hospital collaboration spanning across the disparate locations of pediatric palliative and end-of-life care, a partnership that has initiated a number of specific joint projects (see Table 1) that would have never come into existence without the PPPC.

Conclusion

The PPPC program suggests that if healthcare providers—be they located primarily in hospital or in community settings—are willing to work together as part of a larger multi-institutional team with a shared vision, through their combined skill, knowledge, and expertise, they can offer more high-quality palliative and end-of-life care choices to the population of dying children and their families.

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