

Interdisciplinary Interventions To Improve Pediatric Palliative Care and Reduce Health Care Professional Suffering

CYNDA HYLTON RUSHTON, D.N.Sc., R.N.,^{1,2} ELIZABETH REDER, M.A.,²
BARBARA HALL, R.N.,² KATHERINE COMELLO, M.S.N., R.N.,²
DEBORAH E. SELLERS, Ph.D.,³ and NANCY HUTTON, M.D.⁴

ABSTRACT

Objective: To implement and evaluate a quality improvement program of interdisciplinary palliative care education and support intended to increase the competence, confidence and ability to manage personal grief of health care professionals caring for dying children.

Setting: A children's hospital in an urban academic medical center.

Participants: Pediatric health care professionals of all disciplines caring for children with life-threatening conditions.

Interventions: We initiated a quality improvement program of professional education and support consisting of four interdisciplinary activities facilitated by the pediatric palliative care team. The Compassionate Care Network (CCN) provides an open forum for interdisciplinary networking and education. Palliative Care Rounds (PCR) provides education through monthly case-based discussions on selected units. Patient Care Conferences (PCC) facilitate communication and care planning for selected patients with palliative care needs on any unit in the children's center. Bereavement Debriefing Sessions (BDS) offer health professionals the opportunity to manage their responses to grief after a patient's death.

Evaluation measures: From February 2002 to September 2003, we prospectively tracked the frequency of sessions conducted, the number and discipline of attendees, the age and diagnosis of patients discussed, and themes raised at each session. Participants evaluated each session.

Results: One hundred one sessions were conducted (PCR = 31, PCC = 23, CCN = 9, BDS = 38) for 950 participants (PCR = 312, PCC = 188, CCN = 193, BDS = 257). All units and disciplines participated in one or more sessions. Evaluations report that sessions are informative and will influence future professional practice.

Conclusions: A program of interdisciplinary interventions can successfully educate and support health care professionals in providing palliative and end-of-life care for children. This program model can be applied in diverse pediatric health care settings.

¹School of Nursing, ²The Johns Hopkins Children's Center, ⁴School of Medicine, Department of Pediatrics, The Johns Hopkins University, Baltimore, Maryland.

³Education Development Center, Inc., Newton, Massachusetts.

INTRODUCTION

TO IMPROVE THE QUALITY OF CARE given to dying children and their families, leaders at the Johns Hopkins Children's Center (JHCC) initiated a pediatric palliative care program. An action plan was designed to respond to an initial assessment that found significant distress among health care professionals. Implementation included establishing an interdisciplinary network to support palliative and end-of-life care; its members served as liaisons for pediatric palliative care to the units and disciplines they represented. In addition, three activities—palliative care rounds, patient care conferences, and bereavement debriefings—were implemented on the three units in the JHCC that cared for the most children with life-threatening conditions.

This paper reports on the development and implementation of those interventions and discusses the programs' assumptions and guiding principles.

ASSESSING END-OF-LIFE CARE

The JHCC is a 165-bed tertiary children's hospital within a large academic medical center. With eight different units and a separate pediatric emergency department, the Center provides 7000 inpatient admissions and 70,000 outpatient visits per year. Approximately 120 pediatric and adolescent patients die annually. The three inpatient units with the highest number of children with life-threatening conditions are the Pediatric Intensive Care Unit (PICU), Neonatal Intensive Care Unit (NICU), and Pediatric Oncology (ONC). The JHCC is affiliated with the Johns Hopkins Home Care Group, which provides home care to children with life-threatening conditions, and a regional community-based hospice.

In 1997, the JHCC established an interdisciplinary committee to assess the quality of end-of-life care for its patients. Members, appointed from all disciplines and clinical services caring for children with life-threatening conditions, worked intensively together for 3 years to study this issue. This group met monthly to develop and implement an ambitious plan to evaluate current practices, identify barriers, and develop consensus about solutions.

They launched their planning by assessing knowledge, attitudes, beliefs, and concerns re-

garding palliative and end-of-life care among interdisciplinary health care professionals through the use of a survey, focus groups, and individual interviews with staff and bereaved families. The survey instrument, which was developed after a thorough review of the literature on family-centered care and ethical guidelines for the treatment of children near the end of life, addressed issues specific to pediatric decision-making as well as a wide range of ethical and legal issues in end-of-life care.¹

Findings were provocative. Although families reported satisfaction with the care provided for their dying child, health care professionals expressed significant levels of distress, as reported through all three data collection modalities. Many believed that the care provided was not optimal, in part because it caused undue burdens on children and their families *and* on the health care professionals providing that care. Often they expressed concerns about poor communication or conflict among staff and between staff and families. It also appeared that health care team members were insulating children and families from the stresses associated with poor communication, diminished collaboration, and unacknowledged grief.

The impact on the caregivers was cumulative and significant. Respondents talked of an unspoken burden upon staff members who sustained multiple losses without explicit professional or institutional support for their grief. As the analysis proceeded, it became clear that the health care professionals who care for children with life-threatening conditions were themselves suffering not only in grief over the child's circumstances, but also because of role conflicts, or situations that caused moral distress or loss of professional integrity.

Although the needs assessment underscored the importance of caregiver suffering, it is not a new concept. Suffering and loss are intrinsic and inevitable dimensions of caring for children with life-threatening conditions. According to Reich,² suffering is "an anguish experienced as a threat to our composure, our integrity, the fulfillment of our intentions, and more deeply as a frustration to the concrete meaning that we have found in our personal experience. It is the anguish over the injury or threat to the injury to the self and thus the meaning of the self that is at the core of suffering." Suffering for and with patients and families is inherent in health care professional roles.

Health care professionals struggle to balance competing professional and ethical obligations and preserve a sense of wholeness.³⁻⁶ In a national, multisite survey of health care professional views on decisions near the end of life, almost half (47%) of all respondents reported that they had acted against their consciences in providing care to the terminally ill. Seven out of ten house officers reported distress, and five out of ten nurses.⁷

Their integrity can be threatened in myriad ways, including competing interests of patients, families and other team members, the organization where they practice, and even by their own behaviors and feelings. As a result, nurses and other health care professionals may experience conflicts, dilemmas, and, in some instances, moral distress.⁸⁻¹⁰ Acting in a manner contrary to personal and professional values undermines the individual's integrity and authenticity. Moral distress, in contrast to other kinds of distress, involves an irreconcilable conflict between one's ethical commitments and the action required for congruence between or among them. Although the sources of moral distress and threats to integrity for doctors and nurses are similar, there are differences in how they perceive their distress.⁵

Several of these differences are highlighted in a national survey of attitudes of pediatric critical care physicians and nurses on end-of-life care.¹¹⁻¹⁴ More physicians (78%) than nurses (57%) agreed that withholding and withdrawing care are "ethically the same," while no one in the two groups judged either practice unethical. Physicians were more likely than nurses to believe that families are well informed about the burdens and benefits of further treatment (99% versus 89%); that ethical issues are discussed well within the care team (92% versus 59%); and that ethical issues are discussed well with the family (91% versus 79%).

These differences in perspectives may lead to interdisciplinary conflicts. Such conflicts are identified as a common source of moral distress, a special form of suffering.^{3,9,15} Interdisciplinary conflicts may become more acute when important values are at stake. Values guiding the care of children living with life-threatening conditions may be or be perceived to be in conflict among diverse interdisciplinary team members. When interdisciplinary conflicts are not resolved, the costs to the entire team can be significant and far reaching.¹⁶

CREATING AN ACTION PLAN

The needs assessment led to the establishment of the pediatric palliative care program, known as Harriet Lane Compassionate Care (HLCC) in July 2000. The HLCC Team includes a program director, medical director, bereavement coordinator, and family care coordinator. Through educational initiatives, facilitation, and individual interventions, the program strives to integrate pediatric palliative care into clinical practice, education, and research. Not a typical medical model of consultation, the service uses an empowerment, facilitation model similar to ethics consultation to support members of the health care team to build on their existing knowledge and skills through mentoring, support, and clinical guidance.¹⁷

The team's underlying hypothesis is simple: health care professionals will provide better care and support to seriously ill children and their families when they feel supported personally and professionally in their work.

In collaboration with Education Development Center's Initiative for Pediatric Palliative Care (see www.ippcweb.org), which provided financial support and technical assistance, the JHCC interdisciplinary team initiated a quality improvement program and developed a specific action plan to help health care professionals.

- Increase their competence and confidence in providing pediatric palliative care
- Increase their ability to manage responses of grief
- Restore and maintain their sense of professional integrity.

Implementing the action plan

To achieve these objectives and desired outcomes, the HLCC developed four interventions. Each was designed to foster interdisciplinary participation. The first intervention established a compassionate care network (CCN) to integrate palliative and end-of-life care (PEOLC) information and expertise across all units in the Children's Center.

The remaining three interventions were activities directly linked to the care of individual patients: palliative care rounds, patient care conferences, and bereavement debriefing sessions. During the study period (February 2002 to Sep-

TABLE 1. OVERVIEW OF INTERVENTIONS LINKED TO CARE OF INDIVIDUAL PATIENTS

	<i>Palliative care rounds</i>	<i>Patient care conferences</i>	<i>Bereavement debriefings</i>
# Held	31	23	38 (31 children)
# Attendees	312	188	257
Attendees by discipline in %			
Physicians	40%	41%	14%
Nurses	35%	31%	63%
Social workers	7%	11%	3%
Child life specialists	6%	10%	7%
Other	Chaplains 2%	Medical students 3%	Physician assistants and nurse practitioners 5%
	Respiratory therapists 1%	Physician assistants 2%	
	Students 4%	Nutritionists 2%	Students 5%

tember 2003), each intervention was made available to the three units with the greatest number of children with life-threatening conditions (PICU, NICU, and ONC); other units throughout the JHCC participated in the interventions to a lesser extent. All members of the interdisciplinary care team were invited to participate, and attendance was interdisciplinary, as shown in Table 1. These interventions are described in terms of feasibility and utilization, content and participant assessment of usefulness. A consistent note taker, using forms developed by the HLCC team for each intervention, documented the content of the various intervention sessions. Content analysis was conducted on these forms as well as on the responses to open-ended questions on the participant evaluation forms that were developed for and administered at all intervention activities. A more formal evaluation of the impact of these interventions on clinical attitudes and practice is reported elsewhere.¹⁸

ESTABLISHING THE NETWORK

To build a community to support the work of the group and build capacity in PEOLC, the JHCC established the HLCC Network in June 2001. Currently 69 members, the network includes physicians (22%), nurses (49%), social workers (13%), child life specialists (8%) and other health care professionals (7%) from every unit/department in the Children’s Center, pediatric home care, and Kennedy Krieger Institute (an affiliated rehabilitation hospital).

Recruitment of interdisciplinary team members targeted key clinicians and leaders in the

JHCC. Attention was given to inviting individuals that were from diverse disciplines, practice areas, years of experience (from novice to seasoned clinician), and leadership within the JHCC. Additionally, volunteers who had expressed an interest in palliative care or who were frequently involved in the care of children living with life-threatening conditions were also recruited. The HLCC team sought out individuals who had the time to devote to the initiative, the capacity to be a liaison between their service area and the HLCC, were willing to engage in learning more about the content area, and whose goals were aligned with those of the HLCC. Network members are asked to serve as liaisons for pediatric palliative care to the units and disciplines they represent. They play a key role in clinical case finding and in helping to identify issues and content resource needs for other health care professionals at the JHCC.

Feasibility and utilization

In its first 2 years, the network sponsored three intensive training sessions and held six quarterly meetings. A total of 73 people participated in the intensive training sessions; attendance at quarterly meetings averaged 20 people per session. Participants included all members of the interdisciplinary team and represented a diverse cross section of clinical specialties.

Content

Content of the quarterly meetings and intensive training sessions was based on an initial needs assessment and ongoing feedback from the participants. Each quarterly meeting involved

sharing of progress, networking discussions, an educational component, and community building. The meetings addressed a wide range of issues involved in palliative and end-of-life care. Topics ranged from how to track deaths within the JHCC accurately to how to integrate palliative and end-of-life care into respective patient populations. Other topics discussed included the role of the HLCC, strengths and challenges of each unit or specialty, triggers for palliative and end-of-life care, identifying and documenting goals of care, resources for palliative and end-of-life care, hospice, bereavement, and strategies for offering a new palliative and end-of-life care curriculum.

The first intensive training session was a full-day event in June 2002, designed to raise awareness about palliative care issues, develop a sense of community, and provide a supportive, nurturing setting for learning and renewal. The second day-long event was held in October 2002 to discuss the topics of loss, grief, and bereavement. The third, a half-day session in April 2003, addressed pain and symptom management using components of the IPPC curriculum (www.ippcweb.org) Strategies to build a sense of professional community included using off-site locations that allowed participants to get away from clinical duties and programming the sessions to allow for both education and networking.

Participants' views of usefulness

Evaluation forms were developed for each of the three training sessions to assess usefulness of content and methods, application to clinical practice and assess future needs. Findings indicate high levels of engagement and intentionality about building community. Many participants identified the importance of holding the sessions in a nurturing, off site location where an environment of trust, respect and safety was created. Equally important was the benefit of interdisciplinary exchange and understanding. Participants reported that the sessions increased their capacity to provide palliative care and integrate it into care on the units where they practiced. Participants in each session identified specific new learning that would influence their clinical practice. The initiation of weekly psychosocial rounds on the oncology unit and the development of a pilot program for palliative home care demonstrated the benefits of encouraging the network

members to integrate PEOLC beyond the activities outlined in the study team's original plan.

PALLIATIVE CARE ROUNDS

From February 2002 to September 2003, Palliative Care Rounds (PCR) were held on each of the three inpatient units. These monthly educational sessions used the familiar model of Attending Rounds: health care team members identified in advance a patient from among their current or recent caseload that exemplified the need for palliative and/or end-of-life care. Members of the HLCC team facilitated the discussion, encouraging input from all the professional disciplines represented. Often a physician resident or fellow presented the medical facts of the case, the goals of care for the patient, and members of the interdisciplinary team shared psychosocial, emotional and spiritual information about the patient and family. A discussion of the holistic needs of the patient was facilitated to involve the entire interdisciplinary team. Particular teaching points were highlighted and explored with the group. Each session concluded with a summary of key content and implications for the current and future cases. Often the emotional needs of the health care team were acknowledged and explored.

Feasibility and utilization

During the study period, the HLCC team facilitated 31 palliative care rounds. (see Table 1). Rounds were evenly distributed across the three participating inpatient units (PICU, 10; NICU, 11; ONC, 10). The patients chosen by the unit teams for discussion spanned the pediatric age range from newborn to 17 years old. They had a range of diagnoses and life expectancy. Of the children discussed, 6 had cardiac disease, 6 had leukemia (acute monoblastic leukemia [AML] or acute lymphocytic leukemia [ALL]), 5 were premature newborns, 4 were admitted because of lung disease, 3 had other forms of cancer, and 3 had a genetic disorder. Four children were discussed on two different units (usually ONC and PICU). Eighteen of the children (58%) died during the study period.

Content

Rounds addressed a range of themes. The two most frequently raised themes were "discussion

with the family about prognosis" (19) and "family support" (17). Other family-related topics were "parental/staff disagreement reaching decisions" (8) and "discussion with siblings about prognosis" (7). "Coordination of care" (16) ranked third in number of mentions; this one concept was echoed in "difference in goals between services" (10). "Discussion of the prognosis with patient" was cited at least a third of the time (10).

Finally, the fourth-ranked theme "treatment not working" (11) is also reflected in the discussion of possible medical goals. The most frequent goals that were identified involved "improving function" (18) and "relieving pain" (13). "Cure" was identified as a goal least frequently, with only one mention; "peaceful death" was mentioned only twice. Discharge issues ranked third and fourth (home, 9; facility, 8).

Participants' assessments of usefulness

In 136 of 138 evaluations, participants reported that palliative care rounds were helpful and informative. Seventy-nine participants reported having attended rounds two or more times previously, a strong indication that those who participated valued the experience enough to attend repeatedly. When asked what impact the session would have on the participant's practice, responses included "encourages me to be a strong advocate for the patient and family," "learned feelings of other team members," "shows need for pastoral care perspective," learned "specific ways to help patient and family in terminal phase," and "helped to organize thoughts for upcoming meetings."

The impact of the care rounds may be partially evidenced in the follow-up they inspired. Following the 31 rounds were 38 additional activities. These included patient care conferences, family meetings, and referrals for service (9 each, most often requested by the NICU and PICU), four referrals for hospice requested by oncology, three referrals for other specialty services to be involved, two referrals for both pastoral care and social work services, and four debriefings upon the death of the patient discussed.

PATIENT CARE CONFERENCES

Patient Care Conferences (PCC) were designed to help identify and clarify goals and plans of care

for individual patients with palliative and end-of-life care needs. Health care professionals directly involved in the patient's care were invited to attend these interdisciplinary team meetings.

Each session was facilitated by a member of the HLCC team who followed a set format to clarify issues, identify next steps, develop an implementation plan, and ensuring that all members of the interdisciplinary team had an opportunity to identify and discuss issues of concern. In some cases, the team determined that additional PCCs were needed at regular intervals to discuss evolving issues and goals. The format developed to guide each PCC included patient demographics, reason for the conference, summary of the child's illness, identification of patient/family/staff needs and issues, creating a palliative care plan, formulating a discharge plan, and follow-up.

The Family Care Coordinator (FCC) played a vital role in case finding and in implementing the patient care conference intervention. A highly competent and respected nurse who had long-standing relationships with JHCC health care professionals, particularly physicians, the FCC had broad responsibility for identification of family needs and actual or potential conflicts between families and the health care team.

Surveillance of the JHCC for potential cases included applying a broad set of triggers for palliative and end-of-life care, as shown in Table 2. When a PCC was requested by a member of the health care team or initiated by the HLCC team, the FCC reviewed the patient's chart and consulted with key members of the health care team

TABLE 2. TRIGGERS FOR A PEDIATRIC PALLIATIVE CARE CONFERENCE

Does this patient have a disease that will limit his/her life span?
Would you be surprised if this patient died in the next 6-12 months?
Has the frequency of hospitalizations increased during the past 6-12 months?
Has there been a major clinical event (e.g., relapse, need for transplant) related to this patient's condition?
Does the patient have symptoms that have changed the frequency of clinic visits?
Has there been a change or deterioration in the patient's response to treatment, pain intensity, energy, functional status, respiratory function, mental status, or quality of life?
Is there conflict among the family or the health care team about the goals of care?

to determine essential participants. The goal was to be inclusive of all major services involved in the patient's care, with particular attention to staff members who were experiencing concern or conflict about the case.

Feasibility and utilization

Over the study period, there were 23 patient care conferences conducted with 188 attendees (see Table 1). Patients discussed in PCCs reflected a range of primary diagnoses, including glioblastoma, cystic fibrosis, lissencephaly, HIV disease, renal failure, aplastic anemia, hyperammonemia, and connective tissue disorder. As was true of palliative care rounds, attendees at the patient care conferences were predominantly physicians (41%) and nurses (31%).

Whereas rounds were piloted in three specific units, patient care conferences were available for patients throughout the JHCC and were held in six different units, including outpatient (5), three medical surgical units focusing on different age groups (5, 5, and 2), PICU (4), and a pediatric clinical research unit (2). Two of the 23 conferences were initiated by the FCC, and 21 by others. In seven cases, dialogue with the FCC about the issues in a particular case resulted in a PCC being suggested as a strategy to address the concerns.

Content

Participants cited multiple reasons for the 23 care conferences. The most frequent were goal setting (15) and information sharing (14). Conflicts between family and staff (8) and among staff (6) were also cited. Four conferences involved cases with do-not-resuscitate orders (DNRs). Professional distress was cited twice. Change in the patient's condition and uncertainty were each mentioned five times.

The "primary concern" in 14 of the 23 conferences was parental and staff disagreement about decisions. Differing cultural and religious values was the primary concern in 4 conferences and staff concern about the parents' expectations was primary in 3.

Multiple staff issues were identified during the conferences. Most frequently cited were conflicts and continuity of care. Of 32 mentions, 10 (31%) involved conflict with family and 8 (25%) involved conflict among health care professionals. Eight (25%) identified discontinuity of care as a significant barrier to palliative care.

Participants' views of usefulness

Fifty-six health care professionals evaluated patient care conferences in which they participated. They overwhelmingly indicated that the conferences offered enough opportunities for discussion, were supportive and noncritical, helped make the team well informed, and addressed their needs as health care professionals (52 of 56 on each item, or 93%). Other indicators ranked 86% or higher, with the exception of improved morale, which evaluators ranked higher for their teams (61%) than for themselves as individuals (45%). Intentionally creating opportunities for interdisciplinary dialogue appears to be supportive to health care professionals. Whether there is a direct relationship between the degree of perceived support and the quality of care provided to patients and families requires further study.

BEREAVEMENT DEBRIEFINGS

To provide opportunities for staff to manage their responses to grief, the team instituted bereavement debriefing sessions (BDS) as an intervention after patient deaths and provided opportunities for individual follow-up.

The format for the BDS was adapted from the traditional critical incident stress debriefing model. Initially designed to address responses to unusual situations, the sessions were adapted to help health care professionals realize that the physical, emotional, social, and spiritual responses they experience after patient deaths were normal, natural responses to situations they regularly encounter.

Education about the grief process and recommendations for support were part of each session. This included normal responses to grief and loss and strategies for coping with multiples losses. Recommendations for support included good self-care, healthy expressions of grief, the use of support systems and opportunities for meaning-making.

Consistent with the literature,^{19,20} the committee assumed that reflection on the child's life and meaning-making would help health care professionals to make sense of the losses they experience, find benefit or renew purpose in their work. Therefore, the debriefing format included standard open-ended questions such as, "What will you remember most about this child and family?"

and "How can we honor this child?" These open-ended questions invited participants to reflect on their experiences and to create a sense of meaning from serving a particular child and family. Debriefing sessions also included informal rituals of remembrance, such as sharing a poem or signing sympathy cards.

The Bereavement Coordinator contacted the nurse manager, primary physician, and primary health care professional to offer a session. The sessions were facilitated by the HLCC team using a preset format. In some cases, scheduling involved multiple sessions to accommodate multiple disciplines responsible for a patient's care. In all cases, sessions were scheduled at times convenient to the participants. Special sessions were established for residents to facilitate their involvement.

Feasibility and utilization

From February 2002 to May 2003, 38 bereavement debriefing sessions were held for 31 different children. Seven of the 31 were discussed in multiple debriefing sessions held to accommodate multiple units/services involved in their care. Seventeen of the sessions were for oncology patients, 5 were for patients with chronic renal disease or lung disease, 2 sessions were held for patients with HIV and 2 were for patients on the critical care unit. During this time, there were 159 pediatric deaths (see Table 1 for details on attendees).

Content

Study data showed professional distress was the most frequent reason for initiating a session (33 of the 38 sessions), validating the original intent for establishing the debriefings. Sudden/unexpected death was a factor in 9 of the 38 sessions. Professionals who declined debriefings noted no professional distress and stated that the patient's death was expected.

One of the key questions asked in each session was, "What was the most difficult aspect of the case?" The most common theme in response to this question was that the death ended a long-term relationship with the patient (31 of 38 sessions), validating Papatatou et al.'s^{21,22} conclusion that the loss of such relationships significantly affects health care professionals. Conflict with the family was a difficult aspect in 9 cases; sudden or unexpected death in 6. The inability to

relieve pain and the provision of care perceived as overly aggressive were each cited as factors in 5 cases. The frequency at which these difficult aspects were cited diminished over the study period, perhaps as a result of the increase in patient care conferences specifically designed to explore patient/family goals of care. The concerns cited are consistent with the findings of Solomon and colleagues.¹

One key question was, "What was the most satisfying aspect of the case?" The most frequent theme in response to this question was working as a team (15 of 38 sessions). These data may be interpreted as supporting Papadatou et al.'s²¹ conclusion that lack of team cohesion and collaboration undermines the integrity of health care professionals; alternately, they may be interpreted as suggesting that working as a team is highly satisfying. Responses also cited sense of closure (9), helping the patient die respectfully (10), and helping the family (7) as sources of satisfaction.

Participants' views on usefulness

The evaluation form included questions related to the bereavement debriefing session and questions related to the actual case. Evaluations were received from 29 of the 38 sessions; 184 of the 257 attendees completed an evaluation form. Attendees consistently rated the session as helpful (98.4%), informative (97.8%) and meaningful (97.8%). Many reported that they had attended sessions 2 or more times previously (43%). In response to the question, "How will this session change your professional practice?" attendees acknowledged the importance of effective communication with staff and families (10) and reported they felt less isolated/more connected with their colleagues (12). They also reported that they gained knowledge in coping strategies (12).

DISCUSSION

The goal of the HLCC is to provide excellent care for children who live with life-threatening conditions, some of whom will die. The underlying and operative assumptions are simple: quality palliative care must be integrated into the care of all patients living with life-threatening conditions and that everyone—every health care professional, regardless of discipline—is ac-

countable for having the knowledge and skills to do so.²³

In its initial program assessment, the HLCC acknowledged that issues of disagreement and staff distress and suffering were prominent. The action plan and interventions subsequently developed specifically addressed these concerns as critical to the sense of integrity for health care professionals. In order for every child to receive the highest quality care, regardless of the outcome, the caregivers themselves must be supported in acquiring and using new knowledge and skills.

A comprehensive approach that includes clinical skills, psychosocial support, meaning making, and offering opportunities to integrate palliative and end-of-life knowledge and skills is critical to meeting the diverse needs of the interdisciplinary health care team. Techniques such as using triggers for considering palliative care issues can play a key role in identifying patients or situations that could benefit from a forum for interdisciplinary discussion. Throughout the implementation of the action plan, the voices of suffering became more audible, perhaps because participants were invited to acknowledge it and name it, and respond to it rather than deny or repress it.

The health care professionals who provide palliative and end-of-life care must desire the changes in institutional culture necessary to achieve this goal. The HLCC team devised interventions that respected the strengths, traditions, and values of the institution and its different units, and also recognized individual styles of learning and accommodating change. Instead of developing a more traditional specialty consultation model, the HLCC program stressed an educational and supportive role that is inclusive of all disciplines in every setting. Rather than imposing a model or approach on health care professionals, the HLCC intentionally created partnerships and alliances with interdisciplinary team members.

Anecdotal reports affirmed the effects of this approach on behaviors. One resident in his last year of training commented that, "We never would have had this type of discussion when I was an intern." At a debriefing session for a child who had received care at the JHCC for 15 years, health care team members expressed pride that their efforts had allowed her to live by her own values during the dying process. They also expressed certainty that her family

would be able to go on with their lives as a result of their care.

The interventions tested during the study period created a learning environment where interdisciplinary team members could acquire clinical, psychosocial, and spiritual knowledge and skills and have opportunities to give and receive support from their colleagues. Acquiring new skills in palliative and end-of-life care demanded a departure from the traditional lecture format. Instead, the HLCC used a relationship centered, dialogue format in conjunction with a facilitation model. Facilitation was chosen over an authoritarian approach that privileges the knowledge and skills of an "expert" over the participants in the process, assuming that the "expert" imparts knowledge to others because they are deficient in a particular area.

In contrast, a facilitation model views the leader as a guide and mentor whose role is to illuminate issues and solutions that may not be readily apparent, to offer insights and new ways of thinking about an issue, and to assist others in discovering the learning embedded in the situations themselves. From this perspective, learning occurs in a highly specific context and is flexible enough to accommodate diverse learning needs and styles. Such a model stimulates creativity and "out of the box" thinking. By fostering communication and a sense of community, such a model also engenders respect for the complementary role of each discipline, enhancing understanding. This approach is utilized throughout the IPPC curriculum (www.ippcweb.org).

Similarly, creating an environment of interdisciplinary support required intentional structuring of the sessions to promote trustworthy and respectful dialogue. Formats for rounds and patient care conferences were familiar to participants, but offered an expanded view of how clinical and psychosocial issues could be discussed in an interdisciplinary setting. The familiarity created an initial willingness to participate in a new forum for discussion and built trust among participants. Once established, the repetition of the process created reliability and confidence among participants. The facilitation model also offered health care professionals a safe forum within which to experience interdisciplinary dialogue that witnessed and honored emotions, intellectual confusion, shared vulnerability, and grief.

According to Remen,²⁴ learning how to grieve is a fundamental life skill. Without skills in grieving and the ability to recover a personal sense of

meaning in their work, health care professionals risk becoming "burned out," unable to continue to care for others.

The HLCC findings support, and are supported by, the findings of other researchers in several key areas. Stroebe and Schut²⁵ documented that health care professionals "oscillate" between dealing with the death and grief and learning to adjust to a role that includes life and death, sorrow and joy. Papadatou¹⁹ and Saunders and Valente²⁰ found that providing clinical and emotional support and the opportunity for meaning-making rituals are effective ways to reduce caregiver suffering and increase their ability to manage responses to grief. In another recent study, Papadatou et al.²² found that physicians tend to value opportunities for clinical support, while nurses are more likely to seek emotional support among colleagues. Attendance patterns in the study appear to validate these findings. While physicians most frequently attended the clinical interventions of palliative care rounds and patient care conferences, nurses were in the majority at bereavement debriefings. How physicians address their own needs for emotional support in the care of children with life-threatening conditions merits further study.²⁶

The findings of Papadatou et al.^{19,22} suggested differences in the type of support required by professionals in different units, a finding paralleled by the HLCC study which noted that the themes for oncology debriefing sessions were more often related to the relationship with the patient, while the lessons learned from the case were the most prevalent themes sounded in debriefings in the PICU. The most frequent reason cited for declining debriefing sessions was that the staff did not have a long-term relationship with the patient.

Papadatou et al.^{19,21} also noted that the death of a pediatric patient could lead to loss of assumptions about how the world works which can have a profound impact on the experience of health care professionals. Neimeyer²⁷ proposed that meaning reconstruction is the central aspect of the grieving process: to affirm or reconstruct shattered assumptions. Some people "come to terms with" or reconstruct their beliefs early on in their professional career; others may never do so. This may explain why the NICU staff, who had the longest years of service, declined debriefings. Presumably they and some long-term PICU professionals have reconciled

that some children suffer and die despite best efforts.

LIMITATIONS

Our study outcomes were centered on HCP's self-reports of their competence and confidence with palliative and end-of-life care, their ability to manage their grief and their perceptions of the effectiveness of the methods we used. We did not conduct chart review to assess the content of progress notes pertaining to family conferences, or assess the orders written in the patients' charts following a patient care conference, nor did we assess families' reactions to the process or its impact on them. Nonetheless, the focus on HCP is a strength of the study, as the perceptions of interdisciplinary professionals in these specific areas has been the subject of limited study. Future research might incorporate assessment of all of these domains.

CONTINUING EFFORTS TO IMPROVE CARE

Today the HLCC is building on these findings and continuing its work to improve palliative and end-of-life care through education, clinical practice and research. All of the interventions have continued beyond the study period and utilization of patient care conferences, in particular, have steadily increased and new initiatives to systematically address goals of care and advance care planning have been developed. These beginning efforts have been instrumental in integrating palliative and end of life care into the culture of the Johns Hopkins Children's Center. Next steps include evaluation of the impact of these interventions on the actual care that was provided and on patient outcomes.

Our experience offers a promising model to other pediatric health care settings interested in building pediatric palliative care programs. This approach is flexible and responsive to the unique aspects of each setting. It successfully engages broad participation of professionals from all disciplines and clinical services in promoting pediatric palliative care. These data suggest that the magnitude of situations causing caregiver suffering may not be fully appreciated. In particular, the frequency of and experiences of physicians

and other health care professionals has not been adequately studied.

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Address reprint requests to:
Cynda Hylton Rushton, D.N.Sc., R.N., FAAN
Johns Hopkins University
School of Nursing
525 North Wolfe Street, Box 420
Baltimore, MD 21287

E-mail: crushton@son.jhmi.edu