

# Learning That Leads to Action

## *Impact and Characteristics of a Professional Education Approach to Improve the Care of Critically Ill Children and Their Families*

Mildred Z. Solomon, EdD; David M. Browning, MSW; Deborah L. Dokken, MPA;  
Melanie P. Merriman, PhD, MBA; Cynda H. Rushton, PhD, RN

**Objective:** To determine the impact of an innovative professional educational approach on clinicians' confidence and ability to make institutional improvements in pediatric palliative care.

**Design:** Evaluation to assess impact of educational intervention on participants and participant institutions.

**Setting:** Retreats lasting 2.5 days.

**Participants:** Physicians, nurses, psychosocial staff, and bereaved parents.

**Intervention:** "Relational learning across boundaries" pedagogy.

**Main Outcome Measures:** Analysis of participant questionnaires (n=782, response rate of 84%), team leader surveys (n=72, response rate of 71%), and follow-up interview with subsample (n=21, response rate of 81%). Outcomes included confidence to act and institutional improvements achieved.

**Results:** Seventy-four percent of team leaders reported significant or moderate improvement in pediatric palliative care after the retreat; only 1% reported no improvement. Ninety-one percent credited the retreat experience as being somewhat or very instrumental to the improvements, which included the establishment of pediatric palliative care and bereavement programs, improvements in interdisciplinary communication, care coordination, clinician-family interaction at the bedside, and educational programs. Participants attributed the impact of the 2.5-day retreat to its key pedagogical features, involvement of family members as equal participants and participation of colleagues from other disciplines and care settings, as well as the ground rules used for the small group seminars.

**Conclusions:** The intervention was successful in improving clinicians' confidence and catalyzed improvements in pediatric palliative care within participating institutions. Relational learning holds promise for professional learning, especially when the educational goal is tied to enabling a shift in social and ethical norms.

*Arch Pediatr Adolesc Med.* 2010;164(4):315-322

**T**HERE IS PROBABLY NO MORE challenging a context for health care professionals than caring for critically ill and dying children and their families. Clinicians must confront difficult decisions, wrenching emotions, and

*See also page 389*

 *Journal Club slides available at [www.archpediatrics.com](http://www.archpediatrics.com)*

tragic outcomes, often without adequate preparation or support.<sup>1-5</sup> Embedded in these situations is the challenge of witnessing suffering in children and families,<sup>6,7</sup> discomfort speaking truthfully with children,

uncertainty about sharing decision making with parents, and insufficient skill in communication.<sup>8-11</sup> These factors can lead to cumulative grief<sup>12-14</sup> and emotional distancing from patients and their parents. Additional challenges include ineffective treatment of pain and symptoms,<sup>15,16</sup> confusion about what is ethically and legally permissible,<sup>17,18</sup> insufficient support for parental decision making,<sup>19,20</sup> inadequate bereavement support,<sup>8</sup> and insufficient continuity of care.<sup>21,22</sup>

### ADDRESSING THE CHALLENGES

Bearing these challenges in mind, in 1998, Education Development Center Inc, a non-profit organization with experience in

Author Affiliations are listed at the end of this article.

**Table 1. Curriculum Modules and Number of Activities (Seminars and Lectures)<sup>a</sup>**

|          | <b>Title of Module</b>                                  | <b>No. of Activities</b> |
|----------|---|--------------------------|
| Module 1 | Engaging with children and families                     | 3                        |
| Module 2 | Relieving pain and other symptoms                       | 7                        |
| Module 3 | Analyzing ethical challenges                            | 7                        |
| Module 4 | Responding to suffering and bereavement                 | 6                        |
| Module 5 | Improving communication and strengthening relationships | 3                        |

<sup>a</sup>Facilitator instructions for all modules can be downloaded at [www.ippcweb.org](http://www.ippcweb.org).

medical and nursing education, launched the Initiative for Pediatric Palliative Care (IPPC). The IPPC team identified quality domains and indicators for pediatric palliative care,<sup>23</sup> developed a quality improvement tool to help children's hospitals assess their strengths and areas needing improvement,<sup>24</sup> provided technical assistance to 8 children's hospitals as they developed innovative pediatric palliative care programs,<sup>12,25-27</sup> surveyed clinicians' knowledge and attitudes regarding key ethical issues,<sup>17</sup> and interviewed bereaved parents.<sup>21</sup> Based on this initial research, the IPPC team first developed an interdisciplinary curriculum<sup>28</sup> (**Table 1**) comprising 5 modules and 26 learning activities. Next, they trained a cadre of faculty, drawn from across the United States and Canada, to lead face-to-face retreats designed to expose interdisciplinary teams to the curriculum and, most importantly, to build pediatric palliative care capacity within participating institutions. Two prior articles have outlined the curriculum<sup>29</sup> and its pedagogy.<sup>30</sup> This article describes the impact of the retreats on practitioner and institutional practice.

### THIS STUDY'S AIMS

This study's aim was to determine the impact of the retreats on participants and their home institutions. To do so, the following questions were examined:

Did the retreats enhance participants' confidence in their ability to advocate for pediatric palliative care and their commitment to do so?

Which pedagogical features of the retreat experience did participants assess as most important?

What, if anything, did the teams go on to do at their home institutions postretreat?

To what extent did participants attribute those actions to their participation in the IPPC retreat?

## METHODS

### PURPOSE OF THE RETREATS

The retreats were designed to expose participants to a cross section of activities from the comprehensive IPPC curriculum so clinicians could implement the sessions in an informed manner on return to their home institutions. The retreats aim to inspire and prepare clinicians to play leadership roles in pediatric palliative care education and practice in their own organizations.

## EDUCATIONAL THEORY GUIDING PEDAGOGICAL DESIGN OF THE RETREATS

Unlike the dominant Continuing Medical Education paradigm in which education is conceived as a 1-way transmission of cognitive content from expert to learner, we envisioned a model of education that would go beyond the transmission of knowledge to include the cultivation of self-awareness, interpersonal skills, and cross-disciplinary collaboration as well as support for clinician-led efforts at organizational change.

### Relational Learning Across Boundaries

The development of professional expertise is a highly social and contextualized process involving the integration of a wide repertoire of learning experiences, all of which are situated firmly in relationships with patients, families, and colleagues.<sup>30,31</sup> Thus, a major premise of our approach was that learning aimed at influencing social and ethical norms would require a focus on how health care professionals interact with each other and with patients and families. We have called this approach "relational learning" and have described it in detail elsewhere.<sup>30,32</sup> In designing the IPPC retreats, we took the notion of relational learning one step further, hypothesizing that the most engaging learning would occur across boundaries, in this case, the boundaries that usually exist between professionals and family members, between practitioners of different disciplines, and between professionals working in disparate health care settings.

### Learning Between Professionals and Family Members

The voices of children with life-threatening conditions and their families are heard in the retreats in a number of ways. First, the associate director is a bereaved parent who plays a central role in conducting retreats. Second, parents with strong facilitation skills are part of the faculty that leads the small group seminars. Third, short films document parent perspectives in sessions throughout the retreat. Fourth, parents and other family members who are bereaved or currently caring for a child with a life-threatening condition are invited to attend the retreat by participating teams and the hosting organization. The nature of their involvement is markedly different from the function patients and family members often play in more traditional medical education contexts. Rather than being given only a time-limited opportunity to "tell their stories," family members attend all seminars alongside clinicians as full and equal participants.

### Learning Across Disciplines: Commitment to Interdisciplinary Practice and Teamwork

We request that institutions send an interdisciplinary team, most often comprising physicians and nurses as well as social workers, chaplains, and child life specialists. The team's participation is important for promoting interdisciplinary practice, but also because single change agents, no matter how inspired, often experience burnout and are ineffective in sustaining organizational change.<sup>33</sup>

### Learning Among Professionals Working in Disparate Healthcare Settings

The retreats bring together professionals who work with critically ill children and their families in a wide range of settings,

including hospitals, hospices, rehabilitation facilities, home health, and community-based agencies.

### Ground Rules for Small-Group Learning Across Boundaries

Facilitators must create and maintain a learning atmosphere built on safety, trust, and mutual respect. Therefore, they establish ground rules that have the effect of leveling the hierarchy and enabling quieter members of the group to find their voices. The attributes of openness, honesty, and curiosity reinforced by facilitators in the small groups are consistent with the habits, skills, and attitudes recognized as important by medical educators<sup>34</sup> and professional bodies, such as the Accreditation Council for Graduate Medical Education.<sup>35</sup>

### Invitation to Action

Retreat facilitators encourage every participant, whether family member, nurse, attending physician, or case manager, to see themselves as leaders with a unique role to play in the practice of pediatric palliative care. The invitation to action is made throughout the retreat; participants are asked to translate their learning into personal and institutional action plans. Attendees are encouraged to effect change in everyday practice, such as choosing to speak up when a family is being discussed in a derogatory manner, and in institutional policies and practices, such as initiating a pediatric palliative care consultation service or family advisory group.

### SAMPLING METHOD: SELECTION OF THE IPPC RETREATS FOR THIS STUDY

As of October 1, 2008, 1800 participants, including 250 family members, had been involved in 17 retreats held in 13 states. The 7 retreats held in California, Maryland, North Carolina, Tennessee, Texas, West Virginia, and Wisconsin between March 2006 and March 2007 are the focus of this study. Earlier retreats were excluded because there were slight differences in retreat format as the educational model evolved, and more recent retreats were excluded because insufficient time had elapsed between the retreats and data collection to confidently assess organizational change.

### DATA COLLECTION AND ANALYTIC METHODS

#### Evaluation of the Retreat Experience

To assess learners' views of the immediate impact of the retreats on their confidence to act in new ways and to capture their assessment of the value of the distinct pedagogical features of the retreats, we distributed evaluation questionnaires that participants completed at the end of each retreat.

Retreat evaluation responses were analyzed using SPSS software (SPSS Inc, Chicago, Illinois). Frequencies and means were calculated for 5 disciplinary groups, family members, physicians, nurses, psychosocial staff (child life specialists, child psychologists, and social workers), and chaplains.  $\chi^2$  Analyses and *P* values were calculated to determine differences among respondent categories. For 3 open-ended questions, 2 researchers (M.P.M. and a research assistant) read the comments and developed coded themes. The researchers assigned these codes separately at first and then discussed items for which code assignments differed until agreement was reached. Comments were sorted according to their codes within each disciplinary group.

### Postretreat Survey of Team Leaders

To determine what actions participants may have initiated and sustained after they returned to their home institutions, a 26-item online survey was administered in the spring of 2008 to the 101 leaders of participating interdisciplinary teams 1 to 2 years after they had attended a retreat. Team leaders were identified on the retreat registration materials; e-mail invitations to participate in the postretreat evaluation were sent along with a link to a private online survey. Reminders were sent via e-mail to those who did not respond within 10 days, and an additional reminder was sent 10 days later.

The questionnaire asked respondents what kinds of improvements in pediatric palliative care, if any, had occurred in their organizations since the IPPC retreat. For those who indicated that improvements had occurred, respondents were asked to assess, using a 4-point Likert scale, to what extent the IPPC retreat had been instrumental to those improvements and to indicate which elements of the pedagogy were most instrumental.

Survey data were imported into SPSS for analysis. Frequencies and means were calculated for each item for all respondents. The open-ended responses for the postretreat survey were analyzed by 2 of us (M.P.M. and D.L.D.). One of us (M.P.M.) read all the comments and grouped them by theme, using standard coding procedures for qualitative data.<sup>36</sup>

### Follow-up Telephone Survey With a Subset of Team Leaders

To learn more about why the team leaders attributed these improvements to their participation in the IPPC retreat and how the IPPC educational approach was helpful, we conducted telephone interviews with postretreat survey respondents who (1) had indicated on their surveys that the IPPC retreat was "very instrumental" to organizational improvements and (2) were willing to be interviewed.

The 26 respondents who met criteria for the interviews were contacted via e-mail and/or telephone (according to their preference) to schedule 30-minute interviews. Interviews were conducted by 2 of us (M.P.M. and D.L.D.), using a written interview guide with 3 open-ended questions. After the interviews were completed, the 2 interviewers independently analyzed all the interviews for key themes; any discrepancies were resolved through discussion. All interviews were then reanalyzed for the relative frequency of each key theme. Data collection activities and the study as a whole were approved by the institutional review board of Education Development Center Inc. All study participants gave informed consent.

## RESULTS

### EVALUATION OF THE RETREAT EXPERIENCE

Across the 7 retreats, a total of 782 participants were in attendance, with the smallest retreats accommodating 85 attendees and the largest, 150. A total of 657 retreat participants (84%) completed on-site evaluations.

**Table 2** shows responses by discipline for items assessing confidence to take action on behalf of pediatric palliative care and items related to the pedagogical features of the retreats. Nearly all participants left the retreat reporting enthusiasm for key features of the IPPC pedagogy and enhanced confidence to act as advocates on behalf of pediatric palliative care.

**Table 2. Respondent Confidence to Act and Evaluation of Retreat Pedagogy by Discipline**

|  | Mean Participant Score by Discipline <sup>a</sup> |                   |        |            |                                    |           | Group Comparison<br>P Values <sup>c</sup> |
|--|---|-------------------|--------|------------|------------------------------------|-----------|---|
|  | Overall   | Family<br>Members | Nurses | Physicians | Psychosocial<br>Staff <sup>b</sup> | Chaplains |   |
| <b>Retreat's Effect on Confidence to Act on Behalf of Pediatric Palliative Care</b>  |   |                   |        |            |                                    |           |   |
| To what extent did your experience at the retreat increase your confidence to advocate for improvements in pediatric palliative care?                          | 4.42  | 4.43              | 4.56   | 4.30       | 4.32                               | 4.29      | .005 <sup>d</sup>                         |
| To what extent did your experience at the retreat increase your confidence to be a small-group leader?   | 3.82  | 3.70              | 3.93   | 4.04       | 3.66                               | 3.91      | .02 <sup>d</sup>                          |
| <b>Evaluation of Each Feature of Retreat Pedagogy</b>  |   |                   |        |            |                                    |           |   |
| How valuable for you was the experience of learning collaboratively in a setting that included both professionals and family members?                          | 4.81  | 4.80              | 4.80   | 4.72       | 4.85                               | 4.77      | .02 <sup>d</sup>                          |
| How valuable for you was the experience of learning collaboratively in a setting that included professionals from a variety of disciplines?                    | 4.74  | 4.79              | 4.75   | 4.65       | 4.74                               | 4.71      | .70                                       |
| How satisfied were you with the opportunities to interact with professionals and family members outside your own institution or personal/professional network? | 4.51  | 4.64              | 4.54   | 4.48       | 4.46                               | 4.29      | .24                                       |
| How valuable for you was the experience of learning in a small group?  | 4.66  | 4.93              | 4.66   | 4.60       | 4.56                               | 4.69      | .005 <sup>d</sup>                         |
| How valuable for you was the leadership offered by the IPPC faculty members who led your small group?  | 4.64  | 4.79              | 4.70   | 4.46       | 4.61                               | 4.57      | .008 <sup>d</sup>                         |

Abbreviation: IPPC, Initiative for Pediatric Palliative Care.

<sup>a</sup>Scale: 1 = not at all; 5 = very.

<sup>b</sup>Psychosocial staff include those who identified themselves as child life specialists, psychologists, and social workers.

<sup>c</sup>Some cells have fewer than 5 individuals.

<sup>d</sup>Significant differences between some groups at the 95% confidence level ( $P \leq .05$ ).

Responses to open-ended questions on the retreat evaluation questionnaires underscored respondents' enthusiasm for the 4 main features of the IPPC pedagogy and mirrored responses to the open-ended questions asked later during the telephone interviews with the team leaders.

#### WHAT HAPPENED AFTER THE RETREATS?

Following the retreat, we included family members on our Pediatric Advanced Comfort Team team and also involved them in educational activities, including grand rounds.

I had been feeling rather demoralized and burned out about putting a lot more energy into moving our institution forward on this. Now I am more willing to be one of the "drivers" again.

Seventy-two of 101 team leaders completed the 1- to 2-year postretreat online survey for a response rate of 71%. (See **Table 3** for demographics on respondents.) **Table 4** summarizes the data on teams that reported taking action in their institutions and the reported level of improvement in pediatric palliative care since the IPPC retreat. Notably, 91% of respondents credited the IPPC retreat experience as being very or somewhat instrumental to institutional improvements, which included educational programs, pediatric palliative care services, and bereavement programs, as well as improvements in interdisciplinary communication, care coordination, and family participation in a range of programs and contexts. In addition to identifying the kinds of activities teams implemented postretreat, other items on the survey characterized the reach and scope of the activities.

Perhaps most surprising was the percentage of team leaders who answered in the affirmative about beginning or enhancing collaborative relationships with other organizations in their community or region. Nearly three-quarters (70%) had crafted formal linkages between hospital-based and non-hospital based providers to coordinate care within their communities, and more than one-third of the team leaders (35%) reported initiating formal outreach activities to community agencies, also with the goal of enhancing coordination of care. Seventy-seven percent reported that they had "developed or enhanced a network or coalition to explore collaboration."

With respect to the importance of key pedagogical elements of the retreat in helping start, or sustain, improvements, "learning from and with family members" was reported as most important, but all 4 dimensions were reported as moderately to very important.

#### THE RELATIONSHIP BETWEEN IPPC RETREATS AND INSTITUTIONAL CHANGE

Stepping outside of my [disciplinary] "silo" broadened my sense of possibility and what we have left to achieve.

[Our team members] came back saying, "If I can work with new people (eg, from hospice) at the retreat, then I can do it at home, too."

We interviewed 21 of the 26 team leaders who had met our eligibility criteria, for a response rate of 81%. When asked why they had indicated in their earlier responses that the retreat was very instrumental in bringing about

improvements, each of the 21 interviewees indicated that the retreat was a catalyst for change, using words like “accelerator” and “tipping point.” As in the retreat evaluation and survey responses, family involvement was cited as the major mechanism for the catalytic effect of the retreats, with 18 of the 21 interviewees underscoring its importance.

eTable 1 (<http://www.archpediatrics.com>) provides illustrative quotes pertaining to 7 main retreat outcomes team leaders reported having accomplished in their home institutions: new forms of family involvement in teaching and care delivery, improvements in clinician-family interactions at the bedside, professional renewal, humanizing health care, improved interdisciplinary teamwork, collaboration across units within institutions, and collaboration across care settings.

eTable 2 provides illustrative quotes demonstrating how respondents assessed the importance of the retreats’ key pedagogical features (learning with families, learning across disciplines, learning across health care settings, and learning in small groups) as enablers of the outcomes presented in eTable 1. We note that team leaders’ thoughts about these pedagogical features were nearly identical to comments from individual participants and the views endured over time. Participant and team leader responses remained substantively the same 1 to 2 years after the retreat as what they had reported immediately after the retreats. Therefore, we integrated the qualitative findings about the pedagogy from both sources and present them together in eTable 2.

### COMMENT

This study reports on a pedagogical approach that resulted in widespread institutional improvements, changes that respondents attributed in large measure to the catalyzing impact of a 2.5-day retreat. They attributed the power of their experience to learning across boundaries, especially between clinicians and parents, but also among clinicians from different disciplines and disparate care settings. The retreats appeared to help clinicians regain their aspirational ideals and strengthen their sense of agency both as individual leaders and as members of interdisciplinary teams. This renewal and interdisciplinary engagement, in turn, led a large proportion of participants to engage in informal as well as formal efforts at organizational change.

Respondents typically described the learning experience as profoundly valuable to them, which we believe is tied to having the opportunity for authentic reflection about the day-to-day realities of their work. The depth of interpersonal engagement between family members and clinicians had greater impact than one would expect to find if parents had simply told their stories and departed. This deeper engagement seemed to allow more substantive reflection by clinicians about the impact of their work on the lives of others and on the meaning of their work in their own lives.

**Table 3. IPPC Impact Survey Respondent Characteristics**

| Characteristic                              | No. (%) |
|---|---------|
| Total respondents                           | 72      |
| Retreat attended                            |         |
| Baltimore, MD, March 2006                   | 9 (13)  |
| Wheeling, WV, April 2006                    | 11 (15) |
| Memphis, TN, April 2006                     | 8 (11)  |
| Geneva, WI, June 2006                       | 10 (11) |
| Durham, NC, October 2006                    | 13 (18) |
| Austin, TX, February 2007                   | 12 (17) |
| Monterey, CA, March 2007                    | 9 (13)  |
| Discipline                                  |         |
| Administration/program coordinator          | 15 (21) |
| Physician                                   | 12 (17) |
| Nurse practitioner                          | 10 (14) |
| Staff nurse                                 | 9 (13)  |
| Social worker                               | 9 (13)  |
| Clinical nurse specialist                   | 8 (11)  |
| Pastoral care                               | 3 (4)   |
| Child life specialist                       | 2 (3)   |
| Other                                       | 4 (6)   |
| Setting of care                             |         |
| Pediatric hospital                          | 42 (58) |
| Hospice                                     | 18 (25) |
| Community hospital                          | 5 (7)   |
| Academic medicine                           | 3 (4)   |
| Community coalition                         | 2 (3)   |
| Rehabilitation hospital                     | 1 (1)   |
| Home health agency                          | 1 (1)   |
| Unit/department (hospital-based only; n=49) |         |
| Palliative care                             | 18 (37) |
| Hematology/oncology                         | 12 (24) |
| PICU  | 5 (10)  |
| NICU  | 3 (6)   |
| Pediatrics                                  | 3 (6)   |
| Pediatric palliative care                   | 2 (4)   |
| Other                                       | 6 (12)  |

Abbreviations: IPPC, Initiative for Pediatric Palliative Care; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit.

Moreover, the benefits were reciprocal, with family members learning as much as professionals. As one parent put it,

Before I just saw my grief and my situation from my side of things. It wasn't until I was at the IPPC retreat and was put into a group of medical professionals that I heard their side of the story.

The retreats seemed to fill a gap in the experience parents had with the health care system, wherein they came to appreciate the depth of caring and commitment that clinicians feel toward the children and families they serve.

A limitation of the study is that we do not have patient- or family-level outcomes. During the pilot phase, several hospitals did publish the results of their improvement efforts.<sup>12,25-27</sup> Another limitation concerns the scalability of the learning method. When respondents ranked what they valued about the pedagogy, the small-group work ranked very high. However, a sizeable proportion of respondents also said they did not leave the retreats feeling personally equipped to run similar small group sessions on their own. The structure of the retreats allows only a small percentage of participants to have direct experience with facilitating.

**Table 4. IPPC Impact Survey Responses**

| Question  | Responses, No. (%) |
|---|--------------------|
| To what extent has pediatric palliative care improved at your organization since the IPPC retreat? (All respondents; n=72)  |                    |
| Significant improvement   | 17 (24)            |
| Moderate improvement  | 36 (50)            |
| A little improvement  | 18 (25)            |
| No improvement  | 1 (1)              |
| To what extent do you feel that your team's experience at the IPPC retreat was instrumental in the improvements to pediatric palliative care at your organization? (All respondents; n=72)        |                    |
| Very instrumental   | 29 (40)            |
| Somewhat instrumental   | 37 (51)            |
| Not very instrumental   | 5 (7)              |
| No answer   | 1 (1)              |
| Have new or enhanced formal educational activities been implemented? Multiple answers permitted. (Includes only respondents who had implemented new/enhanced formal educational activities; n=53) |                    |
| Specially designed seminars or workshops  | 38 (72)            |
| Grand rounds  | 25 (47)            |
| New staff orientation   | 21 (40)            |
| Routine bedside rounds  | 12 (23)            |
| Brown bag lunches   | 10 (19)            |
| Student and staff lectures/in service   | 9 (17)             |
| PC team rounds  | 3 (6)              |
| Have you or your colleagues incorporated information from the IPPC retreat into any of the following forms of informal teaching? Multiple answers permitted. (All respondents; n=72)              |                    |
| Formal or informal case discussions   | 49 (68)            |
| Ethics committees   | 13 (18)            |
| Rounds at the bedside   | 10 (14)            |
| Other   | 6 (8)              |
| Team meetings/care conferences  | 4 (6)              |
| Have you or your colleagues used the Internet in any of the following ways to share information about pediatric palliative care? Multiple answers permitted. (All respondents; n=72)              |                    |
| Provided access to links to other Web sites with information  | 23 (32)            |
| Developed/posted resources for patient care   | 14 (19)            |
| Developed/posted formal educational modules   | 10 (14)            |
| Other   | 6 (8)              |
| No, we have not   | 33 (46)            |

(continued)

**Table 4. IPPC Impact Survey Responses (continued)**

| Question   | Responses, No. (%) |
|--|--------------------|
| How much progress has been made toward developing or enhancing the following elements of care? (Those indicating "some" or "a lot" of progress. All respondents; n=72)   |                    |
| Pediatric palliative care team or service  | 63 (88)            |
| Methods to coordinate care for children with life-threatening conditions   | 60 (83)            |
| Communication across interdisciplinary lines   | 59 (82)            |
| Support to families after the death of a child   | 55 (76)            |
| Approaches to communication with children with life-threatening illness and their families   | 54 (75)            |
| Policies or programmatic initiatives aimed at more fully involving parents and families in care and programs   | 48 (67)            |
| Following the IPPC retreat, did 2 or more individuals at your organization function as a work group to implement activities related to pediatric palliative care? (All respondents; n=72)  |                    |
| Yes  | 65 (90)            |
| No   | 7 (10)             |
| Following the IPPC retreat, how did the organization begin or enhance collaborative relationships with other organizations or agencies in your community or region that also care for children with life-threatening conditions? Multiple answers permitted. (Includes only respondents who had begun/enhanced relationships with other organizations or agencies; n=57)                                       |                    |
| Development/enhancement of a network or coalition to explore opportunities to collaborate  | 44 (77)            |
| Crafting formal linkages between hospital-based and non-hospital based providers to coordinate care  | 40 (70)            |
| Formal outreach activities to community agencies   | 20 (35)            |
| Other  | 2 (4)              |
| To what extent did each of the following elements of the IPPC retreat contribute to getting started and/or sustaining the process of improving pediatric palliative care at your organization? (Those indicating "moderately" or "very" important. Includes only respondents who indicated the IPPC retreat was "somewhat" or "very" instrumental in palliative care improvements at their organization; n=66) |                    |
| Learning from and with family members for whom you do not have a direct professional responsibility  | 60 (91)            |
| Learn from and with colleagues of different professional disciplines   | 56 (85)            |
| Learning from and with individuals from different types of organizations   | 52 (79)            |
| Hearing about and exploring new networking opportunities   | 52 (79)            |

Abbreviations: IPPC, Initiative for Pediatric Palliative Care; PC, palliative care.

## CONCLUSIONS

The experience was so formed, enhanced, and illuminated by the parents' presence, generosity, input, and sharing. I was truly blessed by what they brought to our learning. I'm blown away and [as a physician] will never be or teach the same.

Our goal of improving pediatric palliative care required crafting strategies that would enable learners to reflect on their own suffering in the face of tragedy; recognize how their own discomfort can lead to less engagement with children and families; learn how to stay present and interact effectively in the face of such discomfort; share decision-making authority; and work more collaboratively across the boundaries of professional disciplines. It was a learning challenge ideally suited for a

pedagogy that encouraged authentic engagement and honest reflection and brought health care professionals face to face with the ultimate beneficiaries of their work.

We expect that relational learning across boundaries will have an important contribution to make in the education of health care professionals, especially when the goal is tied to enabling a shift in social norms so that everyday practice can become better aligned with ethical norms and professional ideals. We are now applying relational pedagogy to several areas of clinical practice, such as practicing greater transparency in the aftermath of adverse events, assisting family members in decisions about organ donation after cardiac death, and supporting expectant mothers and fathers who are receiving a com-

plex range of advanced fetal care services. In addition, we are adapting the pedagogy for use in disease-specific contexts such as muscular dystrophy. We believe that a thoughtful consideration of learning across boundaries in these contexts, especially how to include patients and family members in more sophisticated ways, may prove an effective means of improving both quality and continuity of care.

**Accepted for Publication:** October 15, 2009.

**Author Affiliations:** Department of Global Health and Social Medicine, Harvard Medical School (Dr Solomon), Department of Anaesthesia (Dr Solomon) and Institute for Professionalism and Ethical Practice (Mr Browning), Children's Hospital of Boston, Boston, and Center for Applied Ethics, Education Development Center Inc, Newton (Dr Solomon, Mr Browning, and Ms Dokken), Massachusetts; Touchstone Consulting, North Bay Village, Florida (Dr Merriman); Johns Hopkins School of Nursing, Berman Bioethics Institute of Johns Hopkins University, and Harriet Lane Compassionate Care Program, Johns Hopkins Children's Center, Baltimore, Maryland (Dr Rushton).

**Correspondence:** Mildred Z. Solomon, EdD, EDC 55 Chapel St, Newton, MA 02458 (msolomon@edc.org).

**Author Contributions:** *Study concept and design:* Solomon, Browning, and Dokken. *Acquisition of data:* Dokken and Merriman. *Analysis and interpretation of data:* Solomon, Dokken, Merriman, and Rushton. *Drafting of the manuscript:* Solomon, Browning, Dokken, Merriman, and Rushton. *Critical revision of the manuscript for important intellectual content:* Solomon, Browning, Dokken, Merriman, and Rushton. *Statistical analysis:* Merriman. *Obtained funding:* Solomon and Dokken. *Administrative, technical, and material support:* Solomon. *Study supervision:* Solomon, Browning, and Dokken.

**Financial Disclosure:** Dr Solomon and Mr Browning are staff of Education Development Center Inc, the entity that offers the IPPC retreats reported in this article. Ms Dokken and Dr Merriman are consultants to the IPPC at Education Development Center Inc.

**Funding/Support:** Development of the IPPC curriculum was funded by the Nathan Cummings Foundation, the Open Society Institute's Project on Death in America, and the Kohlberg Foundation. The retreats were funded by the Aetna Foundation, the Argosy Foundation, the Kenneth B. Schwartz Center, the Sidney and Esther Rabb Charitable Foundation, the Sidney R. Rabb Charitable Trust, participant fees, institutional retreat sponsors, and individual donors.

**Online-Only Material:** The eTables are available at <http://www.archpediatrics.com>. This article is featured in the Archives Journal Club. Go to <http://archpediatrics.com> to download teaching PowerPoint slides.

**Additional Information:** The IPPC was developed in collaboration with 8 children's hospitals: Children's Hospital of Boston/Dana-Farber Cancer Institute, The Children's Hospital of Philadelphia, Children's Mercy Hospital, Kansas City, Missouri, Johns Hopkins Children's Center, The Lucile Packard Children's Hospital at Stanford University Medical Center, University of California, San Francisco, Children's Hospital, Vanderbilt University

Medical Center, and Children's Hospital San Diego. The curriculum was developed by Education Development Center Inc, in collaboration with the New York Academy of Medicine, the National Association of Children's Hospitals and Related Institutions, the Society of Pediatric Nurses, and the Association of Medical School Pediatric Department Chairs.

**Additional Contributions:** We acknowledge Alan R. Fleischman, MD, Karen S. Heller, PhD, Marcia Levetown, MD, Deborah E. Sellers, PhD, and Robert D. Truog, MD, all original IPPC coinvestigators, whose early work on the project was foundational. Laura Riegelhaupt, EdM, ably coauthored several elements of the IPPC curriculum. Loring Conant Jr, MD, played a key role in faculty development. Many local and regional institutions go to great effort to plan and support these events, for which we are most grateful. Most importantly, we are grateful to the parents and other family members for their willingness to share their knowledge and experience.

## REFERENCES

1. Rushton CH, et al. Pediatric palliative care: interdisciplinary systems of support in palliative care. In: Walsh DT, Caraceni AT, Fainsinger R, eds. *Palliative Medicine*. Philadelphia, PA: Saunders; 2009:1110-1114.
2. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics*. 2008;121(2):282-288.
3. Docherty SL, Miles MS, Brandon D. Searching for "the dying point": providers' experiences with palliative care in pediatric acute care. *Pediatr Nurs*. 2007;33(4):335-341.
4. Feudtner C, Santucci G, Feinstein JA, Snyder CR, Rourke MT, Kang TI. Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses. *Pediatrics*. 2007;119(1):e186-e192.
5. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology Survey. *J Clin Oncol*. 2001;19(1):205-212.
6. Rushton CH. The other side of caring: caregiver suffering. In: Carter BS, Levetown M, eds. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. Baltimore, MD: The Johns Hopkins University Press; 2004:220-243.
7. Rushton CH. Caregiver suffering: finding meaning when integrity is threatened. In: Ellenchild Pinch WJ, Haddad AM, eds. *Nursing and Health Care Ethics: A Legacy and A Vision*. Silver Spring, MD: American Nurses Publishing; 2008.
8. Widger K, Picot C. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatr Nurs*. 2008;34(1):53-58.
9. Carter BS, Levetown M. *Palliative Care for Infants, Children, and Adolescents. A Practical Handbook*. Baltimore, MD: The Johns Hopkins University Press; 2004.
10. Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. In: Field MJ, Behrman RE, eds. Washington, DC: The National Academies Press; 2003.
11. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*. 2006;117(3):649-657.
12. Rushton CH, Reeder E, Hall B, Comello K, Sellers DE, Hutton N. Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. *J Palliat Med*. 2006;9(4):922-933.
13. Serwint JR, Rutherford LE, Hutton N. Personal and professional experiences of pediatric residents concerning death. *J Palliat Med*. 2006;9(1):70-81.
14. Papadatou D, Bellali T, Papazoglou I, Petraki D. Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatr Nurs*. 2002;28(4):345-353.
15. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med*. 2000;342(5):326-333.
16. Solomon MZ, Browning DM. Pediatric palliative care: relationships matter and so does pain control. *J Clin Oncol*. 2005;23(36):9055-9057.
17. Solomon MZ, Sellers DE, Heller KS, et al. New and lingering controversies in pediatric end-of-life care. *Pediatrics*. 2005;116(4):872-883.
18. Nelson LJ, Rushton CH, Cranford RE, Nelson RM, Glover JJ, Truog RD. Forgoing medically provided nutrition and hydration in pediatric patients. *J Law Med Ethics*. 1995;23(1):33-46.

19. Dokken DL. In their own voices: families discuss end-of-life decision making—part 1. *Pediatr Nurs*. 2006;32(2):173-175.
20. Berg S. In their own voices: families discuss end-of-life decision making—part 2. *Pediatr Nurs*. 2006;32(3):238-242, 237.
21. Heller KS, Solomon MZ; Initiative for Pediatric Palliative Care (IPPC) Investigator Team. Continuity of caring: what matters to parents of children with life-threatening conditions. *J Pediatr Nurs*. 2005;20(5):335-346.
22. Hsiao JL, Evan EE, Zeltzer LK. Parent and child perspectives on physician communication in pediatric palliative care. *Palliat Support Care*. 2007;5(4):355-365.
23. Dokken DL, Heller KS, Levetown M, et al; the Initiative for Pediatric Palliative Care (IPPC). Quality domains, goals and indicators of family-centered care of children living with life-threatening conditions. Newton, MA: Education Development Center, Inc; 2002. [www.ippcweb.org](http://www.ippcweb.org). Accessed October 13, 2008.
24. Levetown M, Dokken DL, Fleischman AR, et al; the Initiative for Pediatric Palliative Care (IPPC). A pediatric palliative care Institutional Self-Assessment Tool (ISAT). Newton, MA: Education Development Center, Inc; 2002. [www.ippcweb.org](http://www.ippcweb.org). Accessed October 13, 2008.
25. Wolfe J, Hammel JF, Edwards KE, et al. Easing suffering in children with cancer at the end of life: is care changing? *J Clin Oncol*. 2008;26(10):1717-1723.
26. Duncan J, Spengler E, Wolfe J. Providing pediatric palliative care: PACT in action. *MCN Am J Matern Child Nurs*. 2007;32(5):279-287.
27. Carter BS, Howenstein M, Gilmer MJ, Throop P, France D, Whitlock JA. Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care. *Pediatrics*. 2004;114(3):e361-e366.
28. Solomon MZ, Browning DM, Dokken DL, et al. The Initiative for Pediatric Palliative Care curriculum: enhancing family-centered care for children with life-threatening conditions (modules 1-5). Newton, MA: Education Development Center, Inc; 2003. <http://www.ippcweb.org/curriculum.asp>. Accessed October 13, 2009.
29. Browning DM, Solomon MZ; the Initiative for Pediatric Palliative Care (IPPC) Investigator Team. The Initiative for Pediatric Palliative Care: an interdisciplinary educational approach for health care professionals. *J Pediatr Nurs*. 2005;20(5):326-334.
30. Browning DM, Solomon MZ. Relational learning in pediatric palliative care: transformative education and the culture of medicine. *Child Adolesc Psychiatr Clin N Am*. 2006;15(3):795-815.
31. Wenger E. How we learn: communities of practice. the social fabric of a learning organization. *Healthc Forum J*. 1996;39(4):20-26.
32. Browning DM, Meyer EC, Truog RD, Solomon MZ. Difficult conversations in health care: cultivating relational learning to address the hidden curriculum. *Acad Med*. 2007;82(9):905-913.
33. Solomon MZ, Jennings B, Guilfooy V, et al. Toward an expanded vision of clinical ethics education: from the individual to the institution. *Kennedy Inst Ethics J*. 1991;1(3):225-245.
34. Epstein RM, Hundert EM. Defining and assessing professional competence. *JAMA*. 2002;287(2):226-235.
35. Accreditation Council for Graduate Medical Education (ACGME). ACGME's Outcome Project: educating physicians for the 21st Century. a four module educational resource for teaching and learning the competencies, 2006. [www.acgme.org/Outcome/](http://www.acgme.org/Outcome/) Accessed September 29, 2008.
36. Corbin J, Strauss AC. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage Publications, Ltd; 2008.

#### Announcement

**Helmet Protection Equal Despite Price.** Cheap helmets and expensive helmets perform equally in impacts, according to Randy Swart, director of the Bicycle Helmet Safety Institute in Arlington, Virginia. The Bicycle Helmet Safety Institute submitted samples of 6 helmet models to a leading US test laboratory: 3 in the \$150 and higher range and 3 less than \$20. The impact test results were virtually identical. There were very few differences in performance among the helmets. Our conclusion: when you pay more for a helmet you may get an easier fit, more vents, and snazzier graphics, but the basic impact protection of the cheap helmets tested equaled the expensive ones.

The results are a testimony to the effectiveness of our legally required Consumer Product Safety Commission helmet standard. Although our sample was small, the testing indicates that the consumer can shop for a bicycle helmet in the US market without undue concern about the impact performance of the various models on sale, whatever the price level. The most important advice is to find a helmet that fits you well so that it will be positioned correctly when you hit.