JOURNAL CLUB

Learning That Leads to Action

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

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eTable 1. IPPC Retreat Outcomes: Selected Open-Ended Responses to Questionnaires and Telephone Interviews

**New Forms of Family Involvement in Teaching and Care Delivery**

“Since attending an IPPC retreat, our institution has implemented its own 7-week training program in pediatric palliative care using the IPPC curriculum. Two bereaved parents are part of the faculty for the training.”

“Following the retreat, we included family members on our PACT team and also involved them in educational activities, including grand rounds.”

“A parent is now involved on our institution’s palliative care task force and is also cochairing our new state coalition.”

“A parent who attended the retreat on our institutional team was ‘brought into the inner circle’ and provided with the foundation to become involved.”

**Improvements in Everyday Ethics at the Bedside**

“A NICU social worker learned language at the retreat that helped in talking to families. She learned that she could ask a family, ‘Have you thought about what you would do if things get worse with your child?’”

“When we got back to work after the retreat, our team was immediately able to apply what they had learned as we worked in the NICU with a young family and their sweet baby boy. The voices of the parents at the retreat came through loud and clear for the team here, and it helped them keep that perspective. The day when the baby died was incredibly sad but it also held great beauty, despite the pain.”

“Since participating in the retreat, individuals have more courage to speak up about important things.”

“The retreat helped our staff better understand the family point of view. They learned the importance of showing compassion and caring and that tone and body language matter in interactions with patients and families.”

**Professional Renewal**

“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.”

“I had experienced a loss of faith in our health care system and now I am learning there are still a lot of good people who are trying to serve their communities.”

“During the retreat, a chronic care physician on our team started seeing himself as a palliative care physician, saying, ‘I do palliative care.’ Now he is a big advocate for palliative care with other docs and includes palliative rounds in his resident teaching.”

“There was an incredible openness and vulnerability expressed by the participants. Honesty was ‘raw’ and everyone was nonjudgmental. A nurturing experience—healing also.”

**Humanizing Health Care**

“I have new hope about humanizing medical training and daily practice!”

“The retreat brought the humanity of pediatric palliative care into the hearts of the clinicians . . . took them back to the bedside and made them more sensitive.”

“The importance of being human really came across in the retreat; it was a recurrent theme. Participants learned that you can’t script talking to families; every case, every family is different.”

**Greater Interdisciplinary Teamwork**

“In educational activities at our pediatric hospital, we now use the IPPC interdisciplinary model, not just in participants but also in faculty. For example, the physician may present with a child life specialist or with a nurse from the home care program.”

“Before the retreat, we (3 nurses) were stuck in the trap of following the physicians’ and waiting for them to do something. The message of the retreat for us was to just start doing what needs to be done and others will follow. Don’t let anything get in the way.”

“After the retreat, a child life specialist and a nurse in the pediatric emergency department had the courage to say, ‘I can facilitate training sessions like this!’ They identified the need to train new staff in things like talking about death with families and designed their own training session for the emergency department.”

“After I returned from the Faculty Leaders’ Workshop at Marlborough, it was hard to bring back the experience as an individual. But after 5 of us attended the WVA retreat, a team came back; there were others who could help take up the banner. You need a team to effect change.”

**Collaboration Across Units Within the Same Institution**

“As a result of the retreat, we were able to ‘seed’ pediatric palliative care throughout our institution. Now we have an integrative model and palliative care is part of everyone’s practice.”

“We attended the retreat as teams from several units in our institution. Before the retreat, I didn’t really know people from other units. Now I can ask them, ‘Have you ever done this before’ and reduce the need to reinvent the wheel.”

“The retreat provided an opportunity for different groups within our institution to network. That networking mobilized us. We connected and found we had similar goals.”

**Collaboration Across Care Settings**

“After the IPPC retreat, we decided that the planning group should remain intact and become an active and knowledgeable voice for pediatric palliative care at the state level. We are now officially the Pediatric Palliative Care Coalition of North Carolina.”

“Participation in the IPPC retreat had an important intra-agency impact. Different agencies met on common ground at IPPC. It bridged and united our efforts. Now we are sharing information in a deeper way.”

“After the retreat, our hospital and the community hospice now have a common base of respect, coming from our shared IPPC experience.”

Abbreviations: IPPC, Initiative for Pediatric Palliative Care; NICU, neonatal intensive care unit; PACT, Pediatric Advanced Comfort Team; WVA, West Virginia.
Table 2. Participants’ Assessments of the Different Pedagogical Features of Relational Learning Across Boundaries

Learning With Family Members

“The experience was so formed, enhanced, and illuminated by the parents’ presence, generously, input, and sharing. I was truly blessed by what they brought to our learning. I’m blown away and will never be or teach the same.”

“The participation of the family members at the retreat was huge in impact. It modeled that involving family members was not threatening but instead helpful. Health care professionals witnessed and understood that the family perspective was unique and important. It’s different hearing about family needs/perspectives directly vs having clinicians describe them.”

“The presence and interactions of the family members took this retreat to the highest level of learning about caring for pediatric patients.”

“Listening to the family stories was the most instrumental part of the retreat—hearing what’s good for them, what distresses them, learning that things are not black and white in working with families.”

“What stood out in the retreat was the value of true partnering with parents in care and decision making, remembering to keep caring and humanness in all aspects of treatment.”

Learning Across Disciplines

“It was so inspiring to see how many people of different roles came together to be so passionate about pediatric palliative care! The retreat was a place for everyone to find ways of making a difference in their own communities.”

“It was so valuable to hear from other disciplines, so openly, about experiences, success, and areas of need. It was particularly important not to know the disciplines on the name tags, recognizing humanity, and not the work or the level of training.”

“The multidisciplinary focus and inclusion of families made this the best palliative care program I have participated in. Stepping outside of my ‘silo’ broadened my sense of possibility and what we have left to achieve. I will carry with me an appreciation of all the other people who feel as passionately about this as I do.”

Learning Across Health Care Settings

“While at the retreat, our team members saw the need to learn with caregivers from other settings and felt at ease doing that. They came back saying, ‘If I can work with new people (eg, from hospice) at the retreat, then I can do it at home, too.’”

“Our hospice and the children’s hospital were in the same team planning session together. Now we have stronger connections to follow pediatric patients collaboratively.”

Learning in Small Groups

“Trust is established in a short time within small groups. That deepens the learning because you get to hear everyone’s opinions. Even the quiet people talk!”

“I was moved by the community of caring that developed in our small group and hope to be able to bring a similar model of creating safe space to my work.”

“I’ve attended many conferences in lecture format and have felt good at the end of the conference to take away 3 or 4 concepts to implement in practice. The small-group approach offered much more. In fact, the positive affirmations from families and insight from professionals have been life changing! I have truly grown personally and professionally!”