

Impact of Pediatric Palliative Care Education on Healthcare Staff at a Tertiary Care Pediatric Hospital

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ABSTRACT

Importance: There is evidence that healthcare workers' perceptions contribute to suboptimal palliative care. However, there is limited evidence that educational interventions can positively influence these perceptions and overall knowledge of Pediatric Palliative Care (PPC).

Objective: To increase knowledge of and improve perceptions regarding PPC among healthcare personnel at a tertiary-care pediatric hospital. The study hypotheses were aligned with these objectives.

Study Design: Qualitative/mixed-methods. A monthly educational intervention was delivered over 8 months.

Setting: A tertiary-care pediatric hospital in Mexico.

Participants: Healthcare personnel who attended at least one monthly PPC training session from March 2024 to October 2024, for a total of 8 sessions. Convenience sampling was used. Pre- and post-training questionnaires were administered; completed questionnaires were included and incomplete questionnaires were excluded. A subset of attendees at each session was randomly selected for a structured interview.

Main Measures: Initial hypotheses were maintained throughout the study. Pre- and post-training questionnaire results were analyzed with the Mann-Whitney U test. Qualitative analysis of interviews used narrative methods and ATLAS.ti with code-based analysis.

Results: A total of 196 questionnaires were obtained; 8 were excluded due to incomplete data. Narratives were collected from 13 interviewees. The Mann-Whitney U test showed a statistically significant increase in knowledge when comparing pre- vs post-training scores for the second session (bioethical dilemmas in PPC; $p=0.046$), the third session (advance directives; $p=0.033$), and the sixth session (euthanasia vs limitation/adequacy of therapeutic effort; $p=0.031$).

Conclusions: Knowledge increased in three of the eight sessions delivered. Healthcare personnel's perceptions improved. Reassessment of knowledge over time is warranted.

Key Points

Question: What is the impact of PPC education on healthcare personnel's level of knowledge in a tertiary-care pediatric hospital?

Findings: In this qualitative/mixed-methods study with an 8-month monthly educational intervention and 196 questionnaires, there was a statistically significant increase in knowledge in the second ($p=0.046$; bioethical dilemmas in PPC), third ($p=0.033$; advance directives), and sixth sessions ($p=0.031$; euthanasia vs adequacy of therapeutic effort).

Meaning: Educational interventions can improve healthcare workers' knowledge of PPC.

Introduction

Background

Although PPC has a history of more than 50 years, its clinical implementation remains complex even in settings where most resources for palliative care are available. Numerous barriers continue to hinder PPC delivery today; these can be grouped into three broad categories:

- Those arising from family members' misperceptions
- Infrastructure barriers (material and human resources for specialized hospital and home-based care)
- Those arising from healthcare workers' misperceptions [1-4].

These misperceptions, among both families and clinicians, may essentially stem from the erroneous association of palliative care with older adults suffering from chronic diseases that, over time, progress to their severest and final complications. While such conditions are not expected in children and adolescents, various circumstances may place them in similar scenarios, and they therefore require palliative care [1, 5-8]. Among the three barrier groups, it is imperative to address those originating within the healthcare team; we cannot allow this age group to be deprived of comprehensive care due to incorrect perceptions held by those who should be best prepared to provide it.

Theoretical Framework

PPC is the active holistic care of people of all ages with serious health-related suffering due to severe illness, especially those approaching the end of life. Its aim is to improve the quality of life of patients, their families, and their caregivers [4, 9-12]. According to the Association for Children's Palliative Care (ACT) and the U.S. Institute of Medicine, PPC should begin at the time of diagnosis of a life-limiting or life-threatening condition in a child [13].

While recommendations indicate that PPC can begin at diagnosis, some chronic pediatric conditions must meet criteria to warrant palliative follow-up. In either case, these services can accompany the patient through every phase of illness: initially during disease-directed curative treatment or after curative options cease; during periods of stability without variable symptoms or frequent admissions; during advanced stages with more frequent and prolonged hospitalizations; after a "point of no return" when the child enters a terminal phase; during the actively dying phase at the end of life; and even after death, by supporting caregivers and the family. The focus should be adapted over time, but palliative care can, and should, be present throughout this trajectory rather than being limited solely to end-of-life care [1].

In 2018, The Lancet listed the sixteen most common conditions in which children or adolescents require palliative care, including HIV infection and disease, neurologic/CNS disorders, renal disease, cancer, congenital anomalies, malnutrition, liver disease, and CNS infections [14].

Different PPC delivery models exist depending on setting and provider training. The basic model allows any healthcare provider to deliver palliative care at any level of care. The mixed model involves general palliative care, typically in secondary care, with access to consultation from a PPC professional. The consultative model involves PPC experts providing specialized

care, generally at the tertiary level [15]. Ideally, any physician, specialist or not, should be capable of offering at least general palliative care, recognizing how and when to refer the patient for specialized services. Such basic care should be accessible to any patient at home, in any setting, or at any healthcare facility. Unfortunately, the current reality of PPC in many places falls short [1,14,16].

A 2022 JAMA study, in collaboration with St. Jude Global and the WHO Global Initiative for Childhood Cancer, developed the Physician Attitudes Toward Palliative Care Treatment survey to assess physicians' perceptions regarding PPC integration. After its distribution in Eastern Europe and Central Asia, the survey was also administered to assess physicians' perceptions and comfort with primary PPC delivery across 17 countries in Central and South America. A total of 874 physicians from 17 countries participated (overall response rate 39.9%; 874/2193). Most (55.6%) had not received formal PPC training, and 34.7% had no access to PPC experts for consultation. Physicians' perspectives generally aligned with WHO guidance; however, only 50.1% felt comfortable addressing physical symptoms, 33.8% felt comfortable addressing emotional symptoms, and 24.7% felt comfortable addressing family bereavement and loss. Notably, 94.8% wished to receive more PPC training. The study identified opportunities to improve physicians' training in symptom management and emotional support for children with cancer and their families [17].

Problem Statement

It is well known that children with life-limiting or life-threatening illnesses who are referred to palliative care have fewer symptoms and less suffering than those who are not referred. Nevertheless, palliative involvement is still omitted or requested late; palliative interventions continue to be delayed. Despite the passage of time, basic knowledge of PPC remains lacking [13,18,19].

Research Question

What is the pre- and post-intervention impact of an educational program in pediatric palliative care on healthcare personnel's knowledge at a tertiary-care pediatric hospital?

Justification

Almost 20 years ago, the American Academy of Pediatrics (AAP) formally stated that end-of-life care is an important component of training for health professionals, particularly in medical education [20]. The WHO has declared that early integration of palliative care is an "ethical responsibility" in the treatment of children with potentially fatal diseases. It is therefore urgent to promote educational strategies and bring these directives to fruition [21,22].

Providing PPC is a right of those who need it and is part of the General Health Law in Mexico. The WHO emphasizes that even in contexts with limited material and human resources, palliative care should be delivered using whatever is available at the time. Much of primary-level PPC does not require extensive infrastructure; its basic elements can be provided by any clinician with foundational knowledge [23].

Hypotheses

- Knowledge of PPC will increase among healthcare personnel at a tertiary-care pediatric hospital.
- Perceptions regarding PPC will improve among healthcare personnel at a tertiary-care pediatric hospital.

Materials And Methods

Study Design (Qualitative/Mixed-Methods)

Quasi-experimental component, cross-sectional, qualitative.

Procedures

A monthly educational intervention was conducted, presenting a different PPC topic each month (Table 1), from March to October 2024 (excluding April and including an extra session in September). On each training day, a 5-item questionnaire assessing basic knowledge of the topic was administered before and after the session. Outreach was performed via email announcements, WhatsApp groups, posters, and the palliative care service’s social media.

Table 1

Topics	
March	Session 1. General principles of PPC.
May	Session 2. Bioethical dilemmas in PPC.
June	Session 3. Advance directives.
July	Session 4. Communication competencies for breaking bad news.
August	Session 5. Humanizing the end of life.
September	Session 6. Euthanasia vs adequacy of therapeutic effort.
	Session 7. Extra session: Comprehensive management in PPC.
October	Session 8. Social organization in PPC.

Two attendees from each session were randomly selected for a structured interview including the following questions:

- What was your perception of PPC before the training?
- Did your perception of PPC change after the training?
- What is your current perception of PPC?
- Do you think the training produced any change in your daily practice within the hospital?
- Would you recommend others to attend the monthly PPC training sessions?

Study Population

Healthcare personnel who attended at least one monthly PPC training session from March to October 2024.

- Inclusion criteria: Completed pre- and post-training questionnaires and participants who consented to be interviewed.
- Exclusion criteria: Incomplete questionnaires.
- Elimination criteria: None.

Sample Size

Convenience sample; minimum of 100 subjects.

Statistical analysis plan

- Kruskal–Walli’s test to determine statistical differences in mean scores across groups by hospital department/area of assignment.

- Mann–Whitney U test to determine statistical differences between pre- and postquestionnaire mean scores for each session.
- Interviews underwent qualitative analysis using narrative methods and ATLAS.ti (code-based analysis).

Results

Questionnaires

Out of 340 total attendees across all sessions, 196 questionnaires were obtained; 8 were excluded due to incomplete data, yielding 188 questionnaires for analysis. Although attendance for session 7 was not recorded (the session was not originally scheduled), questionnaires from that session were obtained. The overall response rate was 58%, excluding session 7 for the reasons noted above.

Difficulties scanning the QR code to answer the questionnaires on mobile devices occurred in the first two sessions; beginning with the third session, printed questionnaires were provided for those who needed them.

As shown in Table 2, the session with the highest attendance was the sixth (“Euthanasia vs adequacy of therapeutic effort”). In contrast, the eighth session (“Social organization in PPC”) had only 10 attendees.

Table 2

Attendance and response rate			
Session #	Attendees	Completed questionnaires	Response rate
1	57	44	77%
2	65	28	43%
3	38	5	50%
4	53	47	89%
5	43	7	64%
6	74	51	69%
7	NA	37	NA
8	10	6	60%

Note that in the third and fifth sessions, only 10 and 11 questionnaires, respectively, were distributed due to various issues; thus, response rates were calculated based on the number of questionnaires actually distributed. In all other sessions, questionnaires were provided to all attendees.

Session 1

To the question “What is palliative care?”, no one answered “care when nothing more can be done.” The correct option was selected by 90% pretraining and 97% post-training. To “When should palliative care be called?”, no one answered “when the patient is dying” or “when it is time for family members to sign advance directives.”

Session 2

To “What is adequacy of therapeutic effort?”, only 1 of 28 respondents answered “letting the patient die” pre-training; this response disappeared posttraining. For “What is a futile treatment?”, 85% selected the correct answer pretraining and 93% post-training.

Session 3

To “What is orthothanasia?”, 60% answered “it is the same as euthanasia” pre-training; this response disappeared post-training. To “What are advance directives?”, no one answered “letting the patient die” or “scheduled euthanasia.”

Session 4

To “Which items describe the Buckman protocol?”, 97% answered correctly pre-training and 87% post-training, revealing persistent knowledge gaps about strategies/protocols for delivering bad news and suggesting that our intervention may have introduced some confusion.

Session 5

To “What is the tipping point in the evolution of a chronic disease?”, only 57% responded correctly both pre- and post-training. To “Which actions dignify life until the end?”, 100% responded correctly both pre- and post-training.

Session 6

A clinical case was presented (advanced, complex chronic illness without curative options, multiple neurologic sequelae). To “Should all management be continued?”, 82% pre-training answered “no, care should be aligned with the patient’s prognosis,” rising to 98% post-training. The only incorrect post-training response cited possible legal implications of not continuing maximal therapy. When asked, “If treatment is withdrawn, this constitutes...,” 66% pretraining answered “adequacy of therapeutic effort” and 27% associated it with euthanasia; post-training, 96% answered correctly and only 4% associated it with euthanasia.

Session 7

To “What is total pain?”, 86% answered correctly pre-training and 96% post-training.

Session 8

To “By what percentage does quality of life improve at home?”, 25% answered correctly pre-training and 67% post-training.

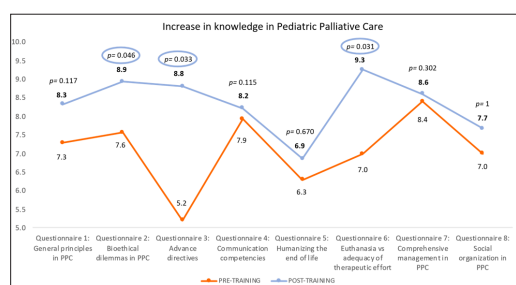


Figure 1

Increase in knowledge in Pediatric Palliative Care.

(Pre- and posttraining mean total scores for each questionnaire with p-values from Mann–Whitney U tests.)

Interviews

A total of 13 interviews were conducted. The questions (as described in Methods) addressed PPC broadly and were not specific to the session attended; interviews took place after the session.

Interviewees included: one public relations staff member, one social worker, one nurse, one first-year pediatrics resident, two second-year pediatrics residents, two attending oncologists, two attending infectious-disease physicians, two attending intensivists, and the head of nephrology.

Qualitative analysis using ATLAS.ti identified 23 codes divided into two groups: codes related to pre- and post-training (Table 3). This citation table is valuable because it shows changes in perceptions regarding PPC across several aspects. A maximum of two citations per person per category was considered.

Table 3

Number of citations (pre and post-training)		
Item	Pre	Post
PPC as end-of-life care	9	1
PPC as support for the medical team	5	3
PPC as comprehensive care	5	16
PPC for pain management	4	1
PPC for patients with poor prognosis	3	5
PPC as bereavement support	1	1
PPC not limited to terminal stages	1	4
Considering adequacy of therapeutic effort	2	10

For example, there was a considerable decrease in citations of “PPC as end-of-life care,” from 9 pre-training to 1 post-training. Citations for “PPC as comprehensive care” increased from 5 pre-training to 16 post-training. Citations for “Considering adequacy of therapeutic effort” increased from 2 pre-training to 10 post-training.

Other changes were smaller but indicate incremental advances. Tables 4 and 5 list pre- and post-training citations that cannot be directly matched one-to-one. Notably, there were 25 post-training citations referring to “Changes in daily practice,” suggesting gains benefitting patients and families; based on the number of citations, this was mentioned at least twice per person. All interviewees recommended the training sessions and expressed interest in inviting their coworkers.

Table 4

Number of pre-training citations	
Item	Count
Prior knowledge of the topic	6
Practices of therapeutic obstinacy	1

Table 5

Number of post-training citations	
Item	Count
Changes in daily practice	25
Recommend the training sessions	13
Identification of the right time to request a consultation	12
General knowledge acquired	11
Recommend making sessions mandatory	2

Personal interest	3
Awareness that a PPC service exists	2
Learning the concept of “total pain”	2
Learning about avoiding suffering	2
Learning about avoiding therapeutic obstinacy	2
Considering palliative sedation	2
Perceived lack of interdepartmental communication	1

Other items highlighted were the 12 citations about “Identifying the right time to request a consultation” and 11 about “General knowledge acquired.”

Selected verbatim comments from different interviewees:

“...I have personally witnessed this transition; I’ve worked in intensive care for 20 years and we didn’t have palliative care support...”

“...moral aspects—given our variability—greatly influence decision-making for our patients...”

“...I think I benefited a great deal; in fact, I’m even considering it as a subspecialty option...”

“...I consider it favorable for my professional development, for my practice...” “...we need to coordinate better because I feel we still lack communication with the palliative care staff or service...”

“...I believe everyone involved in a hospital like this, caring for highly complex patients—some with life-limiting diseases or difficult diagnoses and treatments—should be fully trained, even starting in residency...” “...I think it should be included in the residency curriculum...”

Discussion

Our overall response rate was acceptable at 58%, compared with other studies exploring knowledge and barriers to PPC implementation, which report response rates of 10%–50% [6,13,17,18,24]. From key question analysis, our population appears to have acceptable basic PPC knowledge: they can define PPC, unlike reports from places such as Hungary, where a principal barrier is unfamiliarity with PPC’s definition [15]. Our population also broadly knows when to request a PPC evaluation. It is positive that in this study PPC was rarely associated with terminal or end-of-life care, in contrast with other international studies reporting a stronger association [13,19].

One weakness observed was difficulty identifying the tipping point in the course of a patient’s chronic disease. This item showed no improvement post-training, with 57% correct both before and after. This is problematic because unclear recognition of this point impedes adequacy of therapeutic effort and predisposes clinicians to therapeutic obstinacy.

Another challenge was distinguishing adequacy of therapeutic effort from euthanasia. Even during the session, this topic generated considerable debate among physicians; questions and comments were encouraged. Encouragingly, post-training, up to 96% answered questions on these topics correctly.

We emphasize that PPC knowledge increased, with higher mean scores across all questionnaires and statistically significant differences for three topics: “Bioethical dilemmas in PPC,”

“Advance directives,” and “Euthanasia vs adequacy of therapeutic effort.”

Qualitative analysis revealed perception changes across multiple aspects of PPC. As noted earlier, citations related to identifying the appropriate time to call PPC increased post-training; we also noted paradigm shifts: viewing PPC as comprehensive care rather than solely end-of-life care, considering adequacy of therapeutic effort, and applying PPC in daily practice.

Selected comments (see Results) reflect a transition from a generation without PPC training or support, particularly in critical care, to a younger generation that even considers PPC as a professional path. Respondents also noted that physicians’ moral frameworks can influence clinical decision-making, as well as fear of legal consequences stemming from limited knowledge of the law—phenomena reported elsewhere, such as in Brazil [18].

Some interviewees proposed that PPC education should be included in residency curricula; we propose that palliative care be included in the core undergraduate medical curriculum.

A 2011 Journal of Palliative Medicine study proposed small-group teaching for palliative care, reasoning that small groups facilitate needs assessment, reflective preparation, and perceptive feedback, favorable conditions for PPC education as doubts and experiences emerge that are best explored in smaller settings [25]. A 2018 BMC Research Notes article synthesized 12 qualitative studies to propose an interprofessional educational model for pediatric oncology trainees (potentially generalizable to other residencies) based on three items:

- Establishment of effective teaching modalities/strategies;
- Development of an interprofessional PPC curriculum; and
- Program evaluation through the impact on providers’ self-perceived comfort in delivering PPC.

Proposed evaluation options included

- Obtaining patient/family feedback
- Standardizing care delivery measures
- Assessing care outcomes

Although promising, most articles were level VI evidence and the evaluation model requires follow-up that may be impractical in all hospital settings [26].

A 2024 Journal of Pain and Symptom Management study enrolled 81 medical students in a 4-week PPC elective (2017–2023). After the elective, self-reported preparedness to deliver serious-illness bad-news communication increased from 38% to 100%; comfort leading discussions about patient status increased from 58% to 100%; and students unanimously reported feeling better prepared to manage end-of-life issues and control symptoms in seriously ill patients [27]. These studies highlight the range of strategies for improving PPC knowledge and patient care. Our study employed the methods described, and the evidence points to future opportunities to strengthen PPC culture in our hospital.

Conclusions

The impact of our educational intervention was reflected in increased PPC knowledge in our study population. Interview

analysis identified a meaningful positive impact on interviewees' perceptions of PPC, along with an initiative to translate this into practice.

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