Journal of Palliative Care Research and Reports

SCIENTIFIC Research and Community

Research Article

Open Access

Build and Deliver a Sustainable Pediatric Palliative Care (PPC) Education Training Program and Build a PPC Leadership Network-A Pilot Project

Sukhlal Mandal[1]*, Mukta Mistry[2] and Megan Doherty[3]

[1]Senior Staff Nurse, Dhaka Medical College Hospital, Dhaka-1000, Bangladesh

[2]Bachelor of Science in Nursing, Institute: College of Nursing, Mohakhali, Dhaka-1212, Bangladesh

[3]Pediatric Palliative Director – South Asia, Two Worlds Cancer, Canada

ABSTRACT

Background: There was limited development of Pediatric Palliative Care (PPC) to be exactly found in Bangladesh and even within Dhaka Medical College Hospital (DMCH), where there was no structured PPC education for the nurses. The lack of trained professionals in this field was the critical importance to the quality of care provided to children with life limiting conditions by creating many more children with insufficient pain management and emotional support.

Methods and Materials: In person nurses training conducted at Dhaka Medical College Hospital (DMCH) followed by the Two Worlds Cancer Collaboration (TWCC) guidelines. A purposive sampling technique was also used for the 20 registered nurse participants.

Results: The project increased nurses' knowledge and skills, particularly in symptom management and communication with families. The nurse leaders discussed and implemented PPC protocols in their departments, increasing the institutional awareness and support for PPC services.

Discussion: Project success included heightened nurse competence and the development of a leadership network which ensured long term sustainability. But there were challenges like lack of access to essential medications or resistance from certain hospital departments. These barriers identified the need for assistance through further institutional support and resource investment.

Conclusion: The project was successful in creating PPC education and leadership at DMCH and provided a scalable model for other hospitals in Bangladesh. For PPC services to be sustained and scaled across the country, continued mentorship and institutional backstop were necessary.

***Corresponding author**
Sukhlal Mandal, Senior Staff Nurse, Dhaka Medical College Hospital, Dhaka-1000, Bangladesh.

Received: August 03, 2026; **Accepted:** August 16, 2026; **Published:** August 29, 2026

Keywords: Pediatric Palliative Care (PPC), Education, Communication

Background

Pediatric Palliative Care (PPC) is an essential approach to improving the quality of life of children with life-limiting and life-threatening conditions through holistic care, including symptom management and psychosocial support for patients and their families. The main goal of PPC is to relieve pain and distressing symptoms while ensuring comfort, dignity, and emotional well-being through a child-centered approach that emphasizes quality of life at every stage of illness. According to the World Health Organization (WHO), more than 21 million children worldwide require palliative care annually, yet only a small proportion receive these services, most of whom live in high-income countries where trained healthcare professionals and healthcare resources are more available [1,2].

In low- and middle-income countries such as Bangladesh, the need for PPC remains largely unmet because of limited healthcare resources, inadequate awareness, and the absence of formal training programs for healthcare professionals [3]. In Bangladesh, most PPC services are concentrated in urban areas, particularly in Dhaka, while nearly 90% of children living in rural communities lack access to appropriate palliative care services [4]. This inequality highlights the urgent need to strengthen PPC services across the country to ensure equitable healthcare access for all children.

Nurses play a significant role in delivering PPC in resource-limited settings; however, insufficient training often limits their ability to provide comprehensive symptom management and effective family communication [4]. Evidence suggests that structured PPC training programs can improve nurses' competencies, enhance

patient and family satisfaction, and contribute to better health outcomes [5,6]. To address these challenges, a sustainable PPC education and training program for registered nurses was implemented at Dhaka Medical College Hospital (DMCH). The project aligns with WHO recommendations to integrate palliative care into national healthcare systems [7]. In addition to strengthening nurses' knowledge and clinical skills, the project also aimed to develop nurse leadership capacity within DMCH to promote sustainability, continuous learning, and institutional support for pediatric palliative care services in Bangladesh [6].

The aim of this project was to build and deliver a sustainable pediatric palliative care (PPC) education training program and build a PPC leadership network.

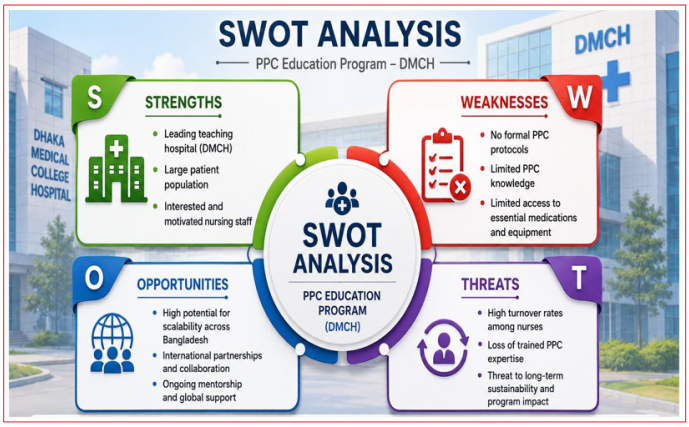
Methods and Materials

In person nurses training conducted at Dhaka Medical College Hospital (DMCH) followed by the Two Worlds Cancer Collaboration (TWCC) guidelines. Twenty registered nurse participants were included in the training, and two nurses were selected as nurse leaders for pediatric palliative care training.

Participants

The key participants in this project were hospital administration, nurses, international and local experts, pediatric patients and families.

SWOT Analysis



Strategies and Processes

The project was implemented in two phases: basic pediatric palliative care (PPC) education for 20 nurses and leadership training for selected nurse leaders.

In Phase 1, nurses were trained in symptom management (pain, nausea, dyspnea), psychosocial support, communication with children and families, and ethical principles of PPC. Training was delivered through lectures, case studies, and practical workshops, ensuring application of knowledge in clinical settings. Pre- and post-training evaluations showed significant improvement in nurses' knowledge, confidence, and ability to provide holistic care.

In Phase 2, high-performing nurses received leadership training to develop advocacy, mentorship, and program implementation skills within their departments. A mentorship program using the Project ECHO model provided ongoing expert guidance, helping nurse leaders successfully implement PPC services.

Results

This project successfully increased the knowledge, comfort, and attitudes of nurses towards pediatric palliative care as measured by pre and post training assessments. These gains represent the extent to which the program dealt with training participants to provide compassionate and knowledgeable care to children and their families.

Table 1: Results of Pre and Post Training Assessment of Knowledge via The Questionnaire

Questions		No. of Responses						
		Strongly Agree	Agree	Somewhat Agree	Neither Agree not Disagree	Somewhat Disagree	Disagree	Strongly Disagree
1.1	I feel confident identifying a child who could benefit from palliative care.							
	Pre	7	11	1				
	Post	14	4					1
1.2	I feel confident explaining to parents the role of palliative care for their child							
	Pre	10	8	1				
	Post	14	4		1			
1.3	I feel confident explaining the role of palliative care to other healthcare providers							
	Pre	9	8	1				1
	Post	13	5		1			
1.4	Palliative care for children can be delivered by health-care workers of all disciplines, not only by palliative care specialists.							
	Pre	6	10		1			1
	Post	12	4	2				
1.5	Palliative care means “End of Life Care”							
	Pre	5	7	1	4		1	1
	Post	7	5	1	2			3
1.6	Stopping aggressive treatments may be in the best interest of a dying child							
	Pre	2	11	1	2	1		2
	Post	13	1	1	1			1
1.7	Addressing the psycho-social issues of a child/family is NOT the role of a doctor or nurse							
	Pre	1	2	1	1	1	7	6
	Post	6	5				1	6
1.8	Talking about death with the parents of a dying child should be avoided							
	Pre		2	1	4	2	2	8
	Post	5	1		1			11
1.9	Uncertain information about their illness should not be given to a family because it may cause additional anxiety							
	Pre	2	4	1	3	3	3	3
	Post	7	1	1			2	7
1.10	Information about prognosis should never be provided to the child, even when they ask about it							
	Pre	5	4	1	1	1	4	3
	Post	6	4				3	6

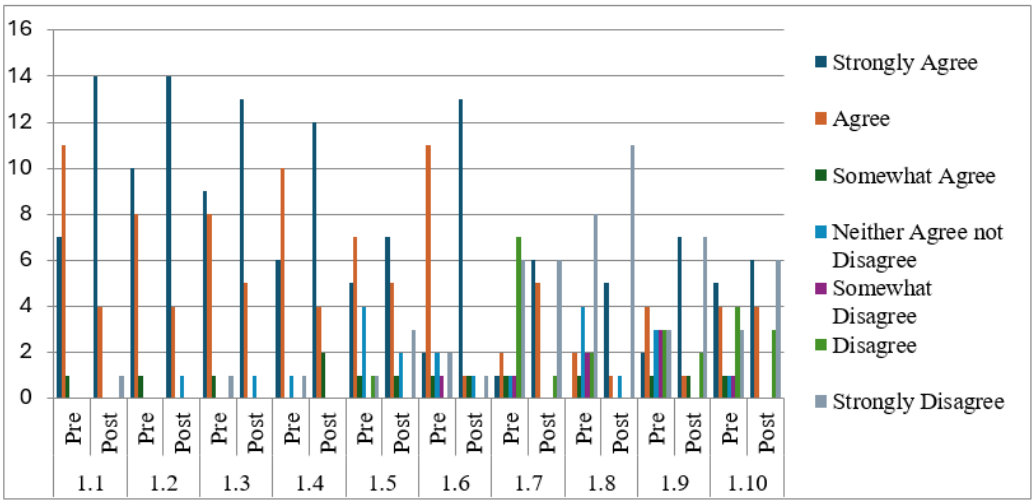


Figure 1: Pre and Post Training Assessment of Knowledge

Participants' knowledge of pediatric palliative care was significantly improved by the training. Children whose palliative care was considered would be identified more confidently (7 – 14 (Strongly Agree)). Strongly Agree answers had increased from 10 to 14 to an increased 14 from 9, in their ability to explain palliative care to parents and healthcare providers. (6 to 12 for Strongly Agree) Once we understood that palliative care is not necessarily a specialty, that is. Bringing misconceptions down such as equating palliative care with end-of-life care, while acceptance of stopping aggressive treatments in the best interest of dying children rose from 2 to 13 (Strongly Agree). However, participants also became much better at understanding psychosocial responsibilities and willingness to discuss sensitive topics such as death.

Table 2: Results of Pre and Post Training Assessment of Comfort Levels and Attitudes of The Participants Via The Questionnaire

Questions		No. of Responses						
		Strongly Agree	Agree	Somewhat Agree	Neither Agree not Disagree	Somewhat Disagree	Disagree	Strongly Disagree
2.1	Early initiation of palliative care will only increase parental burden and anxiety.							
	Pre	2	7	1	3		2	3
	Post	4	5	1			2	6
2.2	Treatment with a placebo is an appropriate treatment for some types of pain.							
	Pre	2	9	1	4			2
	Post	5	7	3	3			
2.3	A patient on morphine never needs paracetamol or NSAIDs.							
	Pre	2	3	2		2	8	2
	Post	12	3	1				1
2.4	When used at appropriate doses, morphine is a safe treatment for moderate to severe pain in children							
	Pre	7	9	1	1			1
	Post	14	3				1	
2.5	I feel confident taking care of the emotional needs of children with serious incurable illnesses							
	Pre	4	10	1	1			
	Post	14	3					
2.6	I feel confident identifying when a child may be in the last days or hours of life.							
	Pre	2	7	5	2		2	2
	Post	12	1	1	1			2
2.7	I feel confident explaining the prognosis of a child's life-threatening illness or incurable diagnosis to their parent(s).							
	Pre	4	9			1	2	1
	Post	15	2					
2.8	I feel confident providing basic grief and bereavement care to the families of children who have died.							
	Pre	9	8				1	1
	Post	14	1	2				

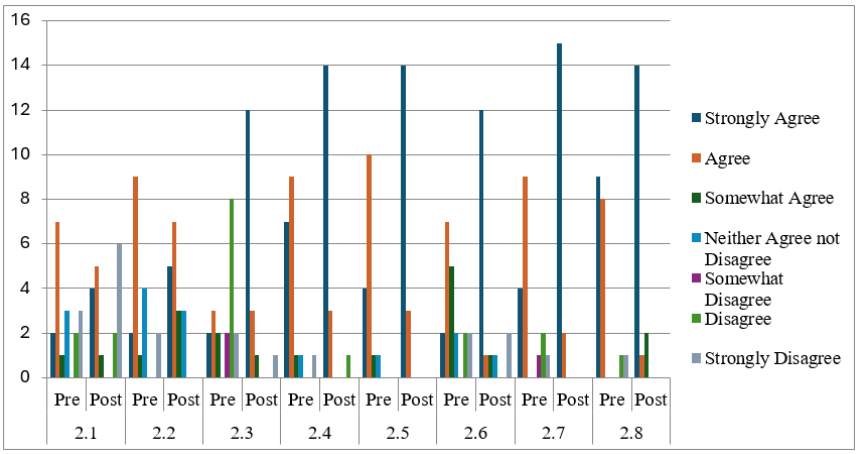


Figure 2: Pre and Post Training Assessment of Comfort Levels and Attitudes of The Participants

Participants felt comfortable and were more comfortable with pediatric palliative care after training. From 4 (Strongly agree) to 14 (strongly agree), confidence in managing emotional needs increased; and from 2 (strongly agree) to 12 (strongly agree), recognition of end of life stages increased. Strongly agree for morphine safety grew from 7 to 14 and complementary analgesics were used from 2 to 12. Confidence in explaining prognosis to patients increased from 4 (Strongly Agree) to 15, as did confidence in counseling grief and bereavement to patients, from 9 (Strongly Agree) to 14. The burden of palliative care was misperceived erroneously, as were the inappropriate use of placebos, or information.

Challenges

The project faced key challenges including limited resources for pain management, resistance from some departments, and heavy nurse workloads affecting training participation. To address these issues, training schedules were adjusted to shorter and more flexible sessions. Continuous advocacy and support from hospital management helped reduce resistance to PPC implementation. Additionally, informal PPC guidelines were developed to ensure consistent and standardized care across departments.

Discussion

This project's outcomes showed that such a sustainable PPC education and leadership training program can be developed and implemented in a resource-limited setting like Dhaka Medical College Hospital. The training curriculum leads to improvements in nurses knowledge; the leadership network was created to ensure that the improvements will sustained over time. Nevertheless the obstacles in the project, particularly those arising from resource constraints and institutional resistance, indicate that more help from the hospital and the entire healthcare system was required. The nurse leaders had come a long way in organizing and implementing the PPC protocols. However if the hospital does not continue to support the involved with the required resources, medications, equipment, and staff training, the efforts will only be for a short time. Furthermore, there were needed for broader institutional support to ensure full integration of PPC into routine care and on a par with curative treatments.

Conclusions

The pilot project demonstrated that pediatric palliative care education at Dhaka Medical College Hospital has been laid successfully. The project has greatly increased the hospital's ability to provide high quality palliative care to pediatric patients by training 20 registered nurses through this project and creating a leadership network. The nurse leaders proceeded to become well positioned to advocate for PPC across the hospital, so that the knowledge learned during the project will be shared and sustained over time. This model of PPC education and leadership development can be replicated in other hospitals across Bangladesh to effectuate a nationwide improvement in pediatric palliative care services with the right resources and institutional support [8,9].

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