


Palliative Care for Newborns in India: Patterns of Care in a Neonatal Palliative Care Program at a Tertiary Government Children's Hospital

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Mohammad Ishak Tayoob¹, Spandana Rayala¹, Megan Doherty^{2,3,4} , Hima Bindu Singh⁵, Madireddy Alimelu⁵, Swapna Lingaldinna⁵ and Gayatri Palat^{1,6}

¹Pain Relief and Palliative Care Society, Hyderabad, India. ²Faculty of Medicine, University of Ottawa, Ottawa, ON, Canada. ³Two Worlds Cancer Collaboration Foundation, Kelowna, Canada. ⁴Children's Hospital of Eastern Ontario, Ottawa, ON, Canada. ⁵Niloufer Hospital, Hyderabad, India. ⁶Mehdi Nawaj Jung Institute of Oncology and Regional Cancer Centre, Hyderabad, India.

ABSTRACT: Neonatal palliative care is a specialized area within children's palliative care, which focusses on the needs of infants with life-limiting or life-threatening conditions. Nearly one quarter of global neonatal deaths occur in India, where neonatal palliative care evidence is limited. This study describes the development and implementation of a neonatal palliative care program within a neonatal intensive care unit (NICU) at a government hospital, describing the implementing an 8-month pilot palliative care program for neonates, including the patterns of care, and barriers and enablers of success. The hospital-based palliative care team included trained pediatric palliative care physicians, a nurse, and a counselor. There was a steady increase in monthly referrals. There were 110 referrals in total, including 89 (81%) deaths and 18 (16%) babies were alive at the time of final follow-up, 10 months after the pilot program was completed. The program addressed physical symptoms, including providing morphine, as well as psychosocial and spiritual concerns of families. A model of hospital-based palliative care for neonates can be implemented within NICUs in tertiary government hospitals in India. Neonatal palliative care programs should include partnerships with charitable organizations to support implementation costs and provide palliative care training, mentorship, and capacity-building support.

KEYWORDS: Palliative care, children, neonatal, hospice, terminal care, end of life

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CORRESPONDING AUTHOR: Megan Doherty, University of Ottawa Faculty of Medicine, 401 Smyth Rd, Ottawa, ON K1H 8L1, Canada. Email: mdoherty@cheo.on.ca

Brief Points

What is already known about this topic

- Neonatal palliative care is a specialized area within children's palliative care, which focusses on the needs of infants with life-limiting or life-threatening conditions
- The practice of neonatal palliative care is well established in high-income countries, however, nearly one quarter of global neonatal deaths occur in India, where neonatal palliative care is virtually absent
- There is limited evidence describing the provision of palliative care for neonates in India or other resource limited settings, which can guide clinicians and health administrators

What this paper adds

- Implementing palliative care for neonates within a government tertiary NICU setting in India is possible, with support from local and international palliative care organizations.
- Program implementation requires trained staff with experience in pediatric palliative care as well as physical space for consultations and essential medications and supplies

- Infants requiring neonatal palliative care include those with sepsis and multi-organ dysfunction, hypoxic ischemic encephalopathy and prematurity as well as a wide variety of other conditions.

Introduction

While India has achieved significant reductions in neonatal mortality over the past 20 years, more than a quarter of worldwide neonatal deaths occur in India.¹ Despite the tremendous advances in the field of neonatology, there are still a significant number of babies who will have serious or life-limiting conditions and require medical care which focusses on relieving physical suffering and supporting the family with caring and compassionate communication. Palliative care focusses on the holistic prevention and relief of suffering, including treatment of both physical symptoms as well as psychosocial and spiritual concerns.

Despite being recognized as an essential component of universal healthcare by the World Health Organization, palliative care is rarely available low- and middle-income countries (LMIC).² In India, less than 1% of children who need palliative care are able to access this type of care.³ Even when healthcare clinicians with palliative care skills are available, the needs of children with serious illnesses differ from adults, and palliative



care clinicians are hesitant to care for children without additional specialized training to enhance their knowledge and skills.⁴

Neonatal palliative care (NPC) is a unique and specialized area within children's palliative care, which focusses on the needs of young infants and their families, when they are faced with the diagnosis of an illness which is expected to be life-limiting or life-threatening.⁵ In high-income countries, there are a wide range of conditions in neonatal period where palliative care is recommended (Table 1) and the practice of neonatal palliative care is well established.⁶

In India, palliative care remains unavailable for the vast majority of infants in neonatal intensive care units (NICU), with significant clinical, administrative, and legal barriers to its implementation.^{7,8} Physicians and nurses lack knowledge of how to appropriately manage pain in neonates and may be unaware of the differences in pain behaviors in term and pre-term infants.^{8,9} Additionally, absence of palliative care policies and procedures and concerns about the legalities of discontinuing intensive care are further barriers.^{7,8} There is a growing recognition that ensuring palliative care for neonates is a priority, since children with congenital and neonatal conditions make up 34% of all children needing palliative care globally, however there have been very few studies describing the provision of NPC in India or other resource-limited settings.¹⁰

The goal of this study is to describe the development and implementation of a pilot NPC program at a tertiary government hospital, to explore the key components of the program and the context, including the patterns of care for babies who received NPC from this pilot program. These experiences can support healthcare professionals and administrators to better understand how best to implement NPC in children's hospitals which can guide further development of future palliative care programs in NICUs across India and other resource-limited settings.

Methods

The study uses qualitative and quantitative research methods from implementation science. Qualitative methods include a program case study describing the pilot NPC program which was developed at a tertiary children's hospital in a resource limited setting, in India. Quantitative methods include a retrospective review of the medical charts for patients who received NPC during the pilot program.

Data collection

Clinical charts were retrospectively reviewed for demographic and clinical data including patient characteristics (gestational age, age, diagnosis, medical treatments, and outcome [death or hospital discharge]), referral characteristics (timing), and palliative care supports provided. Data were collected using a standardized data abstraction form, for NPC patients who

Table 1. Neonatal conditions where palliative care is recommended and was provided in this study (1-3).

CNS malformation and anomalies	<ul style="list-style-type: none"> Anencephaly, Hydranencephaly, Holoprosencephaly, Lissencephaly, Ruptured Meningomyelocele and Encephalocele. Hypoxic Ischemic Encephalopathy due to birth asphyxia.
Respiratory and lung conditions	<ul style="list-style-type: none"> Severe lung hypoplasia Bilateral Congenital Diaphragmatic hernia Skeletal anomalies causing severe lung hypoplasia Severe hydrops fetalis
Cardiac conditions	<ul style="list-style-type: none"> Complex cardiac anomalies, including inoperable or conditions requiring single ventricle repair with poor prognosis such as Hypoplastic left heart syndrome, Double outflow tract, Double outlet right ventricle, Obstructed TAPVC
Structural anomalies	<ul style="list-style-type: none"> Inoperable conjoined twins, limb-body wall complex
GI and renal conditions	<ul style="list-style-type: none"> Bilateral renal agenesis, or dysplasia Liver failure Extreme GI Tract hypoplasia
Genetic and metabolic conditions	<ul style="list-style-type: none"> Trisomy 13, 18, and others genetic conditions, especially when associated with severe structural anomalies Metabolic conditions with short life expectancy despite treatment. Metabolic conditions without treatment options
Extremely premature infants	<ul style="list-style-type: none"> Neonatal not responding to cardiopulmonary resuscitation. Neonates with central apnea associated with severe HIE or severe brain injury secondary to Intraventricular hemorrhage or Periventricular Leukomalacia. Neonates at end-of-life stage because of pulmonary, cardiac, and/or multiorgan failure.

were referred for NPC between July 2019 to February 2020. The time frame was selected by convenience, starting from the date the program enrolled its first patient, until the time of the first COVID lockdown, when the NPC service was temporarily suspended, upon resumption after lockdown, the clinical data collected had been modified. The time of final follow-up for patients who were discharged alive was 10 months after pilot program completion (Dec 31, 2020).

Inclusion and exclusion criteria

Babies with life-limiting or life-threatening conditions who were referred to NPC team during the pilot were included in the retrospective chart review and subsequent data analysis. Babies who were referred to the NPC team but who did not have a life-threatening or life-limiting condition, or who died before being seen by the team were excluded.

Data analysis

Descriptive statistics were obtained using Microsoft Excel. Categorical variables are described as percentage proportions for comparison. Continuous variables are described as mean and standard deviation.

Results

Implementation case study: NPC program at a Tertiary Government Children's Hospital

Program context. Niloufer Hospital (NH) is a tertiary government hospital in Hyderabad, India, providing maternity and pediatric care for children (0–14 years of age) in Telangana, a southern India state with a population of 35 million. There are approximately 8700 deliveries at the hospital annually, with 2200 of these babies being admitted for neonatal care. An additional 14000 out-born babies are admitted annually, and there are 2800 neonatal deaths annually. The hospital has 150 NICU beds, spread between Level 2, Level 3, Triage, and Emergency Stabilization Units, medical supervision is provided by neonatologists and pediatricians, with a team of pediatric residents and trained neonatal nurses. Only general pediatric medical and surgical services are available at NH, with specialized neuro, cardiac, and orthopedic surgery provided by several other government hospitals in Hyderabad. Prior to this project, there were no palliative care services available at NH. The high burden of serious illness and neonatal mortality at NH, led the clinical teams to recognize the need for NPC. The neonatal clinical team identified that NPC would enhance care for the sickest children and their families, by providing holistic care focused on relieving the child's suffering while also supporting the family to understand the child's illness and ensure that the medical care was aligned with the goals of care of the medical team and the family.

Palliative care services in the Hyderabad and Telangana

The Pain Relief and Palliative Care Society (PRPCS) is a local charitable organization, which has been delivering palliative care services in the Hyderabad region since 2011. The organization provides palliative care to 850 children and their families annually, through a pediatric palliative home care service and a standalone hospice facility for children in Hyderabad, and both services are able to provide NPC for seriously ill neonates, if a child is discharged from the hospital. The palliative care services in Hyderabad are complemented by a network of local community-based palliative care centers located in all 33 districts of the state of Telangana, which are funded by the state government. These community-based centers are staffed by physicians, nurses, counselors, and physiotherapists who have completed the Basic Certificate in Palliative Care (1 month training). The PRPCS activities are funded through a combination of locally raised funds and financial support from an

Table 2. NPC program definitions and characteristics.

ITEM	DESCRIPTION
Definition of NPC	"Palliative care for the neonate with a life limiting condition is an active and total approach to care from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the baby and support for the family. It includes the management of distressing symptoms and care through death and bereavement." (4)
Eligible medical conditions	Babies with serious, life-threatening or life-limiting conditions, which would include the conditions shown in Table 1. Other conditions where the child and/or family are experiencing significant suffering (either from physical symptoms or psychosocial or spiritual distress) would also be appropriate for NPC.
Components of care	Physical symptom management, communication, psychological, social and spiritual support, grief and bereavement support
Team members	Palliative care trained physician, nurse and counselor
Discharges	Home-based care can be provided by the PRPCS pediatric palliative care team (Hyderabad) or community-based teams (Telangana state) or in Hospice if desired by family Babies who are well enough may return to the hospital for outpatient follow-up with the NPC team

international organization, Two Worlds Cancer Collaboration Foundation.

Neonatal Palliative Care (NPC) program

During the planning stages, the key stakeholders and leaders from the neonatology department and palliative care team members met and defined the key features which they envisioned of the NPC program, including which patients would be included and the types of supports which the NPC team would provide. The consensus definitions and program characteristics are shown in Table 2.¹¹ In July 2019, the pilot NPC program at NH was initiated by the department of neonatology in collaboration with PRPCS. The goal was to develop a NPC program which could become a model for how neonatal palliative care could be implemented in government hospital settings and other health facilities with limited resources, with a goal of eventually expanding the service to encompass services for all ages of children needing palliative care at NH.

NPC team

The NPC team included 2 pediatricians, who had both completed a 1-year fellowship in pediatric palliative medicine, as

well as a trained palliative care nurse and counselor. The nurse and counselor had experience in palliative care and completed a 1-month basic certificate course in palliative care. Additional training through formal teaching sessions, informal bedside rounds, and case discussions was provided by the physicians to other team members. The nurse and counselor worked full time, while the 2 physicians shared 1 full time position. These positions were all funded by PRPCS during the pilot program. The 2 physicians also worked as PPC consultants for the other palliative care programs as described above.

NPC services

The NPC program provided inpatient consultations for any child admitted to the NICU. The care provided included management of physical symptoms, including pain, dyspnea, and other symptoms. Standardized pain assessment tools were used to assess pain, including the Neonatal Infant Pain Scale (NIPS) and Premature Infant Pain Profile (PIPP). Common palliative nursing care issues which the team addressed included skin care, feeding and general newborn care. The team also focused on ensure that families received adequate communication about the child's condition and prognosis, in coordination with the neonatology team. Psychosocial support, counseling, and telephone support after discharge were also provided. Bereavement support was mainly provided by telephone, with in-person visits when feasible within the city limits of Hyderabad.

For patients who were discharged from the hospital, home-care was provided by the pediatric palliative care services of PRPCS if the child was in Hyderabad, or by the community-based palliative care centers for those in rural districts in Telangana.

NPC services were provided free of cost for patients and families while in hospital, any medications prescribed by the NPC team were also provided to the patient for free. Oral and injectable morphine were available at NH, while other symptom management medications were provided directly by the hospital.

NPC referrals and awareness

Referrals were accepted from healthcare providers at NH and families could also self-refer. Suggested referral criteria, shown in Table 1, were posted in the neonatal units. The referral criteria were also circulated to social media chat groups for NICU physicians and residents. Several sensitization meetings and teaching sessions for residents, nurses, and physicians (consultants) were conducted, with discussion about referral criteria, as well as the key principles of neonatal palliative care and neonatal pain management. These meetings were taught by the NPC physicians and international experts who visited the program to support capacity building and training in palliative care. The

NPC team also conducted bedside teaching with treating physicians, residents, and nursing staff.

Experiences of neonatal palliative care team implementation

Upon completion of the pilot program, the NPC team and stakeholders (neonatology department) provided their reflections on the perceived strengths and weaknesses of the program. Strengths refers to the positive attributes that were helpful to the advancement of NPC program, and weaknesses looks at attributes that were barriers to NPC advancement at NH. Key strengths included supportive senior physicians in the department of neonatology and a highly motivated and committed NPC team which strong physician leadership. Weaknesses included lack of awareness of the concept of PPC among hospital clinicians, particularly those working in the NICUs and frequent rotation of staff in the NICUs. Further details of strengths and weaknesses are shown in Table 3.

Retrospective chart review

Patient characteristics. There were 110 babies with life-limiting or life-threatening conditions who were referred to NPC team during the 8-month pilot program. Most babies who were referred were not preterm (n=68, 61.8%). In total, there were 89 (80.9%) babies who died, 18 (16.4%) who were still alive at the time of the final follow-up (10 months after pilot completion), and 3 (2.7%) who were alive at hospital discharge but lost to follow-up thereafter. The 18 children who were alive at the time of final follow-up were all continuing to receive palliative care; 5 children were living in Hyderabad and are followed by the PRPCS home care program, and 13 resided in rural districts of Telangana and were followed by the community-based palliative care teams.

Types of life-threatening or life-limiting conditions

The most common life-limiting conditions were sepsis with multi-organ dysfunction (22.5%) followed by hypoxic ischemic encephalopathy (19.8%) and complications of prematurity (15.3%). There were 7 babies with severe malformations of the central nervous system, including meningocele, Arnold Chiari malformation, and Dandy Walker syndrome.

Further patient characteristics are shown in Table 4 and Figure 1.

Referrals and timing of death

There were 24 babies (21.8%) who died on the same day as the palliative care referral, and in total 44 (40.0%) babies died within 3 days of referral. There were 25 (28.1%) babies who died between 1 week to 1 month after the palliative care referral

Table 3. Neonatal palliative care team analysis of strengths and weaknesses to implementation.

<p>Strengths:</p> <ul style="list-style-type: none"> • There was continuous support and encouragement from senior leaders in the department of neonatology • Being a teaching hospital, the new subspecialty was received with a mix of curiosity and respect and there was a willingness to have a dialogue to understand better • The team had adequate and appropriate physical space where counseling and communication with family members could be done • The NPC clinic also has space for follow-up visits for babies who came for outpatient palliative care after discharge • The NPC team was highly motivated and committed to ensuring the success of the program • NPC physicians had previous PPC experience and training, enabling them to be confident program leaders • There was a steady source of funding from a local charitable foundation (Pain Relief and Palliative Care Society) and an international organization (Two Worlds Cancer Collaboration)
<p>Weaknesses:</p> <ul style="list-style-type: none"> • The concept of palliative care was relatively unknown at the hospital, and initially there was limited awareness about which babies to refer to NPC and how NPC would help a baby and their family • Initially NICU clinicians were unsure about the role of NPC in caring for sick neonates and of how the NPC team would support families. • NICU clinicians had inadequate knowledge around opioids, their use in neonates, and were concerned about opioid side-effects for neonates • Opioid myths among NICU clinicians made it challenging to provide adequate pain relief for the babies with procedural pain as well as pain related their medical conditions • The NPC team had not previously worked at the hospital and thus lacked knowledge of how to navigate the health care system at the hospital, thus there was significant learning "on the job" and NPC team practices needed to be adapted to the hospital • Frequent rotation of residents and senior physicians at the hospital meant that awareness and advocacy training had to be repeated frequently • Several initial NPC staff found it stressful and difficult to provide care for dying babies, leading to higher staff turnover on the NPC team in the initial few months

Table 4. Clinical and demographic characteristics of neonates receiving palliative care (n= 110).

	N	%
Gestational age		
Preterm	42	38.2
Term	68	61.8
Age at referral (days)	Mean (Range)	
	16.7 days (1-92 days)	
Gender		
Male	65	59.1
Female	45	40.9
Primary reason for referral		
Communication of poor prognosis to family	54	48.6%
Family counseling and long term follow up	34	30.6%
Wound care	12	10.8%
Withdrawal of life-sustaining therapies (compassionate extubation)	8	7.2%
Missing data	2	1.8%
Source of referral		
Senior physician*	64	57.6%
Neonatal or pediatric resident	46	41.4%

*Includes head of department, unit chiefs and consultants.

and 18 (20.2%) died longer than 1 month after referral. The average time between referral and death was 26.2 days (range: 0-269 days). Of the 24 babies that passed away on same day, 7

(29.1%) died after discontinuing mechanical ventilation (compassionate extubation) and 17 (71.9%) died from progression of their life-limiting condition.

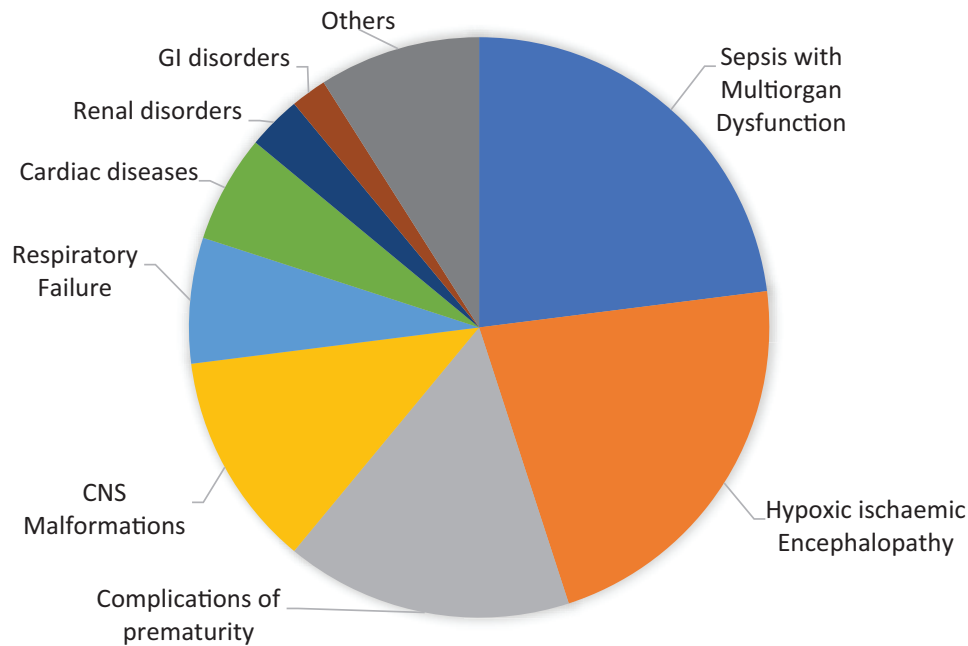


Figure 1. Primary life-limiting condition of infants referred for palliative care.

Referral characteristics

During the first few months of the pilot program, most referrals were from senior physicians including department heads, unit chiefs and senior consultants, however over time referrals from pediatric residents increased. The total number of referrals also increased during the program timeframe, from 7 in the first month, to an average of 9 per month for the first 4 months, and 21 per month in the final 3 months. Table 4 shows additional characteristics of the referrals including reason for referral and source of the referral.

Discontinuation of intensive care supports

There were 8 referrals for babies on mechanical ventilators, where discontinuation of life-sustaining ventilatory support was considered ethically appropriate care. In these situations, after detailed family meetings, caregivers of 7 babies chose to proceed with compassionate extubation. There was 1 baby whose caregivers chose to continue with mechanical ventilation and other high-intensity treatments. The NPC team continued to provide symptomatic support to the patient and emotional support to the family while the baby remained in hospital, the baby passed away while receiving mechanical ventilation 1 day after NPC consultation.

Discussion

We describe the implementation and clinical experiences of a neonatal palliative care program at a large tertiary government hospital. This is the first study in India to capture the patterns of referral and experiences of a NPC team, including the strengths and challenges of establishing NPC in this setting. Activities to raise awareness about which babies should be

referred to palliative care and the pain management including the use of opioids are important steps to consider when developing new palliative care programs in NICU settings. Many babies were referred to the program, with referrals increasing significantly over the 8-month duration of the program.

Our findings highlight the substantial unmet need for palliative care for neonates in NICUs across India. In settings where resources are limited, neonatal morbidity and mortality in intensive care units is significant, and many critically ill neonates and their caregivers can benefit from palliative care to improve symptoms and support families with communication and decision making. In addition to conditions diagnosed after a baby is born, advances in technology have made it possible to diagnose many serious neonatal conditions during pregnancy, highlighting the importance of perinatal counseling and palliative care integration during these pregnancies, should the parents choose to continue the pregnancy, and this represents another area where palliative care is needed in India. A recent review of a perinatal palliative care program in Canada, reported that the average gestational age of the time of referral was 23 weeks, suggesting that there is a substantial period of time when the palliative care team can provide support to parents expecting an infant with a serious condition, and parents value this early involvement of palliative care in supporting decision making and care planning.¹²

In this study there were more than 1800 neonatal deaths at the hospital during pilot study time frame, however the NPC received only 110 referrals, suggesting that there are many more babies who could benefit from palliative care in this setting. Estimates from the United Kingdom (UK) suggest that 85% of neonatal deaths require palliative care supports in a high-income setting, similar estimates in India are not available, but are

expected to be comparable.¹³ In 2016, congenital abnormalities accounted for 34% of new-born deaths in the UK, as the second most common cause of death.¹⁴ In India prematurity (35%), neonatal infections (33%), birth asphyxia (20%) and congenital malformations (9%) are among major causes of neonatal deaths which correlated with findings in this study about the common conditions in infants referred for NPC.¹⁵ Our findings suggest that even when NPC is available, there are a substantial number of babies who required palliative care yet who do not receive these services, suggesting under-referral. Further studies should explore barriers to palliative care referrals and effective interventions to overcome these barriers and improve referrals in India.

Palliative care referral is recommended at the time when a life-threatening or life-limiting condition is diagnosed.¹⁶ A substantial number of infants in this study on the day of death or the day before death. This suggests that palliative care consultations were likely delayed, and earlier referrals may help to reduce suffering and better support families in these challenging situations. Previous studies have identified the importance of early identification and referral to ensure that families receive timely communication and other palliative care supports.^{12,17} When referrals occur early, the palliative care team can develop a trusting relationship with the family members, helping them understanding their child's prognosis and participate in decision making and goals of care discussions. Late referrals limit the opportunity for the palliative care team to build rapport and in successfully communicating with the concerned family members, thus limiting the benefits of palliative care. Further studies seek to identify interventions which improve early referral to palliative care through advocacy and targeted education for NICU staff.

This study describes how the NPC team can provide an extra layer of support for families, helping them to better understand their baby's medical conditions and thereby make decisions about appropriate goals of care for their child. The study describes cases in which infants were referred to NPC for consideration of compassionate extubation. In these cases, the NPC team provided clear and honest information and support families considering withdrawal of life-sustaining treatments and supported compassionate extubation relieving physical symptoms while providing psychosocial support to the family members. Previous studies have identified that high quality communication, through ongoing family meetings are needed to help families to understand the care options and make decisions about discontinuing intensive care supports.¹⁸ Palliative care clinicians' expertise in serious illness communication makes them well suited to engaging in these conversations with parents of critically ill newborns which supports improved outcomes for their grief and bereavement after their child's death. Studies from high income countries suggest that the implementation of palliative care in neonatal intensive care units improves the quality of communication and end of life care around withdrawal of life-sustaining treatment.^{19,20} Future

studies should explore the quality of end-of-life care for neonates after implementation of palliative care in India.

Study limitations

A study limitation is that data collection was a retrospective review of medical records, which did not incorporate data collected directly from those who experienced the NPC service and lacked detail about symptom prevalence and use of high intensity treatments. The follow up period was limited to 10 months, which limits information about the duration of survival for those babies discharged from the hospital after NPC. The study was not able to assess the impact of palliative care for patients and families. Future studies should consider gathering information directly on parents and other family members or their grief and bereavement experiences. Additional research should seek to explore the lived experiences of parents and family members who receive NPC and how services can be designed to meet their needs in India and other LMIC.

Conclusion

Our study describes a simple model of neonatal palliative care which was implemented in a government tertiary NICU setting in India, enabled by support from a local and international palliative care organizations, to fund the palliative care team staff and provide mentorship and training. The program can be adapted and replicated in other resource-limited settings to improve access to palliative care for neonates with life-threatening and life-limiting conditions globally. The integration of palliative care into NICU in India is important to raise awareness about the need for palliative care services in these settings.

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Author Contributions

Study conception and design: MI, SR, GP, MD, MBS, MA, SL

Data collection: MI

Data analysis: MD

Manuscript drafting and revisions: MD, MI, SR, GP, SR

Approval of final manuscript: all authors

Ethical Approval

The study was approved by the institutional review board of Osmania University. A waiver of informed consent is requested for this minimal risk retrospective chart review in which no patient interaction occurred. Obtaining informed consent would have required contacting each patient directly, increasing the risks to patient privacy. Also, requiring informed consent would have resulted in a certain number of patients being lost

to follow up, or who might not agree to be in the study, thereby reducing the sample size and reducing the impact of this study.

ORCID iD

Megan Doherty  <https://orcid.org/0000-0003-3905-2169>

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