

Hospice Care in India—A Pediatrician’s Perspective

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Abstract



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Hospice care plays a vital role in providing compassionate and holistic support to terminally ill patients and their families. While hospice care has gained recognition and acceptance globally, its implementation and understanding in the context of pediatric patients in India remain limited. This article aims to explore the pediatrician’s perspective on hospice care in India, highlighting the challenges and opportunities for enhancing end-of-life care for children. By understanding the unique needs of pediatric patients and their families, healthcare professionals can contribute to the development and improvement in hospice care services across the country.

Introduction

Pediatric palliative care (PPC) focuses on improving the quality of life for children with life-limiting illnesses, aiming to alleviate pain and suffering while providing emotional and psychosocial support.¹ Hospice care, a crucial component of PPC, aims to provide comfort, dignity, and support to children and their families during the end-of-life journey. However, hospice care in India faces several challenges, including limited awareness, cultural beliefs, and resource constraints. This article explores the perspectives of pediatricians on the existing state of hospice care in India and proposes strategies to address the gaps.

Globally, the need for PPC is estimated to be around 20 million, and approximately 1.6 million children in India are in need of specialized PPC.² In India, there is a growing need

for PC for children, as there are many children with life-limiting illnesses such as cancer, HIV/AIDS, and neurological disorders. Unfortunately, access to PC is limited, with only a few specialized centers and hospices providing these services. Around one in ten children with cancer require PC,³ and current evidence supports early involvement of a PPC team for pediatric cancer patients at all stages of disease for positive impact on the quality of life.⁴

Challenges in Hospice Care for Children in India

Limited Awareness and Acceptance

One of the significant challenges in providing hospice care for children in India is the limited awareness and acceptance of

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such care among the general population. Many families are unfamiliar with the concept of hospice care and its benefits. As a result, they may not seek or consider these services for their terminally ill children. The lack of awareness can be attributed to a variety of factors, including inadequate education and outreach programs. Public campaigns and initiatives to increase awareness about pediatric hospice care are essential to ensure families understand the available options and make informed decisions regarding end-of-life care for their children.

Cultural and Religious Factors

Cultural and religious beliefs play a significant role in shaping attitudes toward end-of-life care in India. Some families may hold cultural or religious beliefs that influence their decision-making process regarding hospice care. These beliefs may include notions of accepting fate or avoiding discussions about death and dying. Pediatricians face the challenge of navigating these cultural and religious factors while providing information and support to families. Sensitivity and culturally appropriate communication strategies are necessary to address these challenges and promote acceptance of hospice care among diverse populations.

Lack of Dedicated Pediatric Hospice Facilities

The availability of dedicated pediatric hospice facilities is limited in India. Most hospice care centers primarily focus on adult patients, and the specific needs of children are often overlooked. The lack of dedicated pediatric hospice facilities poses challenges in terms of providing appropriate medical and psychosocial support tailored to the unique requirements of children. In many cases, pediatric patients end up receiving hospice care in general hospitals or at home, where resources and specialized expertise may be insufficient. It is crucial to establish dedicated pediatric hospice facilities equipped with trained staff and child-friendly environments to meet the specific needs of children and their families.

Inadequate Funding and Resource Constraints

Hospice care, particularly for children, requires a multidisciplinary team of healthcare professionals, including doctors, nurses, psychologists, social workers, and volunteers. However, inadequate funding and resource constraints pose significant challenges in establishing and sustaining comprehensive pediatric hospice care programs. The cost of providing specialized care, medications, equipment, and supportive services can be substantial. Limited government funding and a lack of private philanthropic support contribute to the scarcity of resources. Addressing the funding and resource constraints through increased government investment, partnerships with nongovernmental organizations (NGOs), and community involvement can help overcome these challenges and ensure the availability of high-quality hospice care for children in India.

Legal and Regulatory Issues

India has its own legal and regulatory framework for healthcare, and this can make it difficult to implement Western models of PC services. For example, there may be restrictions

on the use of certain medications or on the role of nonphysician healthcare professionals in providing care.

The Role of the Pediatrician in Hospice Care

Early Integration of Palliative Care

The role of the pediatrician in hospice care begins with recognizing the importance of early integration of PC for children with life-limiting illnesses. Pediatricians are often the primary healthcare providers for children, and they play a critical role in identifying patients who may benefit from PC services. By initiating conversations about PC early in the disease trajectory, pediatricians can ensure that children and their families receive comprehensive support from the onset of diagnosis.

Early integration of PC involves addressing pain and symptom management, psychosocial support, and advance care planning. Pediatricians can collaborate with PC specialists and other healthcare professionals to develop a holistic care plan that focuses on enhancing the child's quality of life while respecting their individual needs and goals. By actively involving the child and their family in decision-making processes, pediatricians can provide the necessary support and guidance to ensure that the child's physical, emotional, and spiritual well-being is prioritized throughout the course of their illness.

Communication and Collaboration

Effective communication and collaboration are fundamental aspects of hospice care, and pediatricians play a vital role in facilitating these processes. Pediatricians are skilled in communicating complex medical information in a compassionate and understandable manner, ensuring that families are well-informed and empowered to make informed decisions about their child's care.

Pediatricians collaborate with a multidisciplinary team of healthcare professionals, including nurses, social workers, psychologists, and spiritual care providers, to provide comprehensive care for children and their families. They act as a liaison between the various healthcare providers involved in the child's care, ensuring that information is shared, care plans are coordinated, and the child's needs are addressed comprehensively.

Furthermore, effective communication extends beyond the medical team to include open and honest conversations with the child and their family about their hopes, fears, and goals. Pediatricians can provide emotional support, address concerns, and facilitate discussions regarding end-of-life preferences, enabling families to make informed decisions that align with their values and beliefs.

Care Coordination and Continuity

Pediatricians play a crucial role in ensuring care coordination and continuity for children receiving hospice care. They work closely with the PC team to establish a care plan that addresses the child's physical, emotional, and psychosocial needs. Pediatricians provide ongoing assessments, monitor symptoms, and make appropriate adjustments to the care plan to ensure optimal comfort and well-being for the child.

Care coordination involves collaborating with other healthcare providers involved in the child's care, including specialists, therapists, and home healthcare services. Pediatricians serve as a crucial point of contact, facilitating seamless transitions between different care settings and ensuring that the child's care is well-coordinated across different providers.

Additionally, pediatricians also play a vital role in providing support and guidance to families during transitions, such as hospital-to-home or transitions between different levels of care. They educate families about available resources, coordinate home care services, and provide guidance on managing symptoms and medications, ensuring that the child's care remains consistent and uninterrupted.

Advocacy and Education

Pediatricians function as advocates for pediatric hospice care, both at an individual and systemic level. They have a unique opportunity to advocate for policy reforms that improve access to palliative and hospice care services for children. By engaging in discussions with policymakers, healthcare organizations, and insurance providers, pediatricians can contribute to the development of guidelines and funding mechanisms that support the provision of high-quality pediatric hospice care.

Furthermore, pediatricians play a crucial role in educating fellow healthcare professionals, trainees, and the broader community about pediatric hospice care. By sharing their knowledge and experiences, they can promote a better understanding of the unique needs of children and families facing life-limiting illnesses. Pediatricians can participate in educational initiatives, conferences, and workshops to raise awareness, improve knowledge, and enhance the skills of healthcare professionals in providing compassionate and effective pediatric hospice care.

Through advocacy and education, pediatricians can help reduce the stigma associated with pediatric end-of-life care and foster a supportive environment that values the importance of providing comfort, dignity, and support to children and their families during their final journey.

What is Happening in India?

The Indian government has recognized the need for PC and has taken some steps to address the issue. In 2014, the Ministry of Health and Family Welfare released guidelines for the establishment of PC services in India, which included provisions for PPC. However, implementation of these guidelines has been slow, and much more needs to be done to improve access to PC for children.

Several NGOs are working to improve access to PC for children in India. For example, the Indian Association of Palliative Care has established a PPC working group to promote education and training in this field. Some of the major hospitals that provide PC services for children in India include Tata Memorial Hospital, Mumbai, All India Institute of Medical Sciences (AIIMS), New Delhi, St. John's Medical College Hospital, Bengaluru, Apollo Children's Hospital, Chennai, etc. These

hospitals provide a range of services including pain and symptom management, psychosocial support, and end-of-life care. They also provide support to families and caregivers of children who are facing serious illnesses.

Opportunities for Enhancing Pediatric Hospice Care in India

Policy Reforms and Guidelines

Policy reforms and guidelines are essential for improving and standardizing pediatric hospice care in India. Currently, there is a lack of specific policies and guidelines addressing PPC and hospice services. To enhance pediatric hospice care, it is crucial to advocate for the development and implementation of policies that outline the rights of children with life-limiting illnesses and provide guidelines for healthcare professionals involved in their care. These policies should address issues such as pain management, psychosocial support, ethical considerations, and the integration of PC into mainstream healthcare services. By collaborating with policymakers and relevant stakeholders, pediatricians can actively contribute to shaping policies that prioritize and support pediatric hospice care.

Capacity Building and Training

Effective pediatric hospice care requires healthcare professionals to possess the knowledge, skills, and attitudes necessary to address the complex needs of children and their families. There is a need for comprehensive capacity building and training programs to equip healthcare professionals, including pediatricians, with the necessary expertise in PPC. Training initiatives should focus on symptom management, communication skills, psychosocial support, and ethical considerations in end-of-life care. By investing in ongoing professional development and training programs, healthcare institutions and organizations can ensure that healthcare professionals are adequately prepared to deliver high-quality pediatric hospice care.

Community Engagement and Awareness Programs

Creating awareness about pediatric hospice care within the community is crucial to dispel myths, reduce stigma, and promote acceptance. Community engagement programs can involve collaborating with local organizations, religious leaders, and community influencers to educate the public about the importance of pediatric hospice care. These programs can include workshops, public talks, support groups, and educational materials that raise awareness about the rights and needs of children with life-limiting illnesses and the availability of hospice services. Pediatricians can actively participate in these programs, serving as advocates for pediatric hospice care and fostering a supportive environment within the community.

Research and Data Collection

Research plays a significant role in advancing pediatric hospice care by generating evidence-based practices and improving outcomes for children and their families. There is a need for research studies that focus specifically on pediatric hospice care in the Indian context. These studies can explore various

aspects such as the impact of hospice care on the quality of life of children, the effectiveness of different interventions, and the experiences and needs of families receiving hospice care. Data collection efforts should also include the development of standardized assessment tools and outcome measures specific to pediatric hospice care. By actively participating in research initiatives, pediatricians can contribute to the body of knowledge and drive evidence-based improvements in pediatric hospice care services.

Case Study and Best Practices

Ms. Vishnumaya (name changed), an adolescent girl coming from a poor socioeconomic background, was diagnosed with metastatic medulloblastoma, and received treatment at a tertiary cancer center that is 12 hours journey from her home. Her treatment was covered by government schemes, but the family had to borrow a considerable amount from neighbors and relatives for out-of-pocket expenses including accommodation near the cancer center, travel and food for the treatment duration. She went home after treatment but returned after a short span with progressive symptoms suggesting disease recurrence. She was admitted and provided the necessary supportive care that included anticerebral edema measures, anticonvulsants, pain medications, nasogastric tube, and urinary catheter placement. Her case was discussed in the multidisciplinary tumor board and decision of shifting care to PC was taken. The PC team counseled the parents regarding the poor outcome and lack of curative options and explained that the best course for her would be focused on comfort care at home. The parents fully understood the poor prognosis but did not wish to take her home fearing the pressure by relatives and society that they had given up on their child and let her die at home. They were not confident of managing her complications at home, and despite repeated counselling by the treating team, they preferred not to discharge the child from the hospital. She was retained in the pediatric oncology general ward with only the mother as the bystander, the siblings, or other family members could not visit because of restrictions. During her prolonged hospitalization, her mother had sleep exhaustion, caregiver burnout and major mental and physical health issues because of being the single caretaker. The patient died in the hospital after 22 days, leaving back an emotionally exhausted mother and deprived of the home environment and the care of her siblings and father during the most needed phase of her short life.

The above case is not unique and brings to light some important lacunae in PPC in our country. Worldwide, a lot of effort is on to address the various challenges in PPC utilizing multipronged strategies like public awareness, improvement in services, competency building in providers by education and training, improving access to medications, encouraging research and advocacy.⁵ In well-resourced countries, provision of PPC is considered as quality medical care, and every attempt is made to bring early and timely integration of PPC into clinical practice with the involvement of specialized PPC teams.

The Royal College of Paediatrics and Child Health has developed guidelines for PC for children, which are designed to ensure that children receive high-quality, holistic PC that meets their physical, emotional, and spiritual needs, as well as the needs of their families and caregivers.

These guidelines are organized into four categories:

Category 1: Recognition of dying—this category includes the identification of children who are approaching the end of their life, as well as the development of an individualized care plan.

Category 2: Assessment and management of symptoms—this category includes the management of symptoms such as pain, nausea, and breathlessness, as well as the provision of emotional and spiritual support.

Category 3: Care after death—this category includes the provision of support to the child's family and caregivers after the child has died, as well as guidance on practical matters such as funeral arrangements.

Category 4: Continual quality improvement—this category includes the ongoing evaluation and improvement in PC services for children, as well as the promotion of research and education in this area.

Revisiting the Case of Hospice and Respite Care

As in the case described above, often, families of children with relapsed or progressive cancer are not able to accept the abrupt dissociation from oncology services and sudden care transition to a PC service. Often, they hope for a miracle, or are in denial trying to allay their own feelings of guilt of not having done enough for their child. Nonacceptance of poor prognosis, complex clinical problems in the child, emotional stress of parenting for a sick child, logistic and organizational factors, and societal pressures⁴ make end-of-life care decisions most difficult for families,⁶ leading to most of these availing hospital emergency services during the terminal stages and dying in hospital wards and/or intensive care units.

Hospice can be an important link in PPC and can play an important part in the care transition of children with life-limiting illness by providing medical and nonmedical supportive care outside a hospital setting, bridging the gap between hospital and home. Hospices are currently under-utilized in India mainly due to lack of awareness regarding its idea and functioning, the stigma of them being places of leaving the patient to die, and the financial burden.⁷ Hospices can successfully function as intermediary centers of PC providing pain medication, active symptom management, and can offer minor procedures like ascitic and pleural fluid tapping, colostomy care, lymphoedema care, blood transfusions, and wound dressing in collaboration with nearby hospitals. This will lessen the burden from busy emergency departments in hospitals. In addition, hospices can evolve as centers providing caretaker empowerment, respite care, sibling, and family support, and can take away the feeling of abandonment and help the family gain acceptance of PC. Respite care services for children in India are intended to provide temporary relief and

support to families who are caring for children with special needs or chronic illnesses. These services can be invaluable to families who may be struggling to balance the needs of their children with their other responsibilities and commitments.

There are a few organizations in India that offer respite care services for children, such as:

Tamana Special School: Tamana provides respite care services to children with disabilities, including autism, cerebral palsy, intellectual disabilities, and multiple disabilities. They offer both short-term and long-term care options and provide therapy services.

Umang Charitable Trust: Umang Charitable Trust provides respite care services to children with special needs, including those with autism, cerebral palsy, and intellectual disabilities. They offer a range of programs and services, including day care, residential care, and therapy services.

Cuddles Foundation: The Cuddles Foundation offers respite care services to children with cancer and their families. They provide a range of services, including nutritional support, counselling, and financial assistance.

Sparsh Special School: Sparsh provides respite care services to children with disabilities, including cerebral palsy, Down syndrome, and autism. They offer daycare, residential care, and therapy services.

Repurposing the hospices has its own challenges, the major one being funding. Advocacy of the concept of hospice care at the community and government level and its inclusion under the state PC policies will help to formulate guidelines for uniform staffing pattern and standard operating procedure for hospices and support in the form of workforce and finances. Another method to generate resources for the establishment and functioning of hospices is public-private partnership, with involvement of NGOs and other funding agencies. In the pediatrician's perspective, hospice care is the ideal mid-level specialist PC facility for children affected with life-limiting illness and can make meaningful difference in the quality of life of these children and their families.

Successful Models of Pediatric Hospice Care

In recent years, a few successful models of pediatric hospice care have emerged in India, highlighting innovative approaches to providing compassionate and comprehensive end-of-life care for children. These models serve as inspirations for developing and expanding pediatric hospice care services across the country. Here are some examples:

The Pediatric Palliative Care Program at a Tertiary Hospital

One successful model is the integration of PPC within a tertiary hospital setting. This approach involves a dedicated team of healthcare professionals, including pediatricians, nurses, psychologists, social workers, and volunteers, who work collaboratively to address the physical, emotional, and spiritual needs of children with life-limiting illnesses and

their families. The program focuses on pain and symptom management, psychosocial support, and facilitating open communication between healthcare providers and families. By embedding PPC within the existing healthcare system, this model ensures a seamless transition from curative to PC, thereby improving the quality of life for children during their end-of-life journey.

Home-Based Hospice Care

Another successful model is the implementation of home-based hospice care for children. This model recognizes the importance of providing care in the comfort of the child's own home, surrounded by familiar surroundings, and loved ones. It involves a multidisciplinary team of healthcare professionals who visit the child's home regularly, providing medical care, symptom management, counseling, and support to both the child and their family members. Home-based hospice care not only addresses the physical needs of the child but also focuses on improving the overall well-being and quality of life for the entire family unit. This model has shown positive outcomes in terms of increased family satisfaction, reduced hospitalization rates, and enhanced psychosocial support.

Collaborative Efforts and Partnerships

Collaborative efforts and partnerships play a pivotal role in strengthening and expanding pediatric hospice care services in India. By bringing together various stakeholders, including healthcare organizations, government agencies, NGOs, and community groups, collaborative initiatives can address the complex challenges associated with pediatric end-of-life care. Here are some examples of collaborative efforts and partnerships.

Public-Private Partnerships

Public-private partnerships have proven to be effective in addressing resource constraints and improving access to pediatric hospice care services. By combining the resources, expertise, and networks of both public and private sectors, these partnerships can establish and sustain pediatric hospice care facilities, train healthcare professionals, and provide financial support for families in need. Such collaborations ensure a more comprehensive and coordinated approach to PPC.

Academic and Research Collaborations

Academic institutions, research organizations, and healthcare providers can collaborate to advance knowledge and evidence-based practices in pediatric hospice care. These collaborations can involve conducting research studies to identify the unique needs of pediatric patients, evaluating the effectiveness of different interventions, and developing guidelines and best practices. By sharing knowledge and expertise, these collaborations contribute to the continuous improvement of pediatric hospice care services.

Community Engagement and Volunteer Programs

Engaging the local community and leveraging volunteer programs are essential for enhancing pediatric hospice care.

NGOs, community-based organizations, and volunteers can provide valuable support by offering respite care, emotional support, and assistance with practical needs. Additionally, community awareness programs can help dispel misconceptions and cultural barriers surrounding pediatric end-of-life care, fostering a more supportive environment for families and healthcare providers.

Conclusion

Hospice care for children in India requires a comprehensive and multidisciplinary approach to address the unique challenges faced by pediatric patients and their families. The pediatrician's role is crucial in shaping and improving the quality of pediatric hospice care services. By promoting awareness, advocating for policy reforms, and fostering collaboration among healthcare professionals, policy-makers, and community stakeholders, pediatricians can play a vital role in enhancing end-of-life care for children in India. It is imperative to ensure that every child receives compassionate and dignified care during their final journey, irrespective of their medical condition or socioeconomic background.

Conflict of Interest

None declared.

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