

INTEGRATING PALLIATIVE CARE INTO A CHILDREN'S ONCOLOGY SERVICE IN INDIA



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Provision of palliative care is being recognized increasingly as a human rights issue.¹ Nevertheless, it is not available for many people with cancer and other serious diseases. This is particularly so for vulnerable groups, including children in resource-poor countries.

It has been estimated that in the developing world at least 160,000 children are diagnosed with cancer every year.² Sadly, very few of them will receive adequate pain relief and palliative care at any time in the course of their disease.

In India, the overall incidence of paediatric cancer per year is 38 to 124 per million children under 15 years of age.³ As in other low-income countries, late diagnosis and lack of resources means that, depending on the area in which they live, anything from 17–72% of these children will die as a result of their cancer.⁴ This can be put in perspective when compared with the United States and United Kingdom where only 20–24% of children with cancer will die.^{5,6} But, whether or not they are eventually cured, young patients often find the painful procedures they have to undergo the hardest part of their disease to bear⁷, and the stress this causes can also negatively influence their chances of survival. It is very upsetting for families to watch their children suffering and they feel powerless to help them. Yet there are few paediatric palliative care units in India, or culturally appropriate tools and guidelines for best clinical practice to assess and prevent children's pain.

Paediatric palliative care

Paediatric palliative care has been defined as a sub-specialty that focuses on achieving the best possible quality of life for children and their families living with life-threatening or terminal conditions like HIV, AIDS and cancer. It deals with the control of pain and other symptoms, and addresses the related psychological, social and spiritual problems.⁸

It is vital that all medical facilities caring for children develop paediatric palliative care programmes, along with rural and urban outreach services, and strategies to raise public awareness. As for adults, palliative care for children is

practised using an integrated, interdisciplinary approach (see Figure 1). There should be good continuity of care, including availability of expert nursing and physician help at all times, and a team to help with the psychosocial and spiritual needs of the family. Moreover, doctors and nurses working in oncology should become acquainted with palliative attitudes, techniques and knowledge.

An overly rigid separation between curative and palliative care can lead to problems. As mentioned earlier, children who will likely be cured benefit from pain relief measures just as much as children and families facing deterioration and death. Unfortunately, palliative care is often not offered to them because it is wrongly assumed to be only needed during the terminal period. In summary, using a broader "scope of care", all children living with a life-threatening condition could benefit from palliative management.

For these reasons, the World Health Organization in its description of paediatric palliative care states: "Palliative care begins when an illness is diagnosed, and continues irrespective of whether or not a child receives disease-directed treatment".⁹ Similarly, the American Academy of Pediatrics recommends an integrated model of palliative care "in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death".¹⁰

The paediatric palliative care programme in Hyderabad

The Mehdi Nawaj Jung Institute of Oncology (MNJ) is a 300-bed tertiary care hospital in the state of Andhra Pradesh in India. Every year the hospital cares for around 1,000 children with cancer. Most of the children require intensive curative treatment over a lengthy period. Painful procedures, disease-

related symptoms and the emotional trauma of facing a potentially life-threatening illness all cause enormous suffering. Many children develop severe anxiety, depression, become withdrawn and have difficulty communicating. Families and patients often have to travel long distances and then stay in the hospital for weeks, meaning they are deprived of their extended family and community support when it is needed most.

Very early in the development of the paediatric oncology programme, we realized the dire necessity for an effective palliative care programme for children suffering from cancer and their families aimed at optimizing their physical, psychosocial and spiritual well-being.

The MNJ Pain and Palliative Care Programme, which is a collaboration between MNJ, the International Network for Cancer Treatment and Research (INCTR) and its Canadian branch (Two Worlds Cancer Collaboration Foundation) along with Pallium India, has been caring for adults since 2005. Active advocacy by the team has resulted in the inclusion of palliative care in the state-sponsored health insurance scheme for people who are poor. Generally the programme has been strongly supported by the Government of Andhra Pradesh as well as the leadership of MNJ.

A distinct paediatric palliative care service was created in 2007. The main features of the programme are as follows:

- ▶ Free treatment for all children.
- ▶ A dedicated team of physicians, nurses and social workers trained in paediatric palliative care.
- ▶ Simultaneous enrolment into the palliative programme for every child coming for treatment at the oncology department. Initial support includes pain and other symptom management, relationship building and psychosocial help for the child and family in coping with the diagnosis.
- ▶ Regular weekly support group meetings, and recreational and educational activities on cancer hygiene and the importance of treatment completion.
- ▶ Zero tolerance to pain. Screening for pain is carried out on

all patients and every effort is made to keep each child completely pain free. This includes procedural pain, which is routinely managed using procedure-related pain relief protocols. Examples of these would include:

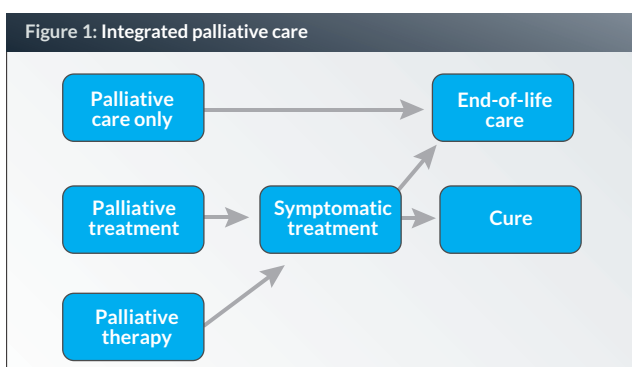
- non-pharmacological approaches such as simple explanation of procedures to the child and the parents, parental involvement during procedures and distraction techniques;
 - EMLA cream at the site of injection for every child undergoing diagnostic or therapeutic procedures;
 - conscious sedation with medications such as midazolam during procedures such as bone marrow aspirations;
 - general anaesthesia with the help of anaesthesiologists in selected situations.
- ▶ Training for all oncology staff in the basics of pain management and palliative care so that pain and distress is recognized, recorded and addressed at the earliest opportunity.
 - ▶ Ready availability of the commonly used opioids (oral and parenteral morphine, and parenteral and transdermal fentanyl) for both inpatients and outpatients.
 - ▶ Maintenance of continuity of care by offering home-based care for patients living in the city of Hyderabad and phone support for those living further away.
 - ▶ Financial support if needed for transportation, food, medicines, health care of siblings and schooling.
 - ▶ Inpatient and hospice care provided for those children with difficult symptoms, psychosocial issues or needing end-of-life or respite care.
 - ▶ A “round the clock” phone helpline for families after their child is discharged.
 - ▶ When necessary, a smooth transition to advanced palliative and end-of-life care.

Since the paediatric programme was established:

- ▶ the number of children treated has increased dramatically (see Figure 2);
- ▶ the total opioid consumption, which is an indicator of the effectiveness of a pain relief programme, has increased from 93 grams of oral morphine equivalent in 2010 to 284 grams in 2012.
- ▶ there has been a reduction in loss to follow-up and abandonment of treatment improving patients' chances of survival. This is a major public health issue in developing countries.¹¹

Training in paediatric palliative care

The basic and one-month palliative care training programmes at MNJ are among the few to include a module on paediatric



palliative care. The first ever Indian Fellow in Paediatric Palliative Care completed his training in 2012. The Open Society Institute generously supported this fellowship programme.

Future plans

The future plans for the service include strengthening the existing programme especially in terms of care at home both in the urban environment and in rural areas. We intend to forge links within India and the wider region as well as in more developed countries to develop the best systems to help children. We envisage also continuing efforts in education and advocacy.

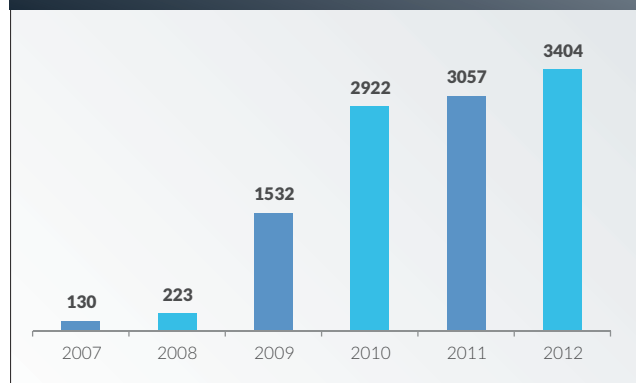
Conclusion

In India, it is estimated that less than 0.4% of those that require it have any access to palliative care.¹² The National Cancer Control Programme of India in 1987 referred to palliative care as a priority. However, most large cancer hospitals in India, including 18 of 29 government-designated lead cancer centres do not have personnel trained in palliative care or are familiar with proper opioid use. In addition, most programmes that do exist lack paediatric expertise and thus deprive children and their families of the benefits of palliative care. Palliative care programmes specifically designed to address the needs of children are few and far between.

We feel we have demonstrated that integration of palliative care into a paediatric oncology programme is possible with a smooth transition to good end-of-life care if needed. The increase in opioid consumption points to improvement in pain management. However, further studies need to be undertaken in this setting to quantify changes in the children's quality of life.

If all paediatric nurses and doctors (both general and oncology) receive some palliative care training we could hope

Figure 2: Number of paediatric consultations by the MNJ palliative care team by year



to significantly improve the quality of life for children with cancer and other life-threatening diseases. To that end we suggest that centres of excellence in specialist children's palliative care be set up in other regions and developing countries to provide service, training, advocacy and research. The integrated programme developed at MNJ could serve as a model and we hope to make some progress in this endeavour next year. ●

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