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Scientific comment

Scientific comment on the theme of palliative care in pediatric hematological oncology patients[☆]



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Some of the most relevant aspects in the care of children with life-limiting illnesses (particularly those with oncologic diseases) concern the team and the care setting, the daily life, bereavement management and the possibility of case review after death.

The main goal of pediatric palliative care (PPC) is family centered homecare which requires the presence of an experienced, and structured interdisciplinary team. The cooperation, generally speaking in different countries, between the hospital and the local health services is quite poor: local pediatricians are involved in a low percentage of cases and rarely attend children in the terminal phase.¹

The hemato-oncologist often remains the only referral physician. Usually, although home care (if present) is proposed, many families refuse. However, the literature suggests that death at home is considered the first choice, but this happens more frequently only when an integrated palliative care team is available to support family decisions and contain their fear of being abandoned.²

The main obstacles to having home care are reportedly the physicians' impression that the patient's clinical management is excessively difficult, the parents' fear of abandonment or the ethnical and subsequent language problem of parents.

The most important barrier to the implementation of PPC is probably the lack of integrated, structured and dedicated teams which could coordinate PPC networks. Some policies could be proposed:³

- more training for physicians and nurses on palliative care including: formal education, as part of medical degree courses, and an adequate period of experience in a palliative care service during pediatric residencies for all pediatricians, as well as educational courses and training periods for nurses. The final aim would be to address these topics in hospital, in the local health system, and in hospices.
- PPC Networks and/or pediatric hospices need to be created to strengthen the link between hospitals and local services.
- A greater promotion of multispecialty networks is needed, including palliative care specialists, local pediatricians, psychologists and nurses working in close cooperation with pediatric oncology centers in order to share decisions concerning patient care and transform the failure of cancer treatment into the continuation of appropriate patient care, providing all the support needed by terminal patients.

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[☆] See paper by Valadares et al. on pages 403–8.

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These policies should be requested because, still today, many challenges exist in the implementation of these integrated models including the pressure to reduce overall health care costs, health care providers lack of necessary tools and skills, and the mistaken tendency to equate palliative care with end-of-life care. Despite the fact that palliative care is now widely recognized as a critical part of excellent care for children with life-limiting diseases such as cancer, patients continue to receive this care very late in their illness trajectory. However, as evidence grows that introducing palliative care early in the course of therapy benefits children with cancer, and as the medical culture becomes more aware of the evidence demonstrating the value of such an approach, pediatric oncology and palliative care will continue to become more integrated. This will benefit children, their families, and the staff members who care for them.

In this issue of the Revista Brasileira de Hematologia e Hemoterapia, Valadares et al. report on the experience of a tertiary hospital in Brazil.⁴

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