

Obstacles to the Promotion of Dialogue between Parents, Children and Health Professionals about Death and Dying in Pediatric Oncology

PERSPECTIVE

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Abstract

Despite advances in cancer treatments and improved prognosis, the number of deaths from the disease is high in the world. In Brazil, cancer is the second leading cause of death among children and adolescents, forcing family members, patients and professionals to deal with the issues of human finitude. The multidisciplinary team considers the discussions at the end of life as a difficult task to be performed on pediatric patients. The family is essential to overcome the communication barriers, acting as liaison between the multidisciplinary team and the patient. Children should be invited to participate in the decision-making process and their wishes should be honored at the end of life. Professionals should be able to meet the physical, psychosocial, spiritual, social and cultural rights of patients and families. Discussions at the end of life with pediatric patients are key to promoting a "good death", however there are few studies that address this issue.

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New cases of cancer are estimated 15,5 million in 2030 [1, 2, 3]. Although advances in cancer and supportive treatments have improved the prognosis and long-term survival rate of children with cancer, an estimated 25% of children will die of their disease [4, 5]. In Brazil, in 2011, there were 2, 812 deaths due to cancer in children and adolescents (0-19 years). Neoplasms occupied the second position (7%) of deaths of children and adolescents in 2011 [1, 6]. Therefore patients and their families are often forced to confront end-of-life (EOL) issues [7, 8, 9] and although the specific impact of the loss of a child may

differ for parents, a child's death is often considered the "ultimate loss" [10, 11].

End-of-life discussions (EOLd) with patients have been reported as one of the most difficult and stressful tasks for an oncologist [12, 13, 14]. However, few studies have dealt with EOLd in the pediatric setting [12, 15]. Physicians have been trained to maintain health and fight illness, but they are generally provided little guidance regarding communication with dying patients and their families [12, 16]. Pediatric oncologists reported "strong emotions" [17, 18]. These included sadness, crying, lack of sleep, feelings of exhaustion and being drained, feeling physically ill, and a sense of personal loss. The impact on oncologists included burnout, compartmentalization, emotional exhaustion, and difficulties in maintaining emotional boundaries [17].

In that context, when a child is diagnosed with cancer, the entire family is diagnosed, therefore EOLd with pediatric patients will have some difference from that of adult patients [1, 19]. The most significant difference is that parents play an important role in the communication with the pediatric patient [12, 20, 21]. However, parents are usually, though not always, gatekeepers or conduits for communication between health professionals and the sick child [12, 22]. They decide what, when and how their child should be told about the illness [12, 23]. When an end-of-life decision has to be made for a child, most parents, independent of their country of origin, seem to prefer a shared approach by their physicians over a paternalistic approach or an informed approach [24, 25, 26, 27, 28, 29, 30, 31, 32, 33].

Previous research suggests that open and honest communication among healthcare practitioners, parents and children about disease and prognosis is important for good medical care [34, 35, 36]. However, transitioning care from a primarily curative to palliative care focus is often challenging to negotiate [37]. Some barriers to adequate EOLd were identified in previous studies irrespective of patient age or

disease. Among them, healthcare provider factors (the lack of experience, discomfort with death and dying [12, 38], lack of knowledge, uncertain prognosis [12, 39], uncertain right time to address the issue [12, 40] and reluctance to discussion [12, 41] and patient and parent factors (the inability of patients to comprehend, lack of readiness, unrealistic expectations [12, 40], family's opposition, [12, 38] lack of familial acknowledgement of terminal condition [12, 39], patient's willingness to protect other people and the inability to imagine a possible death [12, 41]. So, Discussions of advance care planning frequently happen late in illness [37].

Parents of children with cancer and their clinicians prefer home as the location for EOL care and death [42]. But, Whenever possible, caregivers should make an effort to invite children to participate in medical decision making and honor their EOL care wishes [43]. The Institute of Medicine acknowledged that a critical component of the definition of a "good death" generally accords with the wishes of patients and families [42, 44]. Moreover, Regardless of the preferred location, when families are able to choose and plan the location of death, the dying process and bereavement experience both go more smoothly [7, 45].

What parents fear most is that their child will suffer in the process of dying [24]. It is recommended, in this sense, that the interdisciplinary team (IDT) identifies, communicates, and manages the signs and symptoms of patients at the EOL to meet the physical, psychosocial, spiritual, social, and culture needs of patients and families [46, 47]. Thus, the child's suffering from physical and psychological symptoms is reported as an important theme of pediatric palliative care, and illustrates the significance of adequate symptom management during the palliative phase [10, 48, 49, 50, 51].

Children with cancer suffer proximal to death [52, 53, 54] and but symptom control, despite efforts of health care professionals, is sometimes unsuccessful [10, 48, 49, 50, 51]. Therefore, understanding the

degree of symptoms proximal to death and the predictors of those symptoms is an important step toward symptom management and optimization of quality of life in the end-of-life period [52].

Research should be conducted addressing EOLd with groups and children with similar age profiles, because the content of the barriers to these discussions can vary greatly from according to the age. Furthermore, it is necessary to identify the negative and positive point to EOLd in the pediatric setting and to calve what age children can be invited to participate in decision-making processes. Also, discussions at the end of life with pediatric patients should be performed whenever they are requested by patients and their parents. The family must to be part of the process, acting as a link between the child and the health professional. The multi-disciplinary team should be prepared to meet the needs of the child-family binomial. This includes responding in a clear, precise and direct questions to the patients and their families about treatment, management of symptoms, prognosis, suspension of it and place of death therapy. It is essential that professionals follow the family before, during and after the death of children, minimizing the destructive effects of cancer diagnosis and mourning.

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