

Special Edition
"Palliative Care and Oncology:
Time for Increased Collaboration
and Integration"

Commentary

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Palliative Care in Moroccan Children with Cancer: What are the Parent's and Children's Needs?

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Palliative care has been well defined by the World Health Organization (WHO) as a comprehensive care approach which "improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."¹ In 2000, the American Academy of Pediatrics (AAP) emphasized the importance of offering an integrated model of palliative care that continues throughout the course of the illness.²

Yet despite the fact that palliative care has been accepted as a human right, it is widely recognized that palliative care for paediatric cancer patients and their families varies across settings and resources.³

Morocco is a North African country with a total population of 33 million, considered as a middle-income country, ranked 126th out of 188 countries and territories in the Human Development Index (HDI). Paediatric oncology in Morocco was initiated about 30 years ago in two general pediatric units (6-8 beds in each) sustained by parents' associations (AVENIR and AGIR). In the last 10 years significant progress has been made, benefiting by the formation of the princess's foundation - the "Lalla Salma Foundation, Cancer Prevention and Treatment"; the development of a cancer control plan by the Ministry of Health; and international cooperation with the St. Jude Children's Research Hospital and the French African Paediatric Oncology Group partnership.

A report on palliative care in Morocco published by Human Rights Watch, in 2016 found that several positive steps had been taken by the government of Morocco in recent years to develop palliative care services and to expand access to analgesics. Significantly, the government released two national health policies that together set out a vision for the development of palliative care: it reformed the undergraduate medical curriculum to include a module on pain and palliative care, and it removed a large regulatory barrier to accessing opioid analgesics—strong pain medications that are indispensable for pain management.

However, the availability of palliative care in Morocco is very limited. Human Rights Watch (HRW) was unable to identify any palliative care services at lower levels of the health-care system, such as regional, provincial, and local hospitals. Although, some healthcare providers, particularly tertiary level hospitals, have integrated palliative care interventions into their general practice, HRW believes this to be the exception, as most facilities simply do not have staff trained in palliative care or access to key palliative care medications such as morphine.⁴

Since the publication of the HRW report, significant improvement has been achieved with the establishment of dedicated palliative care teams in certain adult oncology departments following international standards and guidelines.

The most relevant guidelines for children have been published by the national hospices

and palliative care organization, and by the AAP.^{5,6} They provide a framework and a certain amount of substance in the provision of adequate palliative care. Importantly, however, other specific factors, such as religion or beliefs prevalent in the country, can affect the attitude toward palliative care.

As a healthcare provider in pediatric oncology with 17 years of experience, we were never trained in how to manage or communicate with a dying child and his/her family in Morocco. We are not aware of their specific needs beyond the physical ones which have been well described in the literature.⁷

To assess the needs of Moroccan terminally ill children and their families, their parents were asked to fill out a questionnaire in a study conducted in the Pediatric Hematology and Oncology Institute of Rabat, Morocco. We interviewed the parents of children who were in palliative care regarding physical symptoms, psychosocial needs, and other issues related to death. Some 80% of the parents interviewed were mothers, and the children's median age was 11 years (range 5 to 16). Most of the cases underwent palliative care after a relapse. The parents interviewed were aware of the disease status, and that the objective had shifted from curing to relieving the symptoms and improving QoL.⁸

We are one of the most important pediatric oncology units in Morocco, dealing with about 300 new cases of pediatric cancer per year. Moreover, the lack of specialized palliative care teams with adequate human resources and financing makes the end-of-life situation a face-to-face interaction between the attending doctor and the patient and his/her family.

The parents were asked to describe their feelings in the above-mentioned survey. They mainly reported the anticipation of the death, resignation, surprise and sometimes denial. Most of them refused that we inform their child. However, they also reported that they indirectly discussed matters related to death with their child by referring to the death of another person or through a religious approach.⁸ Morocco is a majority-Muslim country where faith and religious beliefs are central in the culture. Islamic beliefs continuously remind humans to be prepared for death. As a patient reaches his/her final hours, the family often wishes that death occur with as little suffering as possible. Islamic theology does not allow anger at God as an acceptable response to suffering, although frustration and disappointment in the limitations of the medical interventions are acceptable.⁹

The impact of the Islamic traditions and practices in cancer care and the cultural consideration in palliative care has been reported in several studies. The authors emphasize the fact that Islamic societies are more accepting of death and acknowledge the inevitability of death.¹⁰ These cultural and religious

considerations should be taken into account when interacting with terminal patients and their families.

The interaction and the broader communication within oncology is a core clinical skill yet few oncologists or specialist cancer nurses have received the formal training involved.¹¹ Poor communication between practitioners and patients is associated with patient dissatisfaction with care, uncertainty, denial, anxiety, depression and poor psychological adjustment to the illness.¹²

Practitioners who care for cancer patients acknowledge that insufficient training in communication and management skills is a major factor contributing to their stress and emotional burnout.^{11,13}

In addition to these non-technical elements, which are crucial and require thorough reflection and consideration, the parents in the Moroccan study reported more specific and concrete needs⁸:

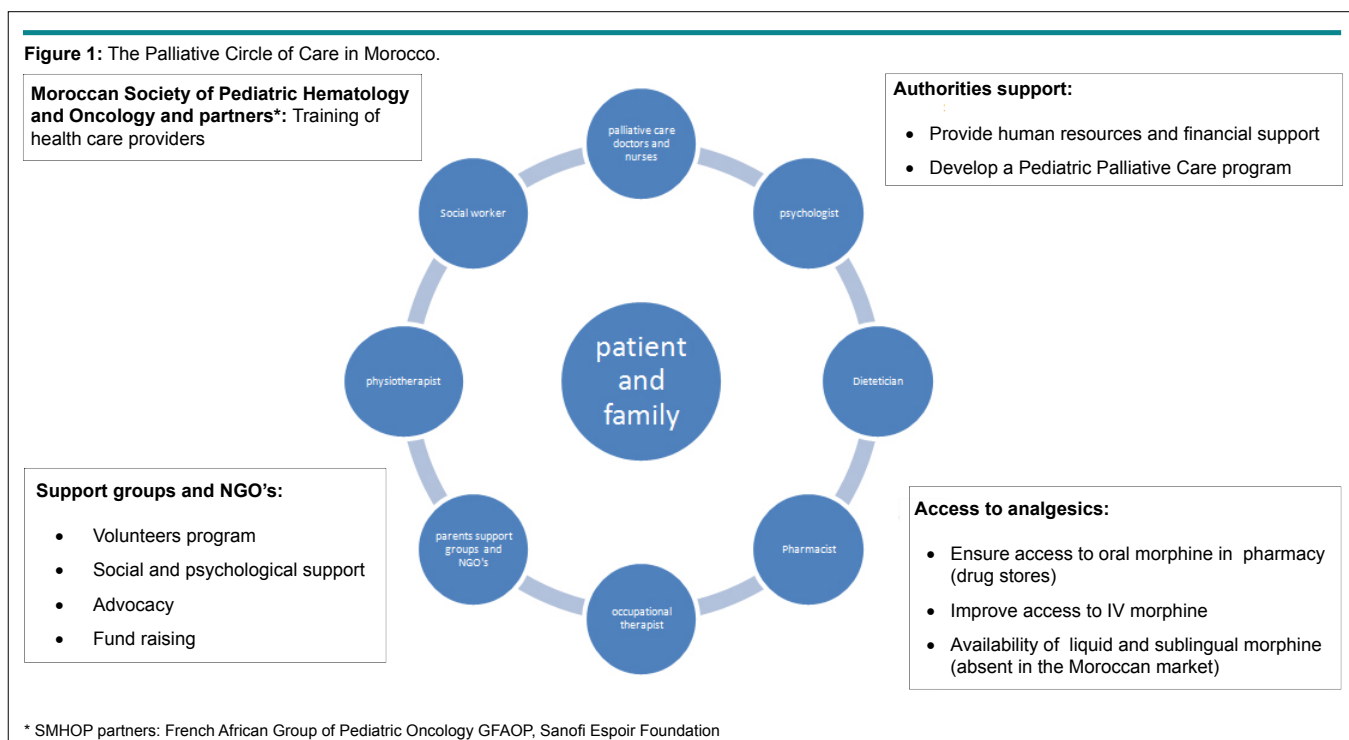
- Physical needs: The most reported symptoms were pain, fatigue, dyspnea, nausea and vomiting. The parents mainly requested improvement of symptom management and an alternative treatment line (chemotherapy, radiation therapy)
- Psychological needs: The parents wished to strengthen family links and resume normal life (school for the child, entertainment, etc.)
- Social needs: The parents requested financial support for daily expenses (transportation, medication, medical hardware, etc.) and for the child's entertainment (toys, computer, video games, etc.)

At the physical symptoms management level, significant progress has been achieved in pain management through a "My Child Matters" initiative complemented by the Lalla Salma Foundation Cancer Prevention and Treatment Project.

It is obvious that we need to accelerate the implementation of palliative care in pediatric oncology primarily by providing sufficient human and financial resources. At the technical level, we can refer to the international guidelines (Figure 1) and replicate the Moroccan adult program which is leading the way. However, developing a culturally-sensitive pediatric palliative care system is mandatory.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.



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