



Contents lists available at ScienceDirect

Pediatric Hematology Oncology Journal

journal homepage: www.journals.elsevier.com/pediatric-hematology-oncology-journal



Withholding and withdrawal of life-sustaining therapy in terminally ill children with cancer: A position statement by the PHO chapter of the Indian Academy of Pediatrics



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ARTICLE INFO

Article history:

Received 20 August 2023

Received in revised form

3 January 2024

Accepted 3 January 2024

Available online 4 January 2024

Keywords:

Pediatric

Palliative care

Childhood cancer

Terminal illness

End of life care

Life-sustaining therapy

ABSTRACT

In the last four decades, survival in childhood cancer in India has improved significantly, however we increasingly face the question that has challenged providers in high-income countries: when care becomes futile and merely prolongs suffering, how should that be addressed? This position statement was prepared by a panel in the Pediatric Hematology-Oncology chapter of the Indian Academy of Pediatrics (IAP-PHO), with external experts, using a process endorsed by the Executive Committee of IAP-PHO. The panel consisted of providers and stakeholders who were committed to improving end-of-life care (EOLC) in children with cancer. Three case scenarios of terminally ill children with cancer were presented, and the various challenges of EOLC in each situation were brought up, including families who wanted everything possible done for their child and the fear of medicolegal issues by physicians. We emphasize the importance of involving palliative care services early in the process to ensure that families receive a consistent message about their child's outcome. With the recent Supreme Court of India decision, there is now a viable EOLC pathway to withdraw life-sustaining therapy (LST) from children who are terminally ill. We outline it and discuss the various barriers to the withdrawal of LST. Increased access to palliative medicine services, which currently exist sporadically across India, is a core necessity. IAP-PHO hopes to actively work with organizations representing colleagues in palliative care and intensive care, to see how we can improve EOLC in childhood cancer.

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1. Introduction

In the last four decades, the expectations for survival in

childhood cancer in India have improved dramatically [1]. The Pediatric Hematology-Oncology Chapter of the Indian Academy of Pediatrics (IAP-PHO) now has a membership of hundreds, who treat a variety of childhood cancers, with survival rates approaching 60% or higher [2]. While there has been a quantum leap in the care we can provide children with cancer in India, we are increasingly facing the question that challenges providers in high-income

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countries: what care should we be providing, and at what point does care become futile, merely prolonging suffering [3]? When nothing else can be done to cure a patient, how can we communicate this to families who want everything possible done for their child [4]? And how can we better work with colleagues from other specialties, including palliative care and intensive care, so that families receive a consistent message about their child's terminal illness and outcome [5]? Access to palliative medicine services currently exists in only a few institutions across India and needs to be expanded. How should individual pediatric oncologists manage patients in the interim? Last but not least, we need to dispel the misunderstandings that still remain amongst many clinicians in India about withdrawing life-sustaining therapy (LST) from children who are terminally ill [6]. The lack of clear guidelines in Pediatric Hematology-Oncology has created moral and ethical dilemmas for practitioners and families [7].

2. Methods

This position statement was created with the approval of the Executive Committee (EC) of the IAP-PHO Chapter, according to established guidelines, and was reviewed and approved by the EC upon completion [8]. A panel of pediatric hemato-oncologists was created by a Senior Consultant (V.K.), many with extensive experience in palliative care, and external experts were also invited (R.G.,P.B). Given the scanty literature in this area it was decided that the paper would be guidance based on group consensus, written in a Socratic style. This position paper presents three case scenarios that describe the current reality of providing end-of-life care (EOLC) for children with cancer in India. It then lays out an EOLC pathway in compliance with the recent Supreme Court of India (SCI) ruling, intended to help children and families where withdrawal or withholding of life-sustaining therapy (LST) is being contemplated, and emphasizes the need to integrate palliative care services into our current health care system [9–12].

3. Case scenario 1

A 5-year-old boy with proptosis and bony pain was diagnosed with high-risk metastatic neuroblastoma. The father was poorly educated, and the mother was a homemaker. The option of intensive treatment was discussed with the parents, along with the low chance of cure. Despite financial constraints, the family wished to pursue treatment for their only child. The child improved markedly after 6 cycles of intensive chemotherapy and opioid support. The parents were grateful to the oncological team. While on follow-up, in a few months, the child presented with progressive disease: multiple skull swellings, pallor, and increasing abdominal distension. The absence of curative treatment options was explained to the parents, and the palliative care team was involved. The child's parents felt the medical team was "giving up their son" and "sending their child home to die." In the next 3 months, relationships between the family and the oncology team deteriorated as the former wished for their child to have multiple blood tests, transfusions, and IV antibiotics, with the father frequently getting into altercations with staff members. In the end, the child was admitted to the pediatric oncology ward amidst threats of legal action. The child died in the hospital.

- This scenario highlights several issues. How can the goals of treatment for patients who are terminally ill or have a poor chance of survival be discussed with families without the breakdown of the therapeutic relationship? How can families be prepared to refocus the goal of care towards end-of-life care at home instead of futile hospital care that prolongs suffering? If

palliative care is available, how can transition take place so that this is not construed as abandonment?

4. Case scenario 2

A 6-year-old boy was diagnosed with medulloblastoma and underwent placement of a ventriculoperitoneal shunt with resection of the tumor, and the oncologist counseled the family in detail, including the 70% likelihood of long-term survival. He was an only son, born after 8 years of married life; his father was a school teacher and mother a homemaker, and they decided to proceed with craniospinal irradiation with a boost to the tumor bed followed by multiagent chemotherapy, with which the child did well. Four months later, he presented in a semi-comatose state with recurrent disease and was admitted to the ICU, intubated and ventilated. The family felt they had been misled by their oncologist, with the father yelling at him in a crowded OPD. A neurosurgeon offered to debulk the tumor, even though an MRI of the brain and spine showed diffuse metastatic disease. There was a breakdown in communication between the intensivist, the pediatric oncologist and the parents, and the palliative care team was involved in communicating the futility of further therapy in a difficult conversation. The family accepted their fate, but the intensivist expressed an inability to extubate the patient as it was "against the law." A request to shift the child to the ward, where the parents could be with him, was considered against hospital policy. It was finally suggested that the parents take the child LAMA (left against medical advice) and the family took the dying child to an ambulance (still intubated), and the mother was left to use an artificial respiration unit (Ambu™ bag) on a 4-h journey home. Halfway, the endotracheal tube was displaced, and a local hospital pronounced the child dead.

- This scenario raises the questions: How can we reduce physicians' legal concerns about withholding care and collaborate to set up standard operating procedures within our institutions for more compassionate withdrawal of LST? How can we advocate for better inpatient palliative care and hospice care for dying children?

5. Case scenario 3

A 9-year-old boy was diagnosed with high-risk B-lineage acute lymphoblastic leukemia (ALL) and treated with standard induction chemotherapy. His family was relatively well-to-do, with his father a businessman and his mother a software engineer, and he was an only child. His post-induction minimal residual disease (MRD) level was 10.3%, and he was referred to a super-specialty center for a potential bone marrow transplant (BMT). He received chemotherapy according to a protocol for refractory ALL, but unfortunately, his MRD kept climbing through subsequent blocks of chemotherapy, finally reaching 78%. He received blinatumomab, but that did not reduce his leukemia burden. He was considered for a CAR-T cell trial but did not meet eligibility criteria due to his high leukemic burden. His parents steadfastly wished to pursue any treatment option that would enable him to receive BMT. They struggled to understand why the oncology team advised against further experimental treatments when their finances were not a limitation. The family could not reconcile themselves to the futility of further therapeutic intervention despite multiple discussions. The family wished for the patient to receive blood products and hemogram monitoring despite knowing it was no benefit. Ultimately, they transferred to another center in the hope of obtaining

a BMT. The child was not considered a candidate again and died a few months later at home.

- This scenario raises the questions: If treatment is self-funded with resources, not a limiting factor, but intervention is likely to worsen the quality of life of a child, where should we draw the line? How can we discuss resource utilization in children with no likelihood of cure while retaining the trust of the families we treat?

6. Discussion

While we live in an age of proton therapy, robotic surgery, targeted therapy, and stem cell transplantation, it is important to confront the ground reality in India in 2023 regarding “end-of-life care” (EOLC) for children. The IAP-PHO strongly feels that while no child should die in the dawn of life, every child with an incurable disease deserves the right to die with dignity and free of pain or distress without his or her parents being subjected to additional burden. Despite available policy guidelines from the Indian Society of Critical Care Medicine (ISCCM) in collaboration with the Indian Association of Palliative Care (IAPC), which have attempted to address these challenges, terminally ill children in India often continue on disease-modifying treatments and LST until the last weeks or days of life, causing needless suffering. The three case scenarios above illustrate that within India, there remain many gaps in palliative care and EOLC that deprive children of the right to “die with dignity” and raise several questions. EOLC is defined by the National Council for Palliative Care UK as “helping all those with an advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support” [13]. Children who are terminally ill but sick and inpatient, often find themselves in the ICU since most hospitals in India do not have a well-defined pathway for end-of-life [14]. It is critical that as we focus on improving survival and outcomes for our children, we also work to create an infrastructure for those children whom we cannot save to make their last journey in life more peaceful and comfortable. There are legal, practical, and ethical concerns that are very clear from the variety of questions raised in each scenario, with overarching themes common to all of them, which we will discuss.

7. Legal background

The Law Commission of India (2006), in its 196th Report titled “Medical Treatment to Terminally Ill Patients (Protection of Patients and Medical Practitioners),” reaffirmed that a patient’s decision not to receive medical treatment was legal, and a doctor who obeyed the instructions of a competent patient to withhold/withdraw medical treatment did not commit a breach of professional duty. However, it was not until 2011 that the Supreme Court of India (SCI) recognized the right to withdraw futile LST in the Aruna Shanbaug case [15]. The SCI in this decision (and others) created some confusion by using the term “passive euthanasia,” and the Indian Council for Medical Research (ICMR) later provided clarity, stating that “withholding or withdrawing a potentially inappropriate treatment in a patient dying with a terminal illness that only prolongs the dying process, cannot be construed as an intention to kill” [16]. We will use the term “withholding or withdrawal of LST” throughout this article to avoid ambiguity. The ISCCM, in collaboration with the IAPC, published detailed guidelines a decade ago on

how to fulfill this ethical need and provide compassionate EOLC, including withholding and withdrawing LST [17]. The IAP in 2017 had touched on several important issues in their guidelines, but some discussions were rendered out of date by the SCI recognition in 2018 of the right of patients who were terminally ill to draw up an advance directive which would allow LST to be withheld or withdrawn [10]. The process was so cumbersome that between 2018 and 23, not a single advance medical directive was filed. As a result, single institutions (such as the All India Institute of Medical Sciences in 2020) had to work around this by creating their own guidelines for patients who needed EOLC, but implementing this was only possible in the setting of a large multispecialty hospital with a robust palliative care department [18].

In 2023, the SCI simplified the requirements to a two-tiered process [10]. The first step required a consensus on the futility of care by three physicians (Primary Medical Board), each with >5 years of experience. This generally meant the treating team, with the physician primarily responsible for treatment decisions. Documentation and communication of this decision to the hospital administration triggered the constitution of a Secondary Medical Board (SMB) of three doctors, all with >5 years of experience, who were not part of the initial step [10]. One member of the SMB is necessarily pre-registered or empaneled by the District Medical Officer or equivalent authority for this responsibility. All three members of the SMB can be from the same institution. The entire process, from PMB proposal to SMB review, should be completed within 48 h [10]. If both PMB and SMB agree on futility, and if the family is in concurrence on withdrawal of LST, the administration is required to intimate the jurisdictional Judicial Magistrate and proceed after documentation. In case of lack of agreement, any one of the parties can approach the local High Court. The Supreme Court simplified the process for Advance Medical Directives by allowing verification by a Notary Public or Gazetted Officer, but this is for adult patients only [10].

8. Approaching EOLC

Much of the literature on this subject refers to the need to observe ethical principles, which are rarely filled out in more detail for the concerned clinician. For large institutions with well-established multidisciplinary teams, the following guidance may be redundant; for smaller institutions, they are essential. The Jonsen 4-box paradigm provides a framework to resolve many of the issues that emerge while discussing these cases in the absence of a Clinical Ethics Team (Table 1) [19]. Getting all the caregivers to meet is often a challenge, and the absence of clear-cut discussion on expectations leads in almost all the scenarios described to conflict between medical caregivers or between families and physicians. The phrase “Do Not Resuscitate” (DNR) is being phased out and replaced by Medical Order for LST (MOLST), where physicians proactively prescribe what they want the patient to receive (or not receive) for comfort after shared decision-making with the family, e.g., to receive nutrition by oral or tube feeding route, and pain relief but not resuscitation in the event of a cardiac or respiratory arrest or inotrope support (Annexure 2) [20]. The practice of sending children home from the ICU by having the family sign a LAMA form is strongly discouraged by the ISCCM as it implies that the medical team feels that ongoing therapy is appropriate and places the burden of withdrawing care on the family [17]. Routinely using MOLST forms and arranging for a structured palliative care transition would help parents of children feel less abandoned after an EOLC decision is taken in the ICU.

The price of ICU care at “end of life” is equally corrosive. While it is recognized that ICU care may be “financially toxic,” the hesitation to withhold or withdraw care in many hospitals leads to a gross

Table 1

Jonsen 4-box paradigm for ethical discussion of patient care

A case-based approach to ethical decision-making. Adapted from AR Jonsen, M Siegler, W Winslade, *Clinical Ethics*, 7th edition. McGraw-Hill, 2010 [19].

MEDICAL INDICATIONS	PATIENT PREFERENCES
The Principles of Beneficence and Nonmaleficence	The Principle of Respect for Autonomy
<ol style="list-style-type: none"> 1. What is the patient's medical problem? Is the problem reversible or terminal? 2. Are the goals of treatment curative? 3. What are the probabilities of success of various treatment options? 4. In sum, how can this patient benefit from medical and nursing care, and how can harm be avoided? 	<ol style="list-style-type: none"> 1. Has the patient and family been informed of the benefits and risks, understood this information, and consented? 2. Is the child's family mentally capable and legally competent to understand the plan of treatment? 3. What preference about treatment is the parent or guardian stating? 4. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
QUALITY OF LIFE	CONTEXTUAL FEATURES
The Principles of Beneficence, Nonmaleficence, and Respect for Autonomy	The Principles of Justice and Fairness
<ol style="list-style-type: none"> 1. What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds? 2. On what grounds can anyone judge that quality of life would be undesirable for a patient who cannot make or express such a judgment? 3. Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment (LST)? 4. What are the plans and rationale to forgo LST? 	<ol style="list-style-type: none"> 1. Are there professional, interprofessional, business, or legal interests that might create conflicts of interest in the clinical treatment of patients? 2. Are there financial factors that create conflicts of interest in clinical decisions, such as scarce health resources? 3. Are there religious factors that might affect clinical decisions? 4. Are there considerations of clinical research that might affect clinical decisions? 5. Are there conflicts of interest within institutions or organizations (e.g., hospitals) that may affect clinical decisions and patient welfare?

waste of resources. In India, some families are forced to take their child LAMA simply because they cannot afford the cost [21,22]. In such cases, pediatric oncology patients, families, nurses, physicians and caregivers all bear a heavy emotional burden and in this respect the healthcare system has failed us; for some families the excruciating memory of their child's final days will leave them scarred for the rest of their lives. For stable outpatient pediatric patients where cure is not possible, counseling about the terminal nature of the illness and administration of oral chemotherapy offers a route that sometimes allows the family to feel that they are receiving care and are not being abandoned by the primary team [23]. It is important to lay out expectations ahead of time, both for the family and the physician. Some families are not going to be able to cope with watching their child die at home, and in the absence of a hospice network or primary care level palliative services will end up back in a hospital bed. However, it is important that they not be admitted to the ICU simply because nobody is sure of their status, and that it is also very important that families understand that patients with recurrent or progressive disease will not recover by placing them in the hospital or ICU [25,26].

While every publication emphasizes the need for early involvement and integration of palliative care services, the sad truth is that this rarely occurs in India, given the high volumes of pediatric oncology patients seen at most centers and the small number of palliative care specialists currently available [26]. As a result, when parents and children are eventually referred to palliative care colleagues towards the end of life, they are often unhappy and mistrustful, which makes it even harder to deal with the normal grief and anger at losing a child, sometimes with a medical team that is not always "on the same page." The lack of meaningful resources, such as hospice care, makes home-based care challenging. A more detailed discussion is beyond the scope of this paper, but the development of palliative care is ultimately the bedrock on which better EOLC will be established [24,27,28]. General and specialist pediatric palliative care is in its infancy in India, as is evident in the case scenarios described. India has attained level 3A integration, that is, "Countries with isolated provision of palliative care services," which means that most pediatric oncologists have to struggle without the services or assistance of a palliative care team [7].

Accordingly, the IAP-PHO Chapter proposes the following:

- 1) EOLC decisions can be taken by family members only if the treating physician ensures a smooth transition to palliative care. In prevailing Indian ethics, physician attitude is mostly curative, and patient autonomy is weak. Physician training, advocacy and the importance of early integration of palliative care may have a significant impact, and palliative care staff should be involved as early as practical in treatment. Providing information by a single contact physician, ensuring adequate duration, frequency, and consistency, and staff implementing the suggested guidelines empathetically is important for children and families.
 - 2) We endorse the workflow originally laid out by ISCCM and IAPC, with changes supported by the recent SCI decision, so that for children who are terminally ill, there should be minimal barriers to treatment decisions on withholding/withdrawing LST [17,18]. We encourage discussion with the patient and family, and amongst all, the treating physicians. We support the standardization of Annexures II and III, incorporating a standardized MOLST form, to clarify and document the family's wishes about EOLC and withdrawal of LST [22].
- Step 1: End-of-life care checklist (Annexure I)

If the primary/treating physician(s) feel that treatment is futile, they will meet with the family to discuss palliative care and go through an EOLC checklist, recognizing that this process involves multiple discussions. Sensitivity, empathy, and patience are paramount, and the discussion should begin by elaborating on the patient's current condition, followed by caregiver preference. Information provided should be free of jargon and in language that relatives can understand. In the event of a cardio-respiratory arrest, there will not be time for discussion.

- Step 2: Establishing "Futility of management" (Annexure II)

The primary treating physicians (PMB), recognizing the 'futility of further management', will enter their reasons and proposed actions in the appropriate form and submit them to the EOLC Review Board. This secondary medical board (SMB) constituted by the hospital to review the documented justification and will ratify the decision if they agree. This process will occur within 48 h, and a

copy of the completed form will be submitted to the district magistrate. The Review Board will consist of at least 3 physicians, each of whom has at least 5 years of experience. If not approved, the primary care team can resubmit the application after 7 days [10].

- Step 3: Consent for withholding or withdrawal of care (Annexure III/MOLST form)

Realistic hope should be provided that is honest but not blunt, and the goals of comfort care that is to be continued should be explained and documented in writing in Annexure III, incorporating a MOLST form. Questions should be encouraged to clarify the situation. There is a need to outline measures that will be taken to provide comfort care to the child. Physicians, nurses, and other caregivers need to be familiar with how care can be withheld/withdrawn from the child to minimize distress to parents.

- 3) We advocate for all private hospitals/medical institutions to dedicate 2% of their annual profit/positive margin to supporting palliative care staff, hospital beds, and hospice care so that medical care is holistic. We urge the Government of India to pass legislation to enforce the same. We advocate that the Government of India dedicate 2% of the Healthcare budget currently allocated to operational costs of Hospital units to support palliative care and to construct nationwide hospices. We support the development of clinical ethics departments in hospitals, increase palliative care staffing, and encourage training for all medical caregivers who deal with children to sensitize them to the challenges of palliative care [23].
- 4) Until meaningful legislation is passed, IAP-PHO will work with colleagues from ISCCM and IAPC, as well as advocacy organizations such as Pallium India and Cankids Kidscan, to implement the pathway for EOLC throughout India for children with cancer as outlined above, and to make the ability to withhold or withdraw futile care in the ICU in an empathetic way a reality. *As long as the ethical principles of autonomy, beneficence, non-maleficence, and distributive justice are followed, with clear-cut documentation of discussions that took place with the family, physicians need not be fearful of withdrawing LST. Litigation usually stems from gross breach of procedure, and poor communication with the family.* In addition, IAP-PHO expresses a commitment to improve pediatric palliative care services for children with cancer so they can have a peaceful death, whether it is inside the hospital or at home.

Ethics review

Exempt for a review article not directly involving patient data or information with three anonymized cases for discussion.

Funding

None.

Patient's consent

Not required.

Declaration of competing interest

Primary author is also Associate Editor of the Journal. He was exempted from the editorial assignment, including peer review of this manuscript. No other conflicts of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.phoj.2024.01.002>.

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