

RESEARCH ARTICLE

Children with cancer in India: An ethical framework for practice

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Abstract

Background: Childhood cancer has been ranked the most common cause of death due to non-communicable disease among 5- to 14-year-old children in India. Ethical concerns have been identified in the care of children with cancer in India, yet there is a paucity of ethical standards for clinical practice to help address these concerns. For example, emerging research has demonstrated that many children are distressed when they are impeded from participating in discussions and decisions regarding their cancer care. Therefore, we sought to create an ethical framework to guide practice with this population.

Methods: We developed this ethical framework by conducting (a) a normative analysis of relevant documents that articulate norms for healthcare providers working with children in India and (b) stakeholder consultations with childhood cancer survivors, parents, and clinicians.

Results: The ethical framework is structured according to twelve key ethical principles and corresponding challenges or implications for clinical practice. We discuss how this ethical framework can help address three leading ethical concerns that we have identified within the care of children with cancer in India: (a) communication problems; (b) inadequate care of symptoms or promotion of comfort; and (c) injustices or inequities related to limited financial means or poverty.

Conclusion: Ethical concerns that have been related to the care of children with cancer in India can be prevented or at least mitigated through the integration of this ethical framework in everyday clinical practice.

Keywords: cancer, children, ethics, paediatric

Introduction

Childhood ethics is an emerging field of inquiry that is striving to advance (a) empirical research on ethical concerns that affect young people, as well as (b) normative research aiming to develop ethical standards for clinical practice that can attend to these concerns [1]. VOICE (Views On Interdisciplinary Childhood Ethics) is an internationally-recognised research programme in childhood ethics affiliated with the team that conducted the inquiry reported in this article [1-2].

An important childhood ethics concern relates to the role of children in discussions and decisions about their healthcare. This concern is especially prominent within the care of children with cancer, where treatment decisions can entail significant impacts — therapeutic effects as well as adverse effects — that are borne by the children.

Globally, 82% of childhood cancer diagnoses come from low- and middle-income countries, including India [3]. India's prioritisation of the prevention and treatment of communicable diseases [4] has led to a significant decrease in the under-five mortality rate [5]. This reduction has unmasked the impact of non-communicable diseases, such as cancer; the proportion of under-five mortality related to non-communicable diseases has therefore increased [5]. Childhood cancer was ranked the most common cause of death due to non-communicable disease among 5- to 14-year-old children in India [6]. Despite this, childhood cancer has not been highlighted as a health priority in India [7]. Further, little research has been conducted to identify the leading ethical concerns associated with the care of this population [8]. Moreover, there is a paucity of ethical standards of practice that have been developed to help orient clinical practices with this population of children.

Behan et al, which also include authors of this article, conducted one of the few empirical ethics studies published with this population [9]. This study sought to better understand the participation of children with cancer (aged 3-17 years old) in decisions, discussions, and actions. Based in three oncology settings in New Delhi, India, all participating children demonstrated interest in participating in various aspects of their cancer care. This participation, however, was impeded, to varying degrees, by contextual factors (eg, staff communication practices). Further, some

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children were distressed when they were not given sufficient information about their treatment, and when they were not given opportunities to enhance their understanding.

One important conclusion from this research was the absence of national ethical standards for clinical care for children with cancer in India. Therefore, together with clinicians, researchers, parents and children, we sought to create such an ethical framework, which we present below.

Methods

We developed this ethical framework for clinical practice with children with cancer in India through two principal steps: by conducting, first, a normative analysis and second, stakeholder consultations.

Normative analysis

We started by collecting all relevant documents that articulate norms (ie, what should be done) for healthcare providers working with children in India (NB: for further details on our normative analysis methods, see Bubadué et al, 2017 [10]). We specifically sought texts that provided legal, ethical and professional norms, and which included both children in general and children with cancer. To do so, documents were identified through a snowball technique, first by consulting clinical and community organisation leaders who work with children with cancer within India — including three clinical leaders with bioethics expertise — and then also using the references cited within the recommended documents to increase the sample. Following a review for relevance, 19 documents were retained, as listed in Table 1 [11–29]. Retained documents were then coded by a research assistant and one of the investigators (FAC) who has advanced training in clinical ethics as well as normative analysis. Coding involved content analysis: for example, all statements that articulated “what should be done” when working with children in India were highlighted as codes. Relevant codes and data were extracted into tables to be reviewed by the investigators to verify soundness. Codes were then categorised into principal themes (see Table 2). The investigators then drafted an ethical framework based on the results of this normative analysis.

Stakeholder consultation

We then asked stakeholders with diverse perspectives to critically examine the draft framework. Stakeholders included childhood cancer survivors and parents (given that they bear the greatest impacts of clinical practices), followed by clinicians (see Table 3 for stakeholder details). Some of the clinicians also contributed bioethics expertise. We began by holding a consultation meeting with a group of childhood cancer survivors and parents, organised by a community organisation working with this population. The discussion was led by one of the investigators (FAC). See [Supplementary File 1](#) for illustrative verbatim excerpts from childhood cancer survivor and parent stakeholders.

The draft framework was then adapted and distributed to a

broader stakeholder group using an online Microsoft Form to allow anonymised comments. Participating stakeholders were invited to (a) rate each of the 12 principles on a 4-point Likert scale (4 = Strongly agree; 3 = Agree; 2 = Disagree; 1 = Strongly disagree) and (b) provide comments regarding each principle. The average approval rating for each ethical principle was at least three. Moreover, comments were supportive of each principle. Some stakeholders highlighted challenges that could be encountered and particular considerations that had to be addressed when applying some of the ethical principles in practice. These challenges and considerations are summarised within the ethical framework.

Following this process, we concluded that the proposed ethical framework, which is presented below, was strongly endorsed by the stakeholders and did not require additional modifications.

An ethical framework for the care of children with cancer in India

The ethical framework is structured according to key ethical principles, which were identified and formulated through the processes described above. For the purposes of this framework, “children” refers to all legal minors in India (ie, below the age of 18).

Ethical frameworks aim to articulate what should be the practice, not what the practice actually is. There will frequently be discrepancies between “what is” and “what should be”; which highlights the basis of an ethical problem. Highlighting ethical problems or concerns is a principal purpose for creating an ethical framework, so that it can help identify these problems or concerns and hopefully lead to discussion and some solutions. Mindful of these “is/should be” tensions and the difficulties that can arise in attempts to apply an ethical framework, we have provided practice challenges or considerations that were identified by stakeholders. In stating these challenges and considerations, stakeholders were not implying that the corresponding ethical principles were any less important. These challenges are listed here to help readers anticipate and navigate them as they use this framework in practice [Table 4] [12, 30].

Discussion

Stakeholders consulted for this project highlighted that while our normative analysis reported relevant norms already existing in India, the results are “at significant variance with what is practised in India” (as quoted by a physician stakeholder). This sentiment led to calls among stakeholders for initiatives that strive to redress this “gap” between “what should be practised” and “what is actually practised”. Thus, this investigation raises important implications for (a) clinical practice, (b) institutional and higher-level policies, (c) education (ie, basic education and continuing education of healthcare professionals and

Table 1: Documents Analysed (Children’s Participation in Discussions & Decisions in Paediatric Oncology)

<p>Legal/governmental body statement</p> <ul style="list-style-type: none"> • Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations, 2002, Medical Council of India.[11] • United Nations. (1989). Convention on the rights of the child. [12]
<p>Professional books/journals (titles listed here)</p> <ul style="list-style-type: none"> • From IAP Textbook of pediatrics (Indian Academy of Pediatrics (2019) <ul style="list-style-type: none"> • Legal and Ethical Issues in Pediatric Practice [13] • Communication and Counselling [14] • Rights of the Child [15] • Child Abuse and Neglect [16] • Consent and medical treatment: The legal paradigm in India [17] • Medical ethics in paediatric practice: a GP’s viewpoint [18] • Who decides the "best interests" of the child? [19] • Age of Consent in Medical Profession: A Food for Thought [20] • Informed consent in Indian patients [21] • Paediatric palliative care: theory to practice [22] • Parental concerns in children requiring palliative care [23] • Communication to Pediatric Cancer Patients and their Families: A Cultural Perspective [24] • End-of-Life Care: Consensus Statement by Indian Academy of Pediatrics [25] • ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation' [26] • Palliative Care in Paediatric Oncology: an Update [27] • Perceptions of the parents of deceased children and of healthcare providers about end-of-life communication and breaking bad news at a tertiary care public hospital in India: A qualitative exploratory study [28]
<p>Institutional documents</p> <ul style="list-style-type: none"> • Communication in Pediatric Palliative Care. In Training Manual on Paediatric Palliative Care, Children’s Palliative Care Project, Indian Association of Palliative Care [29]

educational preparation for community workers and advocates), (d) community advocacy work, and (e) research.

Given the transparent, rigorous process that we have followed, we propose that professional societies and groups in India focused on paediatric oncology (eg, Haematology and Oncology Chapter of the Indian Academy of Paediatrics) or paediatric ethics (eg, Indian Academy of Pediatrics National Independent Ethics Committee) actively promote the use of this ethical framework. These societies and groups can promote the ethical framework as a standard for clinical practice. This can be facilitated through formalisation of this ethical framework within institutional practice policies (eg, clinical practice policies within oncology centres that include actionable steps that demonstrate how the ethical principles should be operationalised in those settings) as well as curricular updates within education programmes (university as well as continuing education in clinical settings) for all

Table 2. Normative Analysis Results — Principal themes identified

All healthcare-related actions (ie, investigations and interventions) require informed consent.
At 18 years of age and over, consent is provided by the patient.
At 12 to 17 years, a child can consent to investigations but not interventions. Parents should provide consent for interventions.
Below 12 years, consent is provided by the parent, based on the child’s best interests.
Children should have an opportunity to assent to care, when they have the capacity to understand the nature, risks and benefits of a treatment but do not have the capacity to give informed consent.
Valid informed consent is premised on effective communication with the person providing consent (parent or child), where the communication is adapted to the person’s capability to understand, literacy as well as other potential social disadvantages (ie, some people living in poverty may be reluctant to ask questions or express disagreement to proposed plan).
Parental consent is not required under certain conditions (eg, emergency situation) or may be overridden (eg, with court authorization)
Inability to pay should not be a criterion for withholding or stopping life support.
<p>The UN Convention on the Rights of the Child (CRC) is recognized by many official bodies within India.[12]</p> <ul style="list-style-type: none"> o This implies that all actions — including healthcare — affecting a child in India should be based on that child’s best interests (Article 3 of the CRC). o The UN CRC also recognizes children’s right to participate in decisions that affect them (Article 12 of the CRC) and that their view should be given ‘due weight’ in decisions that are made (ie, even if they are below the age of majority and consent is provided by parents).
Note: Most sources examined refer to pediatrics in general. Very few documents are specific to pediatric oncology. This analysis has drawn on these general statements to propose a standard for pediatric oncology.

relevant healthcare providers (eg, physicians, nurses, among others).

We call for open forums (eg, work groups) to create opportunities for professional societies (eg, Haematology and Oncology Chapter of the Indian Academy of Paediatrics) to engage in meaningful exchanges with community organisations (eg, CanKids) to identify specific actions that should be undertaken to close this gap between “what should be practised” and “what is actually practised”.

Advocacy efforts to promote respect for the rights of children with cancer and their families can call for changes based on the results of this study. Specifically, community-based stakeholders, including community organisations such as CanKids, can empower and mobilise initiatives that can help children with cancer and their families become

more aware of ways that ethical standards can be advanced to be more inclusive of children’s voices, experiences, and participation — actively promoting patient and family advocacy and calling for changes entailed by the results of this investigation. It may be beneficial to create a “translation” of this framework, adapted to the spoken language of children and families, that can be used by community organisations.

Further empirical research is needed to identify which ethical concerns are particularly problematic for children, parents, and healthcare providers, building on our team’s earlier research [9]. Such work could highlight areas where focused initiatives are required, such as further development or refinement of our ethical framework as well as educational initiatives that can bolster the use of ethical frameworks like the one described here. Empirical research can reveal existing barriers and facilitators to optimising ethical practice, which can further inform changes that should be mobilised. Also, more investigations should be conducted in multiple settings throughout India, to determine if the ethical framework requires any modifications to address any additional ethical concerns that were not identified in this study.

Ethical concerns in clinical practice: Highlighting the need for an ethical framework

While conducting the stakeholder consultations, childhood cancer survivors and parent participants highlighted numerous situations they encountered that they considered ethically problematic. Upon analysis, three principal areas of ethical concern arose within this lived experience, as outlined below. We think these concerns provide exemplars of clinical situations where our proposed ethical framework can be used in practice.

Communication problems

This ethical concern refers to children and parents feeling that the way that clinicians describe the child’s medical condition, treatment plan, and/or prognosis can be inadequate and upsetting. Poor communication includes: use of medical jargon (eg, this may be incomprehensible for families with limited schooling); use of insensitive terms or speaking rudely (eg, speaking in ways that scare children and families or makes them feel humiliated or unsafe); incomplete or no explanations (eg, not being told about a diagnosis, initiation of a clinical trial, or an intervention, such as removal of a child’s eye); as well as frequent changes in medical team members (eg, this led to changes in treatment plans that were not explained). Communication concerns were seen to undermine the development of trust among families toward healthcare providers.

Inadequate care of symptoms or promotion of comfort

This ethical concern refers to situations where children and parents felt that healthcare providers have been inattentive or dismissive toward a child’s symptoms or comfort. This situation included: performing painful procedures without

Table 3. Stakeholder Participant Information

Stakeholder Category	n
Childhood cancer survivors <ul style="list-style-type: none"> • 7 Childhood cancer survivor • 1 Psychologist (Survivor) • 32 Childhood cancer survivor responses submitted by Survivor Leader 	40
Parents of children with cancer <ul style="list-style-type: none"> • 4 Parents of child with cancer (past or present) • 1 Childhood Cancer Advocate • 22 Parent responses submitted by Parent Group Leader 	27
Physicians (some physicians also contributed bioethics expertise) <ul style="list-style-type: none"> • 4 Pediatric oncologists • 1 Primary physician • 1 Treating consultant • 1 Palliative care physician 	7
Other healthcare professionals <ul style="list-style-type: none"> • Nurse • Dietician • Psychologist • Social Worker 	4
Other stakeholder participants <ul style="list-style-type: none"> • 1 Teacher • 1 Volunteer • 1 Home away from home provider • 1 Counsellor (NGO) • 1 CSO- PAN India (childhood cancer) 	5
Total stakeholder participants	83

adequate or any analgesia or anaesthesia (eg, child screaming through a biopsy or bone marrow aspiration without any anaesthesia; inexperienced staff performing a venipuncture on children with difficult-to-access veins); parents forced away from a child’s side during painful procedures (eg, parent is unable to comfort the child); nonresponse to children’s expressed pain (eg, disregarding or distrusting a child’s expression of pain, no analgesia is given when a child is crying in pain); prescribing analgesia that is difficult to access for children with severe uncontrolled pain (eg, where a parent has to travel a great distance to obtain the prescription).

Injustices or inequities related to limited financial means or poverty

This ethical concern refers to situations where families felt they were impacted unfairly because of their financial

Table 4. Ethical framework for the care of children with cancer in India

Ethical principle	Identified practice challenges / considerations
<p>All healthcare-related actions (ie, investigations, interventions) require consent, either by the patient if of legal age, or the surrogate decision-maker as defined by law (eg, parent). Consent should be free (ie, uncoerced) and informed (ie, all relevant information is provided about the health problem in question and relative risks and benefits associated with each proposed investigation or treatment option).</p>	<ul style="list-style-type: none"> • This will be difficult to apply in (a) overburdened, understaffed hospitals; and (b) with parents whose health-related literacy is limited. • It is important that patients and parents make the consent decision; at the same time, however, they are also vulnerable. It is important that physicians state what they think is the best course of action. • Sometimes support may be needed to help reconcile disagreements between patients and parents regarding the treatment decision: while ensuring that patients' views are seriously considered within consent decisions.
<p>At 18 years of age and over, consent should be provided by the patient. All patients are presumed to have the mental capacity to decide which treatment they want, unless a patient demonstrates signs of incapacity. Mental capacity is defined as "the patient's ability to understand information relevant to a treatment decision and to appreciate the reasonably foreseeable consequences of a decision or lack of decision" [30]. If a patient does not have the mental capacity to consent to a particular investigation or treatment, then consent should be provided by a surrogate decision-maker as defined by law (eg, spouse, parent, etc).</p>	<ul style="list-style-type: none"> • Some 18-year-olds may find it difficult to make treatment decisions because they are not empowered to make decisions in other aspects of their lives until they are much older (eg, 21 years). • Some parents prevent physicians from disclosing the diagnosis to a patient, even when the patient may have full decision-making capacity to consent. • Helping the patient understand the treatment decision as well as possible should be fully attempted, before decision making is transferred to a surrogate decision-maker.
<p>At 12 to 17 years, a patient can only consent to investigations but not interventions. The surrogate decision-makers should provide consent for <i>investigations</i> for these children. That is, <i>investigations</i> are actions where the sole aim is to generate information about the patient's medical condition, while <i>interventions</i> refer to actions aiming to remediate some aspect of that medical condition. <i>Interventional investigations</i> would be considered as <i>interventions</i> (eg, interventional radiology).</p>	<ul style="list-style-type: none"> • It may be unclear what should be done when the patient refuses an investigation that is considered necessary. For example, can parents overrule the patient's refusal? • It is unclear how parents should be involved in decisions regarding investigations for this age group. • Consent with adolescents presents a significant challenge in India where culturally (and legally) children are considered dependent on parents' decisions up to 17 years of age or older.
<p>If patients within this age range do not demonstrate the mental capacity required to consent to investigations (ie, referring to the Coughlin, 2018 definition of mental capacity above) — as assessed by the clinicians performing the investigations — then the surrogate decision-makers should provide consent for investigations for these children.</p>	<ul style="list-style-type: none"> • Sometimes adolescents may want a cancer treatment, but parents do not consent. • Problems can arise when there is a disagreement between an older minor and the parents. • Assent should be considered if the minor is interested and capable in participating in treatment decisions. • Institutional policy can consider requiring parental consent for any investigation involving more than minimal trauma (eg, lumbar puncture, bone marrow testing).
<p>Below 12 years, consent should be provided by the surrogate decision-maker (eg, parent).</p>	<ul style="list-style-type: none"> • Assent should be sought from the child from the age of 8 years onward.
<p>Parent consent for a child's treatment should be based on the treatment option that will optimally promote the child's <i>best interests</i>. Best interests can be defined as the treatment option that can ensure the greatest proportion of benefits in relation to burdens (or harms) that are associated with each option. The weighing of benefits and burdens for each decision should be based on an individualised determination of impacts for that specific child, attributing 'due weight' to the child's expressed aspirations and concerns.</p>	<ul style="list-style-type: none"> • Within some families, the interests of girls are defined in an inferior manner, compared to boys, which can result in inequitable conceptions of best interests. • Many questions around best ethical practices also call for a detailed understanding of how information is shared with children. This decision should rest with parents and be done keeping in mind the child's best interests. • Parents should be given complete information (ie, they should be given all the information they request and also the information required to make decisions in the best interests of the child). • A family's values and beliefs should be given due consideration in defining a child's best interests.
<p>In some situations, parental consent may not be required (e.g., emergency situation) or may be overridden (eg, with court authorisation) (NOTE: given the delays involved with the Indian Judicial system, standards are needed to ensure children's rights are protected in an emergency scenario).</p>	<ul style="list-style-type: none"> • Delays in the Indian judicial system make this principle difficult to apply. • Some families abandon curative treatment. • Access to a clinical ethics committee (CEC) consultation can be helpful in such circumstances. CECs should be developed in institutions where access to clinical ethics consultations is limited or absent.

<p>Valid free and informed consent is premised on effective communication with the person providing consent (parent and/or patient), where the communication is adapted to the person's capability to understand, literacy as well as other potential social disadvantages (eg, some people living in poverty may be reluctant to ask questions or express disagreement to a proposed plan).</p>	<ul style="list-style-type: none"> • The use of advocates (eg, family members, social workers, non-family acquaintances) who can translate and relay accurate information to the patient and/or the parents is important, especially for families living in poverty or in rural areas. • Consent forms should be in clear and local language so they can be understood by families with limited education.
<p>Children have a right to participate in discussions and decisions that affect them (as described by Article 12 in the United Nations Convention on the Rights of the Child [12]) and their views should be given 'due weight' in decisions that are made (even if they are below the age of majority and consent is provided by parents or others). This is commonly referred to as 'participation rights'. In situations where a child may not have a legal right to consent on their own or may not have the mental capacity required for that decision, a child's <i>assent</i> to care (ie, voluntary agreement and cooperation with care based on clear information about the planned care, adapted to the child's linguistic and cognitive capabilities) should be sought whenever possible.</p>	<ul style="list-style-type: none"> • Advocates can be helpful in promoting this principle. • This will help ensure the child is being informed to their satisfaction about the intervention being provided.
<p>Information about diagnosis and prognosis should not be withheld from children or parents. This would undermine (a) a clear determination of the child's <i>best interests</i>; (b) promotion of the child's participation rights; and (c) impede truly informed consent and assent.</p>	<ul style="list-style-type: none"> • Financial costs should be disclosed early on, so parents can seek financial support, if necessary. • Some parents may not want clinicians to discuss diagnosis and prognosis openly with their child. • Clear effective communication can help build trust in the system and on the treating team. • A child's age and mental capacity should be kept in mind in determining how information will be provided.
<p>Institutions and professionals providing healthcare for children with cancer should promote fair access to required care for all children with cancer.</p>	<ul style="list-style-type: none"> • Irrespective of their background or prognosis, every child should have equitable access to comparable care.
<p>All children with cancer should have their pain and other symptoms effectively assessed and alleviated.</p>	<ul style="list-style-type: none"> • Although access to some medications may be a challenge, this principle should still be upheld. • Clinicians should be compassionate toward the treatment of pain and other symptoms.
<p>All children should have their privacy and confidentiality respected. Private information should be shared among team members only when it is in the child's best interests to do so. Agreements should be established with children and their parents about what forms of respect for confidentiality can be ensured for children and under which conditions private information disclosed by children to healthcare providers can be disclosed to parents.</p>	<ul style="list-style-type: none"> • This may be difficult to ensure among some families with limited literacy; yet, the principle should be upheld.

disadvantages. Some families became financially impoverished or went bankrupt to pay for treatment (eg, some families cannot afford to pay for the prescribed treatments) while some children were unable to access some forms of necessary care (eg, cancer treatment or care of symptoms).

The ethical concerns described by survivors and parents can be prevented or at least mitigated through the integration of our ethical framework into everyday clinical practice. This would help ensure the continuous (a) provision of information regarding the child's condition, treatment plan, and prognosis, adapted to the child's and parents' ways of understanding; (b) verification of how treatment is aligned with each child's best interests (including active evaluation and effective treatment of each child's current symptoms); (c) ascertaining that free (ie, uncoerced) and informed consent from parents and assent from children is obtained for all investigations and interventions that are undertaken (including the

encouragement of children to participate in discussions and decisions about their care as much as they would like, respecting their privacy interests to the extent that is legally permissible, while also seeking their consent to care whenever they are legally permitted to do so); and (d) identifying inequities or injustices that can result from financial (or other) disadvantages, which can lead to unfair treatment of a child, and advocating for ways to redress this unfairness (eg, seeking financial supports or access to community organisation support for specific families).

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References

- Carnevale FA, Collin-Vézina D, Macdonald ME, Ménard J-F, Talwar V, Van Praagh S. Childhood Ethics: An ontological advancement for childhood studies. *Children & Society*. 2021; 35:110-124. <https://doi.org/10.1111/chso.12406>
- Carnevale FA, Campbell A, Collin-Vézina D, Macdonald ME. Interdisciplinary Studies of Childhood Ethics: Developing a New Field of Inquiry. *Children & Society*. 2015; 29:511-523. <https://doi.org/10.1111/chso.12063>
- American Cancer Society. *Global cancer facts and figures* (4th ed). 2018 [Cited on 2024 Sep 20]. American Cancer Society. Available from: <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/global-cancer-facts-and-figures/global-cancer-facts-and-figures-4th-edition.pdf>
- Choudhury P. Indian pediatrics and child survival. *Indian Pediatr* 2007 Aug[Cited on Nov 22, 2024]; 44(8):567-568. Available from: <http://www.indianpediatrics.net/aug2007/567.pdf>
- World Health Organization. India: WHO statistical profile. 2015 [Cited on 2024 Nov 11]. Available from: <https://data.who.int/countries/356>
- Office of Registrar General India, Ministry of Home Affairs.. Summary-report on causes of death in 2001-2003 in India. 2003 [Cited on 2024 Nov 30]. Available from: https://www.cghr.org/wordpress/wp-content/uploads/Causes_of_death_2001-03.pdf
- Arora RS, Eden TOB, Kapoor G. Epidemiology of childhood cancer in India. *Indian J Cancer*. 2009 Oct-Dec; 46(4):264-273. <https://doi.org/10.4103/0019-509x.55546>
- Wang YW, Behan J, Jeong S, Singh Arora R, Carnevale F, Tsimicalis A. Children's health-related experiences in India: A scoping review. *McGill J Med*. 2023 Nov 25[Cited 2024 Nov 22];21(1). Available from: <https://mjm.mcgill.ca/article/view/1004>
- Behan JM, Arora RS, Carnevale FA, Bakhshi S, Bhattacharjee B, Tsimicalis A. An Ethnographic Study of the Moral Experiences of Children with Cancer in New Delhi, India. *Glob Qual Nurs Res*. 2021;8. <https://doi.org/10.1177/2333393621995814>
- Bubadué RM, Cabral IE, Carnevale F, Asensi FD. Normative analysis of the voice of children in Brazilian child protection legislation. *Rev Gaucha Enferm*. 2017 Feb 9;37(4):e58018. <https://doi.org/10.1590/1983-1447.2016.04.58018>
- Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations, 2002. Medical Council of India, (Published in Part III, Section 4 of the Gazette of India, dated 6th April, 2002), New Delhi, dated 11th March, 2002[Cited 2024 Sep 20]. Available from: <https://wbconsumers.gov.in/writereaddata/ACT%20&%20RULES/Relevant%20Act%20&%20Rules/Code%20of%20Medical%20Ethics%20Regulations.pdf>
- United Nations. 1989. Convention on the rights of the child. Office of the United Nations high commissioner for human rights. Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 [Cited 2024 Nov 11]. Available from <https://www.unicef.org/child-rights-convention/convention-text>
- Moolayil GF. Legal and Ethical Issues in Pediatric Practice. In: Parthasarathy A, Menon PSN, Nair MKC, editors. *IAP Textbook of pediatrics* (Indian Academy of Pediatrics) (7th Edition). Jaypee Brothers Medical Publishers; 2019. p. 21-23.
- Mehta PN. Communication and Counselling. In: Parthasarathy A, Menon PSN, Nair MKC, editors. *IAP Textbook of pediatrics* (Indian Academy of Pediatrics) (7th Edition). Jaypee Brothers Medical Publishers; 2019. p. 18-21.
- Bhave SY, Prasad CS. Rights of the Child. In: Parthasarathy A, Menon PSN, Nair MKC, editors. *IAP Textbook of pediatrics* (Indian Academy of Pediatrics) (7th Edition). Jaypee Brothers Medical Publishers; 2019. p. 1371-1375.
- Mehta MN. Child Abuse and Neglect. In: Parthasarathy A, Menon PSN, Nair MKC, editors. *IAP Textbook of pediatrics* (Indian Academy of Pediatrics) (7th Edition). Jaypee Brothers Medical Publishers; 2019. p. 1381-1385.
- Nandimath OV. Consent and medical treatment: The legal paradigm in India. *Indian J Urol*. 2009 Jul[Cited on 2024 Nov 22];25(3):343-7. Available from: https://journals.lww.com/indianjurol/fulltext/2009/25030/consent_and_medical_treatment_the_legal_paradigm.15.aspx
- Pingle S. Medical ethics in paediatric practice: a GP's viewpoint. *Issues Med Ethics*. 2000 [Cited on 2024 Nov 22];8(2):46-46. Available from: <https://ijme.in/articles/medical-ethics-in-paediatric-practice-a-gps-viewpoint/?galley=html>
- Ayarkar S, Chandrasekhar A. Who decides the "best interests" of the child? *Indian J Med Ethics*. 2016 Jul-Sep[Cited 2024 Nov 22];1(3):184-5. Available from: <https://ijme.in/wp-content/uploads/2016/11/2142-5.pdf>
- Muckaden M, Dighe M, Balaji P, Dhiliwal S, Tilve P, Jadhav S, Goswami S. Paediatric palliative care: theory to practice. *Indian J Palliat Care*. 2011 Jan[Cited 2024 Nov 22];17(Suppl):552-60. Available from: <https://jpalliativecare.com/paediatric-palliative-care-theory-to-practice/>
- Dighe M, Jadhav S, Muckaden M, Sovani A. Parental concerns in children requiring palliative care. *Indian J Palliat Care*. 2008;14(1):16. <https://doi.org/10.4103/0973-1075.41927>
- Seth T. Communication to Pediatric Cancer Patients and their Families: A Cultural Perspective. *Indian J Palliat Care*. 2010 Jan[Cited 2024 Nov 22];16(1):26-9. Available from: <https://jpalliativecare.com/communication-to-pediatric-cancer-patients-and-their-families-a-cultural-perspective/>
- Yadav M. Age of Consent in Medical Profession: A Food for Thought. *J Indian Acad Forensic Med*. 2007 29:80-85.
- Sanwal AK, Kumar S, Sahni P, Nundy S. Informed consent in Indian patients. *J R Soc Med*. 1996 Apr;89(4):196-8. <https://doi.org/10.1177/014107689608900406>
- Mishra S, Mukhopadhyay K, Tiwari S, Bangal R, Yadav BS, Sachdeva A, Kumar V. End-of-Life Care: Consensus Statement by Indian Academy of Pediatrics. *Indian Pediatr*. 2017 Oct 15[Cited 2024 Nov 22];54(10):851-859. Available from: <https://www.indianpediatrics.net/oct2017/851.pdf>
- Mathur R. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation'. *Indian J Med Res*. 2020 Apr[Cited 2024 Nov 22];151(4):303-310. Available from: https://journals.lww.com/ijmr/Fulltext/2020/51040/ICMR_Consensus_Guidelines_on_Do_Not_Attempt.8.aspx
- Salins N, Hughes S, Preston N. Palliative Care in Paediatric Oncology: an Update. *Curr Oncol Rep*. 2022 Feb[Cited 2024 Nov 22];24(2):175-186. Available from: <https://link.springer.com/article/10.1007/s11912-021-01170-3>
- Das MK, Arora NK, Chellani HK, Debata PK, Meena KR, Rasaily R, Kaur G, Malik P, Joshi S, Kumari M. Perceptions of the parents of deceased children and of healthcare providers about end-of-life communication and breaking bad news at a tertiary care public hospital in India: A qualitative exploratory study. *PLoS One*. 2021 Mar 18[Cited 2024 Nov 22];16(3):e0248661. Available from: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0248661>
- Marathe MM.. Communication in Pediatric Palliative Care. In: *Training Manual on Paediatric Palliative Care*. Children's Palliative Care Project, Indian Association of Palliative Care. 2014[Cited 2024 Nov 22]. p.108-114. Available from: <http://palliativecare.in/wp-content/uploads/2014/09/CPC-Training-Manual.pdf#page=115>
- Coughlin KW. Medical decision-making in paediatrics: Infancy to adolescence. *Paediatr Child Health*. 2018 May;23(2):138-146. <https://doi.org/10.1093/pch/pxx127>