

Bagai P, Kanwar VS, Carnevale FA, Macdonald ME, Arora RS. Children with cancer in India: An ethical framework for practice. *Indian J Med Ethics*. Published online first on December 13, 2024. DOI: 10.20529/IJME.2024.085

Supplementary File 1: Verbatim excerpts from childhood cancer survivor and parent stakeholders

Survivor Members of the KCK (KidsCan Konnect) of CanKids...KidsCan, India	
Ethical concerns that were highlighted	Suggested solutions
I have chronic Hep-B as a long-term side effect (LTSE) of cancer. Doctors did not talk to my parents about LTSE pre/during cancer treatment.	LTSE is integral part of being a cancer survivor (depending upon the cancer). LTSE must be discussed with parents of a child to make them aware about the possibility. All the survivors who are above 13 years can become the KCK members and they shall be taught about the late effects of the treatment.
I had retinoblastoma. During my eye surgery I was not informed about my eye would be enucleated.	Children with eye cancer should be told pre surgery about the procedure and extraction of organs etc. So that they will be mentally prepared.
During treatment I had to have a biopsy but I was not given any anesthesia and the 7-8 doctor caught me. I was screaming so much I thought that I was like animal that's why they were doing to me like this. I cannot explain my pain.	Every painful procedure should be done with anesthesia to ensure no pain to the kid. It will help further treatment to go seamlessly and completion can happen without any fear of pain.
He wasn't informed that he had cancer.	Kids have right to be informed about the disease if they are a young adolescent.
If I or my parents did not understand what the doctors/nurses or other hospital staff telling us easily about the treatment or the procedure they would be very rude, rough and impatient to us.	People at healthcare centres need to understand the mental trauma of the families during their kid's treatment and they are initially unable to understand the systems. Everyone at hospital should talk to them politely and help them to understand treatment procedures.
During my treatment, my family went bankrupt, further myths related to cancer led my extended family and friends to leave us.	Government and healthcare centres should emphasise on financial policies for families

	who cannot afford treatment along with cancer awareness programmes.
Parent Members of the P3SG (Path Pradarshak Parivarik Sahayak Group) of CanKids...KidsCan, India	
Ethical concerns that were highlighted	Suggested solutions
Most of the time parents or attendants were asked to remain away from the children during procedures like Bone Marrow, FNAC or even inserting cannula. We as a parent want to see whatever is happening with our kids because they are unable to explain and become panic when away from their parents.	Caretakers should be allowed to be with their children.
There are few common words which are used for the treatment and with these words not only the uneducated family but even educated families are not aware like-Chemotherapy, Biopsy, Bone Marrow. Also, at the time of relapse or palliative care treatment hospital staff play a vital role, their sympathy, their words may be useful to accept the destiny for a family.	There should be pre counselling sessions by the doctors/their assistants or the child life psychologist to explain the terms and the procedures for each family. Doctor should discuss the whole treatment plan with the parents/patients. When child relapses this should be again discussed explained to the parents/patients.
Sometimes hospital staff's as well as Doctor's behavior is very rude. Parents are discouraged with their behaviour and want to leave the treatment.	Behavior of the hospital staff especially Doctor's behaviour should be polite and friendly. Rude behaviour may break the parents' motivation and courage and adolescence child want to abandon the treatment.
In many palliative care cases Tab Morphine is prescribed for pain relief. This tab is not easily available even in the hospital. Sometimes children were in severe pain and to arrange for this drug a family member has to travel from far away the hospital.	Is it possible that hospital staff visits the patient's home to provide counselling and drugs? Or maybe tele-consultancy can be organised.
In Relapse cases families are completely broken, their economic condition does not allow them for the relapsed treatment. Cankids have certain policies or limited funds for Relapse cases treatment. Parents became more demotivated to know about the limited	A National Plan for Childhood Cancer needs to be made in order to ease out the process of availing the benefit of the existing government schemes.

<p>resources. Government. facilitation takes lots of time for fund release. What is advisable in these situations?</p>	
<p>Trust the child. At the time of chemo my daughter was complaining of uneasiness and irritation, I informed the nurse about the same but the nurse ignored us. My daughter again started screaming then I stopped the chemo and asked nurse to check. Initially nurse became annoyed but when she checked the cannula, it was blocked. Then she changed cannula.</p>	<p>Though children cry and shout a lot during treatment, we should not ignore their complaints.</p>