




# Child's Understanding of Cancer when Faced with Advancing Disease: A Retrospective Chart Review

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Ind J Med Paediatr Oncol 2022;43:262–269.

## Abstract

**Introduction** It is difficult to comprehend a child's understanding of disease-related information as they might be unwilling to talk or feel inhibited about raising their concerns. Understanding children's perception is important to facilitate better communication in palliative care.

**Objectives** To study child's understanding of advancing disease when referred to the Pediatric Palliative Care Services.

**Materials and Methods** A retrospective chart review of 34 case record forms from March 2019 to March 2020 was conducted after obtaining a waiver of consent and Institutional Ethics Committee approval. The inclusion criteria were children having advanced cancer referred for palliative care, incomplete records were excluded. Data were analyzed using thematic analysis.

**Results** Twenty-three were male, and 11 were female children, the mean age was 12 years. Five major themes were identified—the child's understanding of disease diagnosis and prognosis, nature of communication between parents and the child, barriers to communication, child's means of support, and interventions used during counseling.

**Conclusion** Communication between children suffering from advanced cancer and their parents/caregivers is a sensitive issue, and noncommunication is often due to mutual effort to shield each other from the stress of difficult conversations. Lack of communication contributes to poor coping and forces children to seek comfort in other sources leaving parents distressed. Psychological interventions like resource building and psychoeducation are effective.

## Keywords

- ▶ cancer
- ▶ palliative care
- ▶ pediatrics
- ▶ thematic analysis
- ▶ qualitative research
- ▶ chart review

DOI <https://doi.org/10.1055/s-0042-1750208>.  
ISSN 0971-5851.

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## Introduction

Most parents would like their child's prognosis to be explained to them, however difficult it could be for them to accept.<sup>1</sup> Sometimes it is the oncologist who is not ready for the discussion.<sup>2</sup> When the prognosis turns adverse due to relapse or resistant disease, a palliative care referral can help parents to cope.<sup>3</sup> Routinely in a pediatric palliative care clinic, communication channels are opened for discussion of prognosis. Keim et al have shown that open communication with parents (especially mothers) helped them to cope with advanced cancer at the end of 1 year.<sup>4</sup>

At the department of palliative medicine, pediatric palliative has been offered to children and their families since 2002. Routinely, the cases are discussed in a tumor board/multidisciplinary clinic, and children with resistant disease or relapse are referred for palliative care. At this clinic, the child is "counseled" separately. With the help of toys, stories, and other diversion methods, the counseling psychologist, along with a trained child life counselor comprehends the concept of what the child understands about the disease and how he/she is coping. These observations are conveyed to the psychologist and doctor who are counseling parents separately. If necessary, they are also communicated to the parents, to aid in communication between the child and parents. All of these are documented routinely in the case record form and this workflow has been described in an earlier paper.<sup>5</sup>

It has been observed that many children, aged 6 years and above, have some understanding of the disease and their condition based on their self-reporting about disease-related questions.<sup>6</sup> This may give rise to related queries and concerns, but in most cases, children do not feel comfortable speaking about this with physicians or parents. Sometimes it is the parents who can be a barrier to effective communication, as they might favor collusion to protect their child from bad news.<sup>7</sup> A major shift in children's understanding of key biological concepts about the structure and function of the human body and disease transmission takes place between the ages of 7 and 11 years.<sup>8</sup> Yet, parents may have their own set of reservations and beliefs against communicating with a child, regarding a child's disease and its progression. Parents' decisions not to talk to their children might also reflect their emotional distress and a desire to protect themselves from the "unbearable reality of the situation."<sup>9</sup>

Like adults, facing challenges against a serious illness like cancer can provoke thoughts of death and dying in children as well; but there can be unique ways in which children cope, and it is worthwhile to provide a supportive framework for such kids to express themselves. Studies have found out that a child might learn about their disease and how serious it is without being explicitly told.<sup>10</sup> Children might be unwilling to talk, or feel inhibited about raising their concerns, particularly if they are aware of their parents' anxiety and discomfort around the subject.<sup>11</sup> Also, a child's perception of the disease can give a deeper insight into their disease burden. According to Rutishauser, understanding this burden of

illness can help in forming the basis for negotiating age-appropriate therapeutic goals and strategies.<sup>12</sup> Also, communication between the child, their parents or caregivers, and health care professionals helps to gain the trust of the child and is associated with enhanced adherence through improved understanding of illness and the importance of treatment.<sup>13</sup>

There is inadequate information in the literature on how the child perceives a referral to the palliative care services amid advancing disease. This retrospective chart review was planned to understand this lacuna and will help the pediatric palliative care team plan future strategies in bridging any communication gaps between the child with cancer and the parents.

This project aimed to record a child's understanding of cancer and its prognosis, and the psychosocial methods employed.

## Objectives

The primary objective is to study the child's understanding of advancing disease when referred to the pediatric palliative care services. Second, to assess how much of a communication gap exists between the child and parents and also to understand psychosocial strategies used to overcome any such barrier.

## Materials and Methods

### Sample and Setting

At the Department of Palliative Medicine, Tata Memorial Centre, Mumbai, Maharashtra, India, pediatric palliative has been offered to children and their families since 2002. The cases are discussed before a multidisciplinary team meeting in pediatric oncology and children with a resistant disease or relapse are referred for palliative care. Every child who is referred to the pediatric palliative care service is seen separately by a counseling psychologist and/or a trained child life counselor. Their evaluation is recorded in the Case Record Form. The notes which are compiled for every interview were retrospectively analyzed to look for:

1. The child's understanding of his/her disease, prognosis, related concerns, and the psychosocial interventions offered in aiding these concerns.
2. Communication between parents and child regarding disease and prognosis and barriers to it.
3. Any other sources of help obtained.

### Inclusion Criteria

Every chart where the child and parents were counseled separately at referral to the Department of Palliative Medicine, Pediatric Unit between March 2019 and March 2020.

Age range was between 6 and 18 years.

### Exclusion Criteria

Any incomplete case records, that is, a medical record that fails to tell the patient's whole story, and lacks clarity, specificity, or completeness.

### Data Collection and Procedure

The primary outcome measure was to record the child's understanding of cancer and its prognosis, while the secondary outcome was to record the psychosocial methods employed. We recorded demographic and clinical data from the patient charts. The data were summarized by descriptive statistics. Counseling notes were analyzed for emerging themes. We could screen through 50 participants from case records. The final sample size was determined by thematic saturation, the point at which new data appears to no longer contribute to the findings due to the repetition of themes and comments by participants.<sup>14</sup> At this point, data generation was terminated.

The information in the study records/audio records was kept confidential and the clinical charts are housed in the Tata Memorial Hospital Clinical Research Secretariat in safe custody, made available only to persons conducting the study and to the regulatory authorities. No reference has been made in oral or written reports which could link the participant to the study. No extra funding was needed for this chart review.

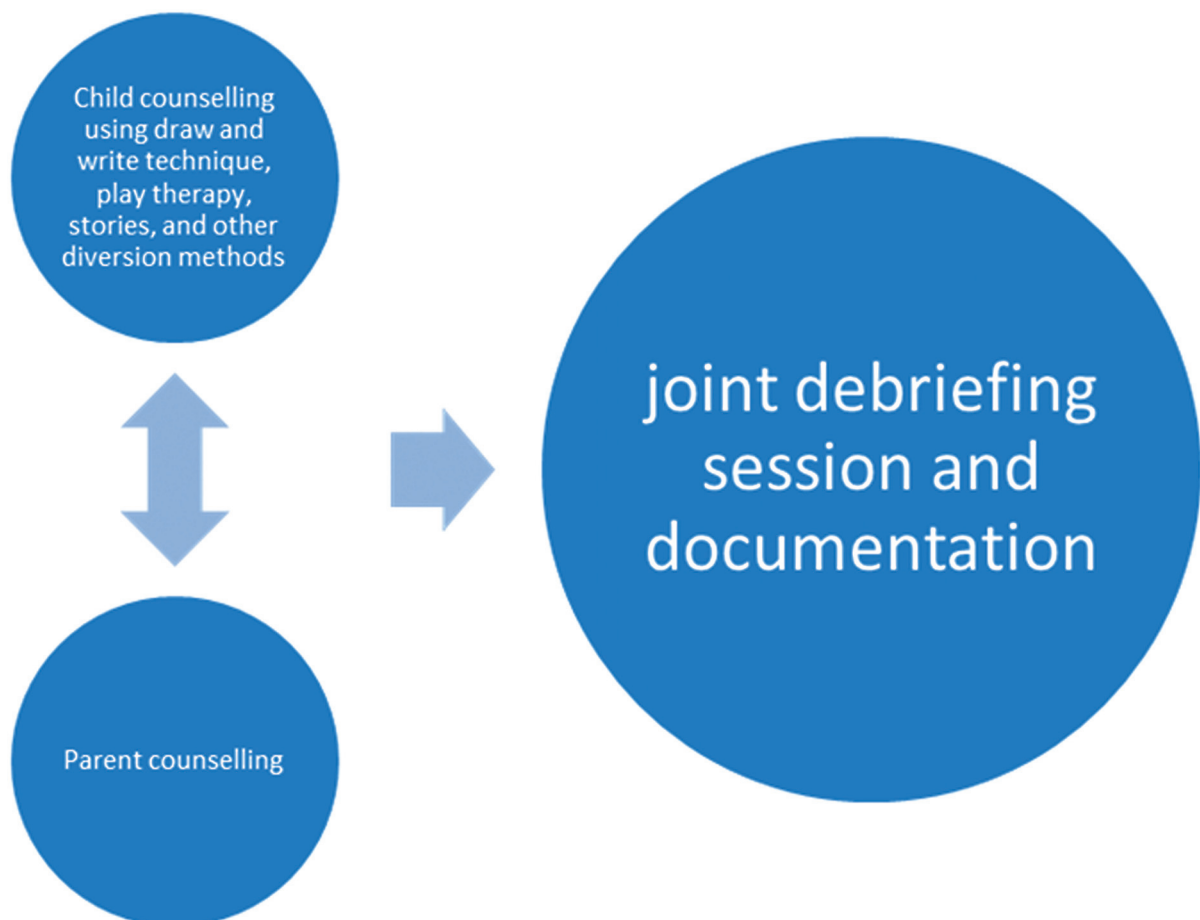
### Workflow Process

In a palliative care clinic, the child is "counseled" separately from the parent with their permission. Child counseling often involves communicating with children

using the draw and write technique, and play therapy with toys, stories, and other diversion methods; duly backed by evidence from the literature.<sup>15-18</sup> The draw and write technique<sup>15</sup> and play therapy<sup>17</sup> are jovial methods of engaging with children,<sup>18</sup> where they draw/write about their thoughts about cancer, and about things which help them to cope. In this activity, children are encouraged to work individually but have the option to clarify doubts with the child psychologist/researcher if they want to. Following this activity, the psychologist has a joint session with the children and their parents for any clarifications. These observations are conveyed to the psychologist and doctor who counsel parents separately. A final debriefing session involves all coming together at the end of the consultation. Everything is documented in the case record form in the English language. Parents are given contact details from the clinic for office/out-of-office hours communication and are scheduled for a follow-up visit.

### Data Analysis

Techniques of thematic content analysis were followed by two different researchers to develop an initial list of codes.<sup>19,20</sup> First, an initial list of codes was generated from the transcripts, followed by discussions to have an agreement on the set of codes. The level of intercoder agreement



from a random selection demonstrated a 98% level of agreement.<sup>21</sup> Remaining data was then systematically examined through these sets of codes to check for consistency and any emerging codes. Finally, themes were generated based on the agreed set of codes. Quantitative data analysis like calculation of median, percentage, and range was done for the demographic and clinical variables collected.

### Ethical Approval and Informed Consent

All procedures performed in studies involving human participants were per the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethics approval was granted by the Institutional Ethics Committee (Project 900683/IEC III) at the Tata Memorial Centre, dated 18.11.2020. The committee

waived the need for informed consent as the study utilized anonymized patient charts.

### Results

Data from the chart review are presented below using tally counts to indicate the frequency of specific codes, sub-themes, and themes. Most of the cases provided more than one, so the codes have been collapsed together to generate the final number of subthemes and themes. Of the 50 charts screened, 34 charts with complete data were identified and analyzed after reaching the point at which no new themes emerged.<sup>14</sup> Out of 34 participants, 23 were male and 11 were female. The demographic and clinical details of the patients are presented in ►Table 1. Average age of patients was 12 years (range 2–16 years).

**Table 1** Demographic and clinical profile of participants

	Numbers (%)	
Gender distribution of primary decision maker in family		
Male	28 (82.35)	
Female	6 (17.65)	
Monthly family income (₹)		
5,000 or below	15 (44.12)	
5,001–10,000	9 (26.47)	
10,001–20,000	5 (14.71)	
20,001–30,000	5 (14.71)	
Children		
Gender distribution of child		
Male	23 (67.65)	
Female	11 (32.35)	
Age distribution (y)		
2–12	13 (38.24)	
13–16	21 (61.76)	
Cancer diagnosis		
Medulloblastoma	2 (5.88)	
Ewing's sarcoma	5 (14.71)	
Hematological malignancy	12 (35.29)	
Melanoma	2 (5.88)	
Neuroblastoma	1 (2.94)	
Osteosarcoma	9 (26.47)	
Retinoblastoma	1 (2.94)	
Rhabdoid cancer of kidney	1 (2.94)	
Pancreatoblastoma	1 (2.94)	
	<b>Median</b>	<b>Range</b>
Age at diagnosis (y)	12	3–17
Months since diagnosis	3	0–85

**Table 2** Themes and subthemes of the chart reviews from participants

Themes	Subthemes	Example quotes
Child's understanding of the disease diagnosis and prognosis	Ignorance/avoidance of communication about the disease	I do not want to talk about it (P7)
	Something is there which is bad	I am not sure, but I do not have a good feel about it (P13)
	Everything is fine	All is well (P22)
	God will help with illness	I leave it to God (P20)
	Knows it is cancer	I know it is a dreadful disease (P16)
Nature of communication between the child and the parents	Knows the exact diagnosis	I know I have cancer (P17)
	Child not communicating with the parents because they take stress	I cannot watch my parents sad (P33)
	Child suspects parents have given partial information	I am sure that my parents know everything, but they never tell me (P12)
	Caregivers choosing not to tell child	We cannot tell him this (P18)
	Child choosing not to speak to parents	I better not speak about it (P1)
Recognized barriers to communication	Open communication	I share everything with my parents (P2)
	Child worries for the caregiver	I feel sad for my parents (P30)
	Poor coping of the parents	We cannot see him like this (P5)
	Parent's wishes to protect the child	Nothing will happen to him (P31)
	Hope for cure	My child will get better (P34)
Psychosocial interventions to improve communication	Child's preference	I do not want to talk about it (P29)
	Conflicts and issues other than the disease	My parents have dispute with my uncle (P23)
	Encouraged parents to communicate about the disease with the child	You should talk to each other about this (P10)
	Supported child for better coping	You should share your thoughts with someone (P21)
	Counseled caregivers to cope and support child	You must be open and supportive about this (P11)

**Thematic Findings (–Table 2)**

Five major themes regarding the child's understanding of advanced illness were identified: (1) child's understanding of disease diagnosis and prognosis, (2) nature of communication between parents and the child, (3) barriers to communication, (4) child's means of support, and (5) interventions used. Fourteen of 34 (41%) children were inquisitive about the illness, 13/34 (38%) of children were inquisitive but were not communicated openly about their disease, only 3/34 (9%) of children did not want to talk about the disease despite acknowledging the parents' stress about it, and there was no data for the remaining 4 (12%).

**Theme 1: Child's Understanding of the Disease Diagnosis and Prognosis**

The child's understanding of disease-related information ranged from not knowing that something is wrong with them to know the exact diagnosis and prognosis. Four

children reported not knowing anything—one child wanted to know more about the disease, while the rest expressed their wish to go back home based on what the authority figure (parent/doctor) had told them. This kind of avoidant coping was found in parents and children alike. Four children were aware of something bad happening as the symptoms worsened, two children understood that the lack of chemotherapy is not a good indication, four children knew that something bad is awaiting them as they could sense helplessness in their parents, and one child knew about a bad prognosis. The children who believed everything is fine were around the ages of 10 to 14 years. They were in denial and were accompanied by family collusion. Six children knew about the diagnosis of advanced cancer—two believed that their disease was curable, while four chose to not discuss anything with their primary caregiver to prevent further stress. Children who were aware of the exact diagnosis also tend to be better informed about the prognosis and were

between 13 and 15 years of age. Five children belonging to a relatively higher socioeconomic group had better awareness about treatment options for cancer care which had a positive bearing on their illness experience, compared with the rest.

### **Theme 2: Nature of Communication between the Child and the Parents**

Children who knew that something bad is happening preferred not to talk to their parents at all, however, often they expressed their hopelessness through their behavior (11 cases). Eight caregivers decided to avoid all sorts of disease-related communication with their children as they felt overwhelmed with the emotional burden. Family dynamics also resulted in lesser communication when the primary caregiver was someone other than the parents like a brother or cousin (in two cases). One child was unable to communicate with his parents due to parenteral conflict, and in another case, the mother was suffering from mental illness. Six children could open up to their parents. In one such case, the parent and the child both shared anger and resentment toward the doctors and the hospital for cancer to progress to advanced stages despite early initiation of therapy.

### **Theme 3: Identified Barriers to Communication**

There were both parent-related and child-related factors. The most common reason was to protect each other from distress; however, one child did not want to talk because he did not like to talk to anyone about his feelings. Poor coping on the part of parents was a deterrent, however, some resorted to avoidance by trying to play down the seriousness of the situation (two cases). Three families were in denial and believed in the cure. These ideas were often backed up by alternate support systems like alternative forms of medicine or belief in a higher power like God, all hampering communication about poor prognosis. Six children, who preferred not to talk to parents, were utilizing peer networks to share their feelings.

### **Theme 4: Psychosocial Interventions to Improve Communication**

After recognizing the communication barriers, interventions like psychoeducation, resource building, relaxation therapy, diversion, and cognitive behavior therapy were utilized and were found to be useful. The decision on the technique(s) used was made by the team. Parents were encouraged to communicate more with their children in friendly ways to reduce stress and mend communication gaps. This resulted in many families finding their communication portals and resulted in adaptive coping. The caregivers were supported to cope with anticipatory grief and were advised to seek support for themselves if overwhelmed. Family counseling sessions were organized to help in decision making, psychosocial support systems were strengthened for parents to take better care of children, work with collusion, and involve siblings in care. However, in four cases the families did not return for counseling as they shifted to their native place

knowing that cancer has become incurable. The psychologist reached out to those families by telephone.

### **Theme 5: Sources of Support**

The sources of support were varied—extended family (14 cases), siblings (13 cases), mother (8 cases), father (3 cases), and friends (3 cases). Only in one case, did the child use diversion as a method of support.

## **Discussion**

These results demonstrate the variations in awareness levels of children, their belief systems, coping strategies, and the magnitude of possible improvement in communication between parents and their children using case-directed psychosocial interventions. The cues and methods we followed in the clinic were based on standard practice patterns.<sup>22</sup> Children demonstrated good awareness of advanced cancer, thoughts about potential outcomes, and unique coping skills; however, there were wide variations in children's views about their diagnosis and prognosis.

The nature of communication between the child and their parents were influenced by interpersonal relationships and family dynamics. The psychosocial interventions implied here to improve communication ranged from encouraging parents and children toward opening up with each other for support and supporting parents to cope better.<sup>23</sup> For engaging with children we followed the draw and write and play therapy approach, as backed up by literature evidence. However, it was more effective in older children compared with the rest. The older children also had more defined ideas about the issues related to the advanced nature of cancer which was not found in the younger children. Interestingly, we could also appreciate that affluent children were better aware of therapeutic options for relapsed/advanced cancers compared with children from socioeconomically weaker sections of the society, who found poverty, job loss, and debts cause hindrance to their treatment. It is well known, that in the developing world, socioeconomic conditions are an important determinant for outcomes in children's health, but not much is known about how these complex factors shape their perspectives about health or the health care system.<sup>24</sup> In this era of "choosing wisely" in cancer therapeutics, we think that this is an important area that can be further explored.<sup>25</sup>

When comparing the contents of drawings/writing in this study with the seminal paper by Oakley et al.,<sup>26</sup> we found that our study participants score similarly in terms of cancer awareness, casualty, and its overall impact; but differ in the psychological coping strategies. This is expected, as advanced cancer, unlike other pediatric illnesses or cancers, possesses unique challenges like options of experimental therapy, a higher burden of suffering due to complex physical-psycho-social issues, and a lot of time being spent in the health care institutions rather than a home which makes the whole thing challenging for kids. In the absence

of previous experience or learning, children's expression highlighted the influence that social media, television, print media, and peer network can have on them in illness understanding. This highlights the importance of formal channels of health/disease-related communication between school and community. Drawing parallels from this, we think that ethnographic research can be a better way to understand how information about advanced cancer needs to be delivered to kids in their social worlds as has been shown elsewhere.<sup>27</sup>

The draw and write technique proved to be useful in a busy clinic like ours, as it is open-ended; and some children enjoyed it so much that similar techniques were started in the inpatient settings. It is important to note here that literature suggests using a combination of writing and drawing as it can elicit more information than either technique used alone.<sup>16</sup> One challenge to using this technique within the typical clinic setting is to provide children with a quiet place free from interruption to work independently, and supervision to avoid copying from others. In our study, the psychologist tried her best to watch the children carefully so that they were able to work in peace, and discouraged copying as best as she could. Also, as we could see a similar pattern of the main responses at different periods, the findings as depicted here are likely independent of any instances of such copying if that ever happened. It is interesting to note that the median time since diagnosis of the cohort was 3 months, compared with 18 months in a recent review.<sup>28</sup> This observation is a reflection of our local practice for palliative care referral which is typically triggered earlier in the cancer journey for children with high symptom burden, but also is short as many patients attend the cancer clinic at a refractory or early relapse stage after being referred from elsewhere. Other limitations in this study relate to the retrospective nature of the data extraction, and information that may have been expressed by parents/caregivers in local languages was documented in the charts in the English language following the working policy of the institute, which might have had a bearing on the results and interpretation related to translations of quotes.

## Conclusion

This study suggests that the knowledge of children on advanced cancer and cancer care is shaped not only by formal channels of health information communication but also by informal routes like peer groups, and the Internet. Illness-related communication between such children and their parents/caregivers is stressful and results in avoidance. There are wide variations, however, which need careful psychosocial assessments. Interventions like resource building and psychoeducation are effective but would need to take into consideration the socioeconomic and cultural contexts of children's lives which can influence their choices and behavior. A prospective study and/or large sample size will be needed for validating these results.

**Funding**  
None.

**Conflict of Interest**  
None declared.

## Acknowledgments

To all the project staff from the Department of Palliative Medicine at the Tata Memorial Centre, the participants, and their families.

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