

Original Article

# Experiences of Adolescents with Cancer Attending a Tertiary Care Cancer Centre: A Thematic Analysis

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## ABSTRACT

**Objectives:** Adolescents with cancer experience several psychosocial concerns. Cancer among adolescents contributes to one-fifth of cancers in India. Most of the published empirical literature on adolescents' views about their cancer experience is from high-income countries.

The objectives of the study were to explore the experiences of adolescents with cancer in India.

**Materials and Methods:** Twenty-eight adolescents were purposively recruited and participated in prospectively conducted qualitative interviews conducted at the Tata Memorial Hospital, Mumbai, between 2013 and 2015. Interview data were transcribed and analysed using Braun and Clarke's reflexive thematic analysis.

**Results:** Two themes and several subthemes were generated during the analysis. The transition to the new reality of illness was traumatic. It embodied fear about the unknown, disease and symptoms. The experience was isolating and disfigurement further led to peer separation. Inadequate information made the adolescents anxious and worried, and children and parents experienced moments of severe distress. The love and support received from parents, siblings and extended family facilitated positive coping. Peer support was reassuring and enabled them to have a normalising experience. Discovering their inner strength, acceptance of the situation and faith in God made them resilient and hopeful.

**Conclusion:** Adolescents with cancer experience significant emotional concerns, which are often unexplored and unaddressed. An adolescent-specific communication framework and psychosocial programme contextual to the Indian setting may be developed based on the study findings.

**Keywords:** Adolescent, Neoplasms, Palliative care, Thematic analysis

## INTRODUCTION

Globally, age-standardised cancer rates in adolescents are 43.3 new cancer cases/100,000 people/year and 15.9 cancer-associated deaths/100,000 people/year.<sup>[1]</sup> Palliative care needs in the paediatric population in low- and low-middle-income countries are significantly higher than in high-income countries. Adolescents and young adults constituted one-fifth of India's overall cancer incidence.<sup>[2]</sup> Apart from physical symptoms, adolescents with cancer experience significant emotional distress. Guilt, fear of death, loss of peers, negative views about their body and isolation were the common emotions adolescents perceive with cancer.<sup>[3-5]</sup> They preferred to know about their diagnosis and prognosis, but it was often withheld from them. They perceived it as an unmet communication need and poor quality of interaction with healthcare providers.

Paediatric palliative care providers have always felt a need for adolescent palliative care programmes. However, exploring adolescents' experience with cancer and their interpretative meaning informs policies and practices and enables the development of a comprehensive programme. The views of adolescents about their cancer experience have already been published.<sup>[6-22]</sup> However, most of this literature was studies from high-income countries. Moreover, there were no published studies from India expounding on this phenomenon, justifying the conduct of this study. This study aimed to explore the experiences of adolescents with cancer in India.

## MATERIAL AND METHODS

The experiences of adolescents with cancer in the Indian setting are not known a priori. There are no studies from India exploring the study research question. It is a new area of social

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science research contextual to the Indian paediatric oncology setting that explored these experiences. The study was not limited to the systematic collection of data but co-creation of knowledge between the interviewer with paediatric palliative care experience and the adolescents participating in the research where participant's experiences of cancer are explored in detail and interpreted. Therefore, a qualitative approach was used to explore the study phenomenon.

The study was conducted at the paediatric oncology and palliative care outpatient services of India's tertiary cancer centre between 2013 and 2015. Participants were adolescents aged 12–19 years, diagnosed with cancer and assented to participate in the study. Participants who could not speak either Hindi, Marathi or English were excluded from the study. The primary outcome of this study was to explore the experiences of adolescents with cancer in India. The secondary outcome was to enable the child psychologists working in a cancer centre to develop an adolescent communication framework contextual to the Indian setting. Participants were purposively recruited. Consent was sought from the parents only when participants assented to participate. All participants were interviewed face to face using a semi-structured interview topic guide by a psychologist well trained in qualitative research methods [Appendix]. Recruitment was sought through posters in the clinics free from any commercial bias, and the participants and their parents received the participant information sheet a week before the study. The informed consent form and assent form were completed before study recruitment [Appendix].

The interviews were conducted in a private environment at the premises of the hospital and were 45–60 min in duration. All interviews were audio-recorded and transcribed in the local language (Hindi and Marathi) and then translated into English for analysis (back-translation was not necessary) in a designated space within the outpatients. To facilitate analysis, the interviews were uploaded into the NVivo software version 12.6.0 for Mac.<sup>[23]</sup> The interview data were analysed using Braun and Clarke's reflexive thematic analysis.<sup>[24]</sup> The inductive reflexive approach was used to allow the researcher's subjectivity as a resource during data analysis<sup>1</sup>.

1 Braun and Clarke describe reflexive thematic analysis (RTA) as 'a theoretically flexible method' for 'developing, analysing and interpreting patterns across a qualitative dataset'. A central component of RTA is that the researcher's position and contribution are necessary, unavoidable and an integral ingredient of the process. It is not something to remove, reduce, avoid or minimise, but a valuable resource to be drawn on. To capitalise on this resource, Braun and Clarke invoke the use of the term 'reflexive'. Reflexivity involves drawing on your experiences, pre-existing knowledge and social position (such as ethnicity, gender and class) and 'critically interrogating' how these aspects influence and contribute to the research process and potential insights into qualitative data. This invites the researcher to explore, understand, bring forth and make explicit their values, ideas about themselves, the world and their beliefs. Braun and Clarke outline four domains of reflexive thematic analysis (orientation to data, focus of meaning and qualitative framework, theoretical frameworks) and each one reflects orientations to data. These polarities or dimensions are not mutually exclusive, thus will often overlap.

## Statistical analysis

No formal statistical analysis was conducted, but we followed the concept of data saturation, defined as 'information redundancy' or the point at which no new themes or codes 'emerge' from data for thematic analysis<sup>2</sup>.

## Ethics

The study complied with the Declaration of Helsinki and was approved by the Ethics Review Board of the Hospital project number 1223 dated 27<sup>th</sup> November, 2013.

## RESULTS

A total of 62 adolescents were approached for the study, of which 40 agreed to participate. Among them, 28 could complete the interviews and send back the diaries. There were 18 male and 10 female participants with an average age of 15 years [Table 1]. The reason for non-participation was lack of interest in the study (8), poor health (12) and lack of time (2). The reasons for non-completion were the loss of diaries (12).

2 Saturation is a core principle used in qualitative research. It is used to determine when there is adequate data from a study to develop a robust and valid understanding of the study phenomenon. Saturation is applied to purposive (non-probability) samples, which are commonly used in qualitative research. Saturation is an important concept because it provides an indication of data validity and, therefore, is often included in criteria to assess the quality of qualitative research. Saturation has its origins in the grounded theory approach to qualitative research, where it is used to determine data adequacy for theory development; however, it is also used outside of grounded theory to justify sample sizes for qualitative studies.

**Table 1:** Demographic and clinical data of the participants.

	Number of patients (n=28) (%)
Gender distribution	
Male	18 (64.3)
Female	10 (35.7)
Education	
Illiterate	3 (10.7)
Primary school certificate	17 (60.7)
Middle school certificate	8 (28.6)
Cancer diagnosis	
Leukaemia	13 (46.4)
Lymphoma	8 (28.6)
Retinoblastoma	3 (10.7)
Sarcomas	4 (14.3)
Treatment received	
Multimodal	24 (85.7)
Chemotherapy	2 (7.1)
Radiotherapy	2 (7.1)
ECOG score	Number of patients (%)
0	0 (0.0)
1	0 (0.0)
2	8 (28.6)
3	18 (64.3)
4	2 (7.1)

Two major themes were generated that is, A. New reality: A traumatic transition and B. Coping: Family, friends and self. Several subthemes informed each of these major themes.

### **Theme 1: New reality: A traumatic transition**

The abrupt diagnosis of cancer and the transition to a new reality was traumatic. The new reality embodied fear, isolation, disfigurement, lack of information and distress. These were the subthemes informing this theme.

#### **Subtheme 1A: Fear**

In this subtheme, participants expressed several kinds of fear. The fear of the unknown was often associated with moving to a new city for treatment. Parents accompanying the adolescent were often worried and they seldom knew the purpose of the travel or what to expect.

‘I was scared at what was happening... My mother and father were crying. I felt sad looking at them...as I was going for the treatment. I was numb. I did not know what the feeling was.’

Moreover, the participants also expressed fear about the poorly controlled physical symptoms that caused them anxiety and lack of sleep

‘Initially, I used to have pain, so I used to be worried because of that’ and ‘I could not sleep for 1 month because of pain.’

#### **Subtheme 1B: Isolation**

In this subtheme, participants discussed several factors contributing to the feelings of isolation. It often resulted from parents separating their children with cancer from other children due to the fear of contracting infections.

‘Many people feel that children with cancer easily get infections from others, which is not good.’

Furthermore, a myth about the transmissibility of cancer from one child to another also led to the isolation of children with cancer.

‘One of my friend’s mothers did not allow her to come to meet me because I had cancer.’ Moving away from their regular home-school environment, peer separation and inability to carry out their childhood activities triggered feelings of isolation.

‘Now, I am not able to go to school... due to this disease, I feel I could not do many things and I feel isolated.’

A transition from an active and spirited purposeful life to a sedentary uncertain existence also contributed to the feelings of isolation.

‘I used to have an active life. After cancer, I am just sitting at home... I feel all alone, despite family around.’

#### **Subtheme 1C: Disfigurement**

In this subtheme, several adolescents experienced feelings of disfigurement due to treatment-associated loss of hair,

amputation or enucleation. It denied them to have an everyday life like their peers.

‘During chemo, your hair will fall off. I was shocked to know’ and ‘My all-other friends are living a normal life, but I was not able to.’

These body changes caught the attention of their peers, which led to the experience of some form of stigmatisation, forcing them to play board games indoors instead of outdoor play.

‘I was pained and hurt... I will never be able to play. What will I do?. Indoor games also I can play, such as chess carom and ludo.’

Furthermore, disfigurement hindered adolescents from pursuing their interests, which made them sad and worried.

‘I wanted to become a musician. I have played the guitar, piano, table, harmonium, etc. Now I cannot.’

#### **Subtheme 1D: Lack of information**

In this subtheme, many adolescents reported information inadequacies. Parents not being open with the children about their diagnosis and prognosis and concealment of information contributed to uncertainty and distress.

‘No one spoke to me about it’. However, another child said – ‘no one told me. I saw the hospital and came to know’.

Parents were evasive when questioned by the children and often provided unsatisfactory blanket reassurances. Children did not appreciate these communications and felt a need to know.

‘He told me differently; he told me that it is a risky disease and it is a grave issue and he did not tell me directly’.

‘Not telling is not good’.

Moreover, the concealment of information was not limited to children. Women in the family, including mothers, were withheld information about the child’s illness.

‘Father never showed it to me... my mother also did not know about it’.

#### **Subtheme 1E: Distress**

In this subtheme, distress was often associated with knowing the diagnosis. However, knowledge of the diagnosis in an indirect manner augmented this distress.

‘I have listened while they were talking... Mummy started crying in the next room... I managed myself. Crying’.

Adolescents had a strong sense of duty to care for their parents and felt that it was their responsibility to care for their parents when they are ageing. Inability to accomplish this role made them guilty and distressed.

'Mother and I were at home. We both burst into tears. Who will look after my mother now?'

Furthermore, the lack of societal understanding of their illness and their needs significantly contributed to distress. The adolescents were unable to voice their concerns openly and express their distress.

The ones who do not have the disease are not able to understand it.

## **Theme 2: Coping: Family, friends and self**

Although the transition to the new reality was traumatic, adolescents could find few strategies that enabled them to cope with this situation. Family bonding, peer support and being positive facilitated them to navigate these challenging times. These were the subthemes informing this theme.

### ***Subtheme 2A: Family bonding***

Strong family ties enabled the adolescents to cope with the challenges effectively. They were able to discuss fears and concerns openly.

'My mother is very nice. My sister cares for me a lot and I am happy that I am with my family.'

Constant parental reassurance boosted confidence among the adolescents. Moreover, adolescents believed that parents are always there for them and will do everything possible in their best interest.

'My family members asked me not to worry. Things will be fine.'

'My mother has done everything. Day-night, she used to run around for me.'

Although sibling rivalry is typical when the sick child is getting more attention, adolescents felt that they received a lot of support from their siblings in this study. It helped them to have an everyday experience at home.

'My brothers are so helpful. My younger brother takes so much care of me while playing.'

Furthermore, the support the adolescents and their families received from their extended family played a significant role while accessing cancer therapies at places away from their homes.

'After that, I got operated here and at that time my aunt was here. Her contribution was also remarkable. No aunt does so much.'

### ***Subtheme 2B: Peer support***

The adolescents appreciated the peer support they received at the hospital and at their school. Seeing other children having similar conditions and receiving similar treatment helped them realise that their situation is not unique and could happen to anyone.

'Now, I do not feel anything because here, everyone is going through the same. So, I do not feel much now' and 'Everyone was struggling'.

Adolescents saw that parents were less worried in the hospital and were more reassured to see many families experiencing similar challenges.

'When we were at home, we were worried, but when we came here, we saw so many patients, and then, my parents were a little okay.'

Peer interaction in the hospital setting enabled them to build resilience and develop empathy and compassion towards other children with similar illnesses.

'They are also like me and they should also get well.'

Their friends and the school provided them with enormous support.

'The support from friends was enormous. I am grateful to them.'

The peers at school felt sad and concerned and the adolescents with cancer found it easy to share their intimate thoughts with their peers than with parents.

'They were all sad and disappointed. They were in worry about what happened to me.'

'I share things with friends which I cannot with my parents.'

Furthermore, peers supported these adolescents with cancer by helping them in their studies by filling in lost days at school and the peers did not want them to lose an academic year due to illness.

'They tell me you should not fail so that we can be together in the same class.'

### ***Subtheme 2C: Being positive***

The adolescents with cancer tried their best to be positive. It was an effective strategy to overcome the challenges they were facing. Older children (16–19 years age group) made a conscious effort to overcome the negative emotions. They were worried that their negativity might adversely impact the emotions of their parents. Moreover, they felt duty bound to comfort their parents who were grieving due to their child's illness.

'Then, slowly, I started feeling positive and thought that if I am like that then how my parents will be positive.'

'I speak to father and tell him not to take tension.'

Acceptance of the situation also enabled them to cope with their illness and they felt that they have the innate strength to overcome it. The feeling of acceptance enabled them to overlook any negative emotions arising due to conditions like disfigurement.

'Loss of hair did not matter; it would come back again.'

Although some questioned God for their current situation, most adolescents had unflinching faith and assurance that God will protect and keep them.

'Why he did do this to such a small child like me?'

'God will not let this happen; he is a good God. Faith in Allah will make the disease go away.'

## DISCUSSION

This study is a novel area of social science research in the Indian sociocultural context exploring the adolescents' experiences of living with cancer. The phenomenon has not been studied earlier and contributes contextual new knowledge.

Children with cancer often experience low mood, worry, anxiety, fear, irritability and anger.<sup>[25,26]</sup> In this study, adolescents had several sources of fear and worry. The fear of the unknown was the most common source of worry. Pain is one of the common symptoms seen in cancer,<sup>[27]</sup> and internationally, children with cancer often felt inadequately addressed.<sup>[28-30]</sup> In our study, inadequately controlled pain and physical symptoms led to the experience of fear and worry.

The prolonged duration of cancer-directed therapies led to feelings of isolation and disruption from school and play and changed the home-school play cycle to the home-hospital cycle.<sup>[31]</sup> In our study, isolation was partly imposed by the parents fearing the risk of infection to the child. It was partly due to avoidance of the adolescents with cancer by other parents due to perceived fear of transmissibility of cancer.

Some adolescents with cancer report body image issues, which often cause distress due to peer attention, peer isolation and bullying. In our study, cancer-associated disfigurement led to restriction of the pursuit of outdoor interests.

Most of the children with cancer receive little information about their diagnosis and prognosis and the adolescents, who were able to understand, often felt a need to know.<sup>[32,33]</sup> In our study, adolescents experienced information inadequacies and evasive approaches from parents and healthcare providers, which led to feelings of uncertainty and anxiety.

Adolescents often experience distress as they feel that the illness has destroyed the hope of a promising future. Their fears are seldom addressed and they are often not at peace and unable to reconcile their losses.<sup>[34,35]</sup> In our study, distress was mainly due to knowledge about the illness, the guilt of inability to fulfil their future responsibilities towards their parents and a lack of societal understanding of their grief. Studies have shown that a lack of societal acknowledgment and understanding of grief can cause feelings of isolation among adolescents and their parents.<sup>[36,37]</sup>

A gap between the child's understanding and experience of illness and parental perception of what the child knows could often lead to a break in family communication and bonding.<sup>[38]</sup> Able to have open communication about the illness in the family, reassurance and support enabled the adolescents to cope with their illness.

Adolescents with cancer often have challenges conveying their feelings, experience low self-worth and feel less resilient.<sup>[39,40]</sup> In our study, peer support was reassuring, enabled the adolescents to share their intimate feelings and

helped them have a normalising experience. It also facilitated personal growth and they felt more compassionate and resilient. Moreover, their inner strength, faith in God and acceptance of the situation contributed to their effective coping.

### Limitations

Many children attended the hospital services coming from faraway places/states and wanted to return home soon after discontinuation of potentially curative therapies. While it was understandable, for the researchers, it possessed a challenge to recruit/motivate such participants to stay back for extra days. Member checking to ensure participant validation of the results was not performed to ensure the protection of the participant.

### Future research directions

Adolescent distress, especially in advanced cancer, is influenced strongly by the environment they live in. Careful understanding of these issues will help us to provide individualised and specialised care which can be researched in the future through a larger trial. It will enable the child psychologists working in a cancer centre to develop an adolescent communication framework contextual to the Indian setting.

## CONCLUSION

Adolescents with cancer experience several psychosocial concerns, which are often unexplored and unaddressed. Feelings of fear, isolation, disfigurement and guilt can be distressing. Information inadequacy and concealment of illness information often lead to anxiety and worry. Family and peer support and finding their inner strength and faith in God enabled the adolescents to cope with the illness positively. The study findings will inform future practices towards developing an adolescent-specific communication framework and psychosocial programme contextual to the Indian setting.

(i) Each author's contribution

- 1) NS, MAM, AG and SJ made substantial contributions to the conception or design of the work; or the acquisition, analysis or interpretation of data.
- 2) NS, MAM and AG drafted the work or revised it critically for important intellectual content.
- 3) NS, MAM, AG and SJ approved the version to be published.
- 4) NS and MAM agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

(ii) Conflicts of interest

The authors have no conflicts of interest to declare that are relevant to the content of this article.

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**Declaration of patient consent**

The authors certify that they have obtained all appropriate patient consent.

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