

# Bias, Stigma and Empowerment among Girl Childhood Cancer Patients and Survivors: A Survivor-led Study

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## Abstract

**Background:** Childhood cancers cause significant morbidity and mortality, with notable gender disparities in access to healthcare. The Girl Child Project Initiative by CanKids addresses these inequities by offering holistic care and empowerment for young female cancer survivors. The study focuses on challenges, worries and stigma experienced by girl child survivors.

**Methods:** The study included 82 female childhood cancer survivors registered with Cankids from six major Indian cities- Delhi, Mumbai, Ahmedabad, Lucknow, Kolkata, and Chennai. A five-point Likert scale questionnaire was used for eliciting information on challenges before start of treatment, worries during treatment and stigma as well as other problems experienced as cancer survivors and facilitators of survivorship.

**Conclusion:** Social support and counselling from fellow survivors were highly valued by the participants. The findings of the study suggest that developing countries can leverage survivors to manage and mitigate cancer-related stigma.

**Keywords:** girl child cancer survivors, social support, childhood cancer, gender disparities, peer support, stigma, survivorship

## Background

Cancers in the 0–14 age group account for 4.0% of

all cancers in India.<sup>1</sup> It remains unclear whether girls with cancer in India have a higher likelihood of being “missed” (i.e., not diagnosed or treated) compared

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to boys. This potential issue raises concern about the barriers faced by female childhood cancer survivors in accessing adequate healthcare, adhering to medical advice, and seamlessly reintegrating into society.<sup>2</sup>

CanKids KidsCan, a National Society for Change for Childhood Cancer in India was established in 2004 with a vision of achieving global standards of survival and holistic quality of life for childhood cancer patients. The organization works to support children and their families affected with cancer, operating through a network of 141 Hospital Support Units, 20 Care Centres, 1 Paediatric Palliative Care Centre, and 2 Canshalas (a special school for children with cancer).

A study conducted by Cankids through PGIMS Rohtak revealed significant gender disparities in childhood cancer care as only one in every three children diagnosed with cancer were females, boys were twice as likely to complete treatment, and treatment abandonment rates were higher among girls (14% vs. 6% for boys).<sup>3</sup>

In response to these findings, Cankids initiated the Girl Child Project in 2013 to understand the reasons for gender inequality and cancer stigma, and to empower girl child survivors and their peers. This project employs "girl brigades," comprised of cancer-surviving girls, who work with newly diagnosed peers to enhance treatment adherence, reduce abandonment rates, and support a smooth return to society after completing treatment.

Present study aims at understanding the challenges/ Worries / Concerns experienced by girl child survivors before, during and after treatment through a scientifically planned study.

## Material & Methods

### Study Design and Participants

This cross-sectional study was conducted in six cities (Delhi, Mumbai, Ahmedabad, Lucknow, Kolkata, Chennai) included 210 registered female childhood cancer survivors, with 100 recruited and 82 responding.

### Study tool and data collection

A structured questionnaire with Likert scale options was used, covering four domains:

pre-treatment challenges, worries during treatment, survivor concerns, and opinions on improving treatment adherence and reintegration. Interviewers administered the questionnaire after obtaining informed consent.

### Ethics Approval

The study received ethical approval from the Genbandhu Ethics Committee (ECG002/2019). Informed consent was obtained from all participants prior to their enrolment in the study.

### Data management and Statistical analysis

Data was entered into Excel and analyzed using SPSS version 24.0. The analysis profiled girl child cancer survivors by socio-demographic parameters. Likert scale responses were analyzed for four domains, expressed in frequencies with scores presented as mean and standard deviation.

## Results

### Profile of pediatric girl cancer survivors

The study included 82 pediatric girl cancer survivors aged 11-34, with an average age of 19 years. The median survival time was 8 years. Importantly though, a large proportion of girl child cancer survivors missed education however, with CanShala's assistance, 25% completed graduation, 17% senior secondary education, and 18% secondary education. The socioeconomic background of parents reflects poor financial situations and moderate education levels. The findings on challenges, problems and concerns experienced by girl child cancer survivors as elicited through 5 point likert scale are presented in subsequent sections.

### Challenges faced even before starting treatment

On pre-treatment challenges, a Likert scale questionnaire with 12 questions was used, rating each from "Not at all" =0, "A little" = 1, "Moderate" =2, and "A lot" =3. Average scores were calculated for each of the 12 questions. The questions with scores of 2 or more indicated major challenges while scores between 1.5 to 2 as moderate challenges and below 1.5 indicating minor challenges. Of the 12, five concerns were seen as major one namely, disruption in education (Mean: 2.1), coping with symptoms

(Mean: 2.0), financial constraints (Mean: 2.0), travel difficulties (Mean: 2.0), and getting diagnosed (Mean: 1.8).

**Table 1: Major challenges faced before starting treatment: Response to likert scale and mean scores**

List of challenges	LIKERT SCALE					SCORE	
	Not at all	A little	Moderate	A lot	Don't Know	Mean	Standard Deviation
Disruption in education	12 (14.6%)	9 (11%)	18 (22%)	37 (45.1%)	6 (7.3%)	2.1	1.1
Coping up with initial disease symptoms	12 (14.6%)	13 (15.9%)	8 (9.8%)	38 (46.3%)	11 (13.4%)	2.0	1.2
Lack of Finances for treatment	13 (15.9%)	8 (9.8%)	14 (17.1%)	37 (45.1%)	10 (12.2%)	2.0	1.2
Travelling to hospital and back	12 (14.6%)	12 (14.6%)	15 (18.3%)	38 (46.3%)	5 (6.1%)	2.0	1.1
Getting diagnosed	17 (20.7%)	10 (12.2%)	15 (18.3%)	29 (35.4%)	11 (13.4%)	1.8	1.2

### Worries experienced during treatment

On experiences of the paediatric girl cancer survivors during treatment likert scale questionnaire included 18 questions. Here also responses were measured on a Likert scale as **Never = 0, Sometimes = 1, Often = 2 and All the time = 3**.

The major concerns during treatment as reported by girl child cancer survivors were only two: that is *"painful treatment and procedures and the*

*pain"*(Mean Score: 2.3), *"Will I lose my hair and have other side effects"* (Mean Score: 2.0). Moderate concerns included *"financial worry"* (Mean Score: 1.7), *"Will I miss years of school/college"* (Mean Score: 1.7), *"Comments on appearance"* (Mean Score:1.6) and *"fear of the future"* (Mean Score: 1.6), *"Depression and anxiety"*(Mean score: 1.5). Importantly, fear of death, integration into society were noted as minor worries.

**Table 2: Major and moderate worries experienced during treatment: Response on likert scale and average scores**

List of worries during treatment	LIKERT SCALE					SCORE	
	Never	Sometimes	Often	All the time	Don't Know	Mean	SD
Painful treatment and procedures and the pain	6 (7.3%)	14 (17.1%)	9 (11%)	46 (56.1%)	7 (8.5%)	2.3	1
Will I lose my hair and have other side effects	11 (13.4%)	15 (18.3%)	13 (15.9%)	34 (41.5%)	9 (11%)	2	1.1
Financial worry - where will the funds come from for treatment	16 (19.5%)	19 (23.2%)	8 (9.8%)	29 (35.4%)	10 (12.2%)	1.7	1.2
Will I miss years of school/college	14 (17.1%)	25 (30.5%)	12 (14.6%)	25 (30.5%)	6 (7.3%)	1.6	1.1
Comments on appearance	16 (19.5%)	23 (28%)	8 (9.8%)	27 (32.9%)	8 (9.8%)	1.6	1.2
Fear of the future	22 (26.8%)	10 (12.2%)	14 (17.1%)	27 (32.9%)	9 (11%)	1.6	1.3
Depression/ sadness/anxiety	18 (22%)	24 (29.3%)	13 (15.9%)	20 (24.4%)	7 (8.5%)	1.5	1.1

### Problems/challenges and issues of concern for survivors after treatment

In order to understand the problems & challenges of survivors after treatment, Likert scale questionnaire contained 23 questions.

The major challenges and concerns reported by survivors were **to be self sufficient and to take care of myself without depending on others** (Mean: 2.1) and **to selflook after and manage side effects** (Mean: 2). Importantly, the survivors expressed their

desire to help other diagnosed girl child cancer patients (Mean: 2.5). However, concerns such as relapse, pursuing education, getting job, getting

married, keeping cancer as secret, self-image were seen as minor concerns.

**Table 3: Major problems/challenges and issues of concern for survivors: Response to likert scale and average scores**

List of problems/challenges and issues that most concern you as a survivor	LIKERT SCALE					SCORE	
	Not at all	A little	Moderate	A Lot	Don't Know	Mean	Standard Deviation
I want to help other girls diagnosed with cancer and during their treatment	8 (9.8%)	5 (6.1%)	11 (13.4%)	58 (70.7%)	0 (0%)	2.5	1
I want to take care of all difficulties I face without depending on others	15 (18.3%)	8 (9.8%)	8 (9.8%)	50 (61%)	1 (1.2%)	2.1	1.2
I want to be responsible for looking after my own late side effects and my health	16 (19.5%)	9 (11%)	16 (19.5%)	39 (47.6%)	2 (2.4%)	2	1.2

**Opinion about what can help more girls to initiate treatment, stay with treatment, complete treatment, reintegrate into society, and become survivor advocates**

Paediatric girl cancer patients, as members of the KidsCan Konnect group, were asked to give their opinion on measures that could help more girls seek, continue, and complete cancer treatment, seamlessly reintegrate into society, and become survivor advocates. This was done using a Likert scale questionnaire with 7 points. Average scores were calculated for each concern related to these opinions where Not at all = 0, A little = 1, Moderate = 2 and A lot = 3. Concerns with a mean score of 2 or more were categorized as major, while those scoring less than 1.5

were categorized as minor.

Almost all paediatric cancer survivors emphasized the importance of having events for girl cancer patients/ survivors with public participation and encouragement (Mean Score: 2.9), more girl child cancer survivor role models to motivate and inspire (Mean Score: 2.8), KCK girl brigade to help fight stigma and gender bias (Mean Score: 2.8), a girl survivor support group to provide counseling throughout the treatment journey (Mean Score: 2.7), Counselling for parents to attend the forum (Mean Score: 2.7), a dedicated helpline/communication platform (girl child cancer helpline/whatsapp group) (Mean Score: 2.7), and regular support group meetings of the forum (Mean Score: 2.6).

**Table 4: Opinion about what can help more girls to come for treatment, stay with treatment, complete treatment, reintegrate into society and become survivor advocates: Response on likert scale and average scores**

List of opinion about what can help more girls come for treatment, stay with treatment, complete treatment, reintegrate into society and become survivor advocates	LIKERT SCALE					SCORE	
	Not at all	A little	Moderate	A Lot	Don't Know	Mean	Standard Deviation
There should be events for girl cancer patients/survivors with public participation and encouragement.	0 (0%)	4 (4.9%)	13 (15.9%)	64 (78%)	1 (1.2%)	2.9	0.4

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There should be more girl child cancer role models to motivate and inspire	0 (0%)	3 (3.7%)	11 (13.4%)	67 (81.7%)	1 (1.2%)	2.8	0.5
The KCK girl brigades will help fight stigma and gender bias	(0%)	2 (2.4%)	9 (11%)	68 (82.9%)	3 (3.7%)	2.8	0.4
If girl survivor group/parents had been there to talk to at the beginning and during treatment	2 (2.4%)	2 (2.4%)	15 (18.3%)	60 (73.2%)	3 (3.7%)	2.7	0.7
Parents should also be counselled and attend the forums	2 (2.4%)	4 (4.9%)	14 (17.1%)	61 (74.4%)	1 (1.2%)	2.7	0.7
There should be a girl child cancer helpline/WhatsApp group/Communication Platform	0 (0%)	4 (4.9%)	13 (15.9%)	64 (78%)	1 (1.2%)	2.7	0.5
There should be regular girl child forums and support group meetings	0 (0%)	2 (2.4%)	24 (29.3%)	53 (64.6%)	3 (3.7%)	2.6	0.5

## Discussion

The characterization of the study, girl paediatric cancer survivors' in terms of age at diagnosis aligns with the other studies which revealed a similar trend of adolescent diagnoses<sup>4,5</sup>.

Educational attainment is a key measure of the quality of long-term survivorship. The support provided by CanShalas helped cancer survivors in completing their education. Highlights CanShala's impact on childhood cancer survivors' educational success.

Childhood cancers are often curable, but barriers prevent treatment. Sneha and colleagues found that financial burdens of childhood cancer, including nonmedical costs like transportation and accommodation, significantly impact families' financial stability, second only to the disease itself.<sup>6</sup> Consistent with these previous reports it was notably evident in our study that lack of finances for treatment and travelling to hospital and back were significant challenges for survivors.

The findings of the other studies indicated that childhood cancer survivors face a myriad of challenges during and after treatment, impacting their lives. Our study also revealed coping with symptoms as major concerns for survivors. In addition to transportation, education disruption, financial constraints, and Social pressure, treatment perception, and family

issues were minor concerns, with diet-related issues being least challenging.

Several investigations have documented that paediatric cancer patients endure demanding healthcare treatment modalities<sup>7</sup>, painful medical procedures<sup>8-9</sup>, unpleasant treatment side effects<sup>11,12</sup>, and the fear of death<sup>7</sup>. In our study childhood cancer survivors reported that during the course of cancer treatment, they often tussle with a multitude of worries. At the forefront of these apprehensions is the fear of painful treatment procedures and the associated discomfort. Additionally, the uncertainty surrounding potential hair loss and other treatment side effects weighs heavily on the minds of patients. Children and their families frequently report psychosocial cancer-related stressors, such as distressing emotional reactions<sup>13</sup>, disruption in routines and in social, occupational, and family roles<sup>15</sup>, and issues with peers including bullying and restricted participation in peer activities<sup>13</sup>. Specifically, a significant subset of children undergoing cancer treatment experience persistent cancer-related distress, including increased symptoms of anxiety, irritability, depression<sup>16-18</sup>, and posttraumatic stress<sup>19</sup>. Due to the unanimous counselling and support to the survivors provided by the CanKids during the entire treatment journey, the emotional toll of depression, guilt, anxiety and fear of death were considered as minor worries.

Most populations commonly exhibit a behaviour of not revealing the diagnosis of cancer, especially to close friends and relatives<sup>20</sup>. A study conducted by Ray et al. found that 11.6% of the participants cited social stigmas, such as concerns about their daughter's marriage, as the primary reason for not revealing their illness<sup>21</sup>. A study conducted by Krishnan and his colleagues found that 75% of the volunteers believed it is more advantageous to withhold the diagnosis within the community. Additionally, 30% of the participants expressed concerns that disclosing the diagnosis could negatively impact the child's future and have enduring consequences for the family<sup>20</sup>. Contrary to expectations, the findings of the current study suggest that young female cancer survivors who received treatment and counselling in our specialist paediatric research advocacy group had rather high levels of empowerment. They expressed the view that revealing the cancer diagnosis, adapting to it, and forming new friendships were not perceived as difficult, but rather seen as minor issues.

The seamless reintegration of children after completing their treatment was not a major concern in our study, due to the robust social and psychological support provided by CanKids. The comprehensive support system offered by CanKids alleviated many of these worries. Cankids unique approach offers uninterrupted psychosocial resources, combating stigma and bias. Our study highlights unanimous support for this indispensable model.

### Conclusion

Five major barriers identified were disruption in education, travelling time to access treatment, lack of finances, diagnostic delays and initial ability to deal with the disease. These were particularly challenging for families with low socio-economic conditions.

Stigmatizing factors were primarily to do with body self-image, fear of the future and lack of finances, for which good psycho-social and peer support could make a real difference.

The measures undertaken to empower girl survivors, like the girl brigades, girl forum, communication platforms and awareness events and their participation in these have a very real impact.

This important survivor-led research study, was able to evaluate the Cankids Girl Child project and its interventions over the last decades to

demonstrate that it has achieved desired results in some measure to overcome bias and stigma, and that empowerment of the girl survivor members and through the girl brigades, girl child forums by improving and maintaining their health leads to better health outcomes.

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