



Pediatric Cancer

Cancer in the Adolescent and Young Adults (AYA) and Children: A Comprehensive Analysis of the Epidemiology and Psychosocial Morbidity in the Indian Population

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Abstract



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Keywords

- ▶ adolescents and young adults and children
- ▶ epidemiology
- ▶ health-related quality of life
- ▶ measurement tools
- ▶ psychosocial morbidity

Aims Adolescent and young adults (AYAs), children with cancer, and their guardians have unique psychosocial morbidities adversely effecting quality of life (QOL). This is measurable using patented tools. We analyzed epidemiological and clinicopathological patterns of solid organ cancers in this subgroup. We also assessed psychosocial morbidity and changes in QOL faced by them.

Methods All patients aged 2 to 39 years, newly diagnosed with cancer from April 2017 to March 2019 were included. Clinical history, diagnosis, staging, treatment, outcomes, and follow-up were recorded. The National Comprehensive Cancer Network (NCCN) distress thermometer and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30) were used to assess psychosocial morbidity of AYAs, children ≥ 12 years, and parents of children < 12 years. Pediatric Quality of Life Inventory (Peds QL) version 3.0 was used for children < 12 years. Data was analyzed using descriptive statistics.

Results A total of 571 patients (512 AYAs, 59 children) were enrolled. Median age was 30 years with male predominance (58.1%). Most cases (98.6%) were absent from school or work. Carcinoma breast was the most common in females (29.3%) and non-Hodgkin lymphoma in males (12.6%). 91.06% had overall NCCN distress score ≥ 4 . Also, 73.81 and 79.49% had “quite a bit” or “very much” responses on functional and symptom

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scales, respectively, in EORTC QLQ C-30 questionnaire. Peds QL version 3.0 revealed total score ranging from 276 to 523 for each patient.

Conclusion AYAs and children with cancer are extremely vulnerable to psychological stress and morbidity. Use of well-established tools help in assessing their mental status and timely psychiatric referral can be initiated.

Introduction

Adolescent and young adults (AYAs) and children with cancer have distinct tumor biology, causing delayed diagnosis, unique outcomes, and lack of evidence-based guidelines.¹⁻³ It is imperative to develop multidisciplinary approach to deal with issues relevant to them.^{4,5} The spectrum of cancers affecting this subgroup is unique and different from adults.⁶

AYAs and parents of children with cancer face unique psychological challenges in seeking and understanding cancer-related information, accepting the diagnosis, coping with treatment-related side effects and stress, maintaining active and independent life, and maintaining a positive attitude and adherence to treatment.⁷⁻¹⁰ The psychosocial morbidity can be measured using tools to monitor health-related quality of life (HRQOL).¹¹

Through this study, we endeavor to analyze various epidemiological and clinicopathological patterns of solid organ cancers in AYA and children and to identify psychosocial morbidity and changes in the QOL faced by them.

Materials and Methods

This observational study was performed in a tertiary care cancer hospital of North India from April 1, 2017 to March 31, 2019. All children and AYAs aged between 2 and 39 years, newly diagnosed with cancer were included. Patients > 39 years and those with diseases other than solid organ malignancies were excluded. The detailed clinical history, diagnosis, staging, treatment, outcomes, and follow-up were recorded for each patient. Data on the diagnosis was coded based on the International Classification of Diseases for Oncology and further categorized according to Birch classification.¹²

The National Comprehensive Cancer Network (NCCN) distress thermometer using visual analogue scale¹³ with problem list was given to AYAs, children ≥ 12 years, and parents of children < 12 years. The thermometer measured the distress levels with scores from 0 (no distress) to 10 (extreme distress). Distress score of ≥ 4 was taken as cutoff for overall distress assessment.¹⁴ The scale assessed problems under the headings of practical problems, family, emotional, spiritual, and physical problems and generated an overall distress score.

The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30)¹⁵ was also used for assessment of all study subjects > 12 years.

Parameters pertaining to married individuals were applied to only married subjects. Patients were evaluated for the effect of the disease on their day-to-day functionality as well as symptoms faced by them. There were 14 questions pertaining to each of the two and the response was scored as (1) Not at all: 1, (2) A little bit: 2, (3) Quite a bit: 3, and (4) Very much: 4. Thereafter, an overall functional scale and overall symptom scale was obtained for each patient (minimum score 14 and maximum 56). At the end of the questionnaire, the study subjects were asked to rate their overall physical health and overall QOL on a scale of 1 to 10.

The Pediatric QOL Inventory (Peds QL version 3.0)¹⁶ for ages 2 to 4, 5 to 7, and 8 to 12 were used to assess the pediatric population and were answered by their parents. It assessed eight dimensions, namely, pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication with various items in each dimension. The number of items in each dimension differed for the three different age groups mentioned above. The steps of calculating scores using this questionnaire were as follows:

- All items were scored on a five-point Likert scale as: 0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem.
- Transform score: Items were then reverse-scored from 0 to 100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) such that higher scores indicated better HRQOL.¹⁷
- Calculation of scores by dimensions:
- Mean score = Sum of the items over the number of items answered.
- Total score = Sum of all the items over the number of items answered on all the scales.

Therefore, a child with no problems would have a maximum total score of 800 and one with most problems would have score 0.

All the questionnaires were obtained after prior permission from the respective international bodies and were provided to the patients or their guardians on treatment completion.

Statistical Analysis

Data was tabulated in MS-Office Excel worksheet and analyzed using the SPSS version 17 (IBM Corp., New York, United States). Descriptive statistics in the form of mean, frequency, and percentages were used to summarize the data.

Results

A total of 4,804 patients registered in our center between April 2017 and March 2019. Children and AYAs comprised 571 (11.88%) patients which included 512 (10.6%) AYAs and 59 (1.2%) children (< 12 years of age). The age ranged from 2 to 39 years with a median of 30 years. Gender distribution showed a slightly male predominance with 332 (58.1%) males and 239 (41.8%) females; male:female ratio was 1.39. 417 (73%) were married. Almost all the cases (563; 98.6%) (excluding children < 3 years) were either not attending school or missing work.

The spectrum of malignancies and distribution of cases according to different age subgroups is shown in ▶Table 1. Distribution of cases according to Birch classification¹² is shown in ▶Fig. 1A. The most common cancer among females was carcinoma breast (29.3%) and

among males was non-Hodgkin lymphoma (NHL) (12.6%) (▶Fig. 1B, C).

Assessment of NCCN Visual Analogue Scale

The NCCN visual analogue scale has been attached as a [Supplementary File S1](#) (available online only).¹³ An overall NCCN distress score showed 91.06% having score ≥ 4 (▶Fig. 2A). The response for the problem list given by the study subjects has been shown in ▶Fig. 2B.

Assessment of EORTC QLQ C-30

Using the EORTC QLQ C-30 questionnaire,¹⁵ we found “quite a bit” or “very much” response in 73.81% on the functional scale and 79.49% on the symptom scale (▶Fig. 3A, B) with median score of 40 in both the scales. The overall health on a scale of 0 (very poor) to 7 (excellent) had maximum responses at 4 (34.45%) (▶Fig. 3C, D).

Table 1 Demography of different malignancies in the AYA study population

Types of malignancies (n = 571)	Frequency	Percentage
Astrocytoma	20	3.5%
Carcinoma gallbladder/cholangiocarcinoma	12	2.1%
Carcinoma breast	71	12.4%
Carcinoma cervix	7	1.2%
Carcinoma lung	33	5.8%
Carcinoma nasopharynx	11	1.9%
Carcinoma oral cavity	19	3.3%
Carcinoma ovary	12	2.1%
Carcinoma pancreas	6	1.05%
Carcinoma parotid	7	1.2%
Carcinoma thyroid	39	6.8%
Carcinoma urinary bladder	2	0.35%
Chondrosarcoma	5	0.88%
Colorectal carcinoma	38	6.65%
CUPS	2	0.35%
Ewing's sarcoma	16	2.80%
Gastric carcinoma	12	2.1%
Germ cell tumor	1	0.17%
Giant cell tumor	5	0.88%
GIST	2	0.35%
Glioblastoma multiforme	12	2.1%
GTN	4	0.7%
Hepatocellular carcinoma	3	0.53%
Hodgkin's lymphoma	37	6.48%
IMFT	3	0.53%
LCH	1	0.17%
Malignant melanoma	2	0.35%
Medulloblastoma	16	2.8%

(Continued)

Table 1 (Continued)

Types of malignancies (<i>n</i> = 571)	Frequency	Percentage		
Meningioma	1	0.17%		
MPNST	2	0.35%		
Multiple myeloma	2	0.35%		
NET	1	0.17%		
Neuroblastoma	16	2.8%		
Non-Hodgkin's lymphoma	46	8.05%		
NSGCT	30	5.25%		
Osteosarcoma	14	2.45%		
Renal cell carcinoma	2	0.35%		
Retinoblastoma	1	0.17%		
RMS	6	1.05%		
Seminoma	16	2.8%		
Soft tissue sarcoma	29	5.08%		
Thymic carcinoid	1	0.17%		
Wilms' tumor	6	1.05%		
Distribution of cancer subtypes in different age subgroups				
	1–10 y (<i>n</i> = 52)	11–20 y (<i>n</i> = 42)	21–30 y (<i>n</i> = 200)	31–40 y (<i>n</i> = 277)
CNS tumors	2 (3.6%)	1 (2.4%)	10 (5%)	20 (7.2%)
Carcinomas	1 (1.8%)	3 (7.1%)	86 (43%)	187 (67.5%)
Hodgkin lymphoma	5 (8.9%)	7 (16.7%)	15 (7.5%)	10 (3.6%)
Undifferentiated/embryonal tumors	22 (39.3%)	10 (23.8%)	3 (1.5%)	4 (1.4%)
Non-Hodgkin lymphoma	3 (5.4%)	2 (4.8%)	26 (13%)	15 (5.4%)
Bone tumors	4 (7.1%)	5 (11.9%)	8 (4%)	7 (2.5%)
Ewing's sarcoma	6 (10.7%)	4 (9.5%)	3 (1.5%)	3 (1.1%)
Soft tissue sarcomas	2 (3.6%)	4 (9.5%)	18 (9%)	13 (4.7%)
Seminoma	1 (1.8%)	1 (2.4%)	8 (4%)	7 (2.5%)
NSGCT	0 (0%)	5 (11.9%)	20 (10%)	5 (1.8%)
GTN	0 (0%)	0 (0%)	2 (1%)	2 (0.7%)
Melanoma	0 (0%)	0 (0%)	0 (0%)	2 (0.7%)
Neuroendocrine tumors	0 (0%)	0 (0%)	1 (0.5%)	2 (0.7%)
Wilms' tumor	6 (10.7%)	0 (0%)	0 (0%)	0 (0%)

Abbreviations: AYA, adolescent and young adult; CNS, central nervous system; CUPS, carcinoma of unknown primary; GIST, gastrointestinal stromal tumor; GTN, gestational trophoblastic neoplasia; IMFT, inflammatory myofibroblastic tumor; LCH, Langerhans cell histiocytosis; MPNST, malignant peripheral nerve sheath tumor; NET, neuroendocrine tumor; NSGCT, non-seminomatous germ cell tumor; RMS, rhabdomyosarcoma.

Assessment of Pediatric Patients Using Peds QL Version 3.0

Three age-related questionnaires of Peds QL version 3.0¹⁶ were used to assess children in the age groups 2 to 4, 5 to 7, and 8 to 12 years. There were 11 children in 2 to 4, 22 in 5 to 7, and 29 in the 8 to 12 age groups. The mean score of each item assessed in each age group is shown in ▶Fig. 4A. The mean score of all items together was 54, 45.5, and 48 in the 2 to 4, 5 to 7, and the 8 to 12 age groups, respectively. The median of total score obtained was 461 (range 404–528), 414 (range 316–479), and 384 (range 276–523) in the three age subgroups, respectively. The distribution of the

number of children with their total scores is depicted in ▶Fig. 4B.

Discussion

AYA oncology explores the unique physical and psychosocial challenges faced by AYAs with cancer. Advances in diagnostics and effective cancer therapies have led to an unprecedented improvement in the number of cancer survivors across the world.¹⁷ However, 5-year survival rates in AYAs with cancer have remained stagnant since 1975, and for individuals aged 30 to 34, survival rates have actually decreased.² The reasons

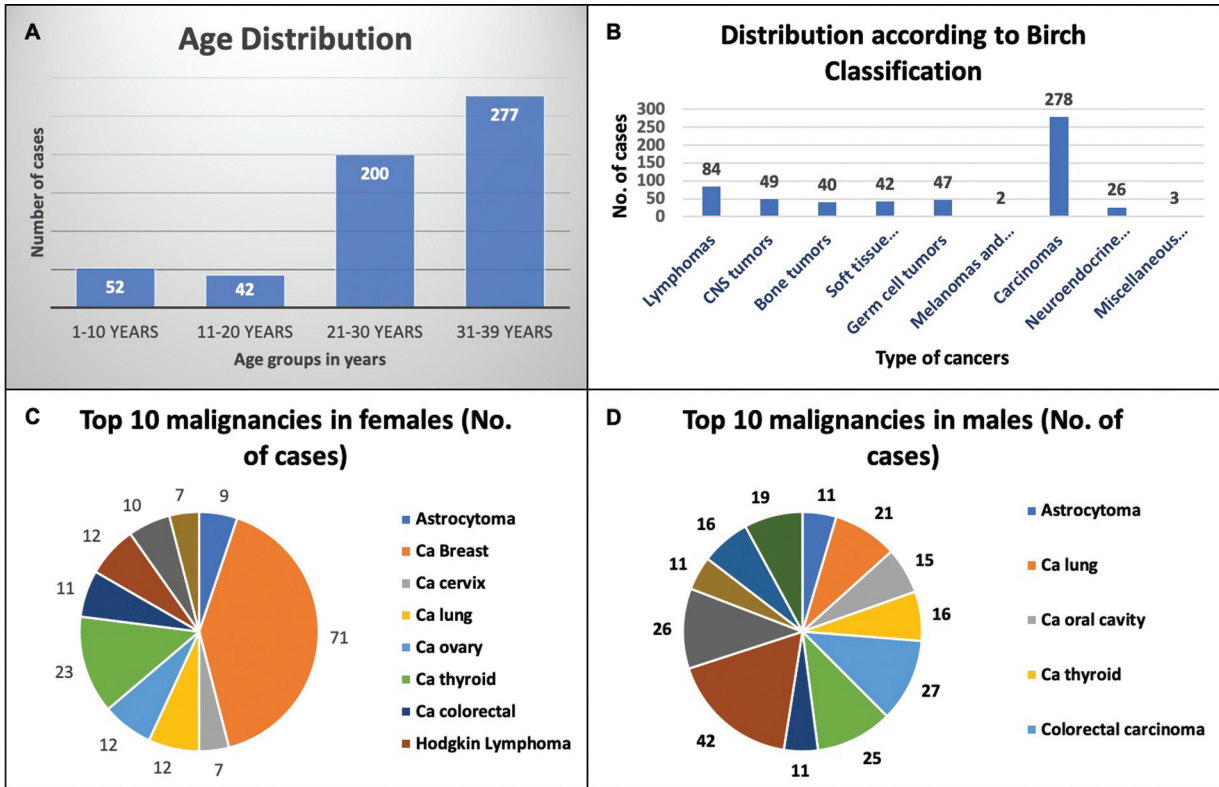


Fig. 1 Demographic distribution of cases. (A) Distribution according to different age subgroups. (B) Distribution of cases according to Birch classification. (C) Incidence of the 10 most common cancers among females. (D) Incidence of the 10 most common cancers among males.

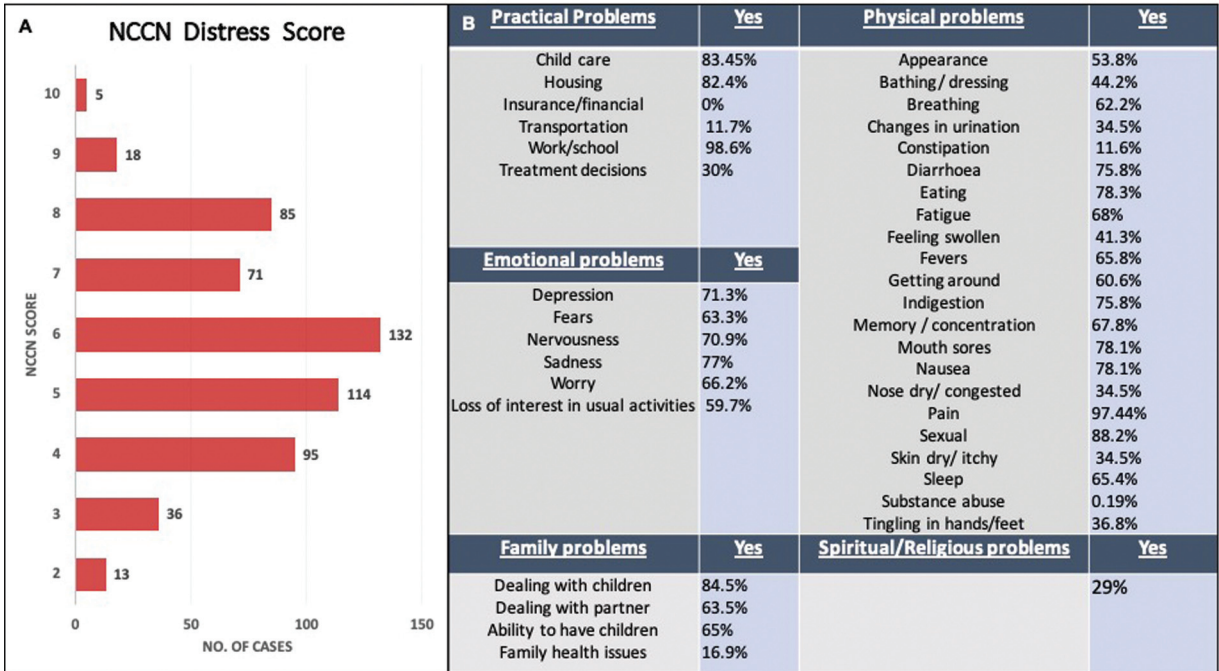


Fig. 2 The National Comprehensive Cancer Network (NCCN) Visual Analogue Scale. (A) Distribution of NCCN distress score. (B) Problem list with percentage of “yes” as response.

for disparity in survival rates for AYAs are many and will take myriad approaches on several fronts to solve, including filling the gaps in the clinical and supportive care they receive. Further, a resolute research is needed to determine the most effective comprehensive models of care that incorporate the

uniquely diverse needs of cancer survivors of this subgroup including their psychosocial needs.

This study presents a comprehensive overview of the patterns of cancers in children and AYAs in a tertiary care referral hospital along with their age-wise, sex, and

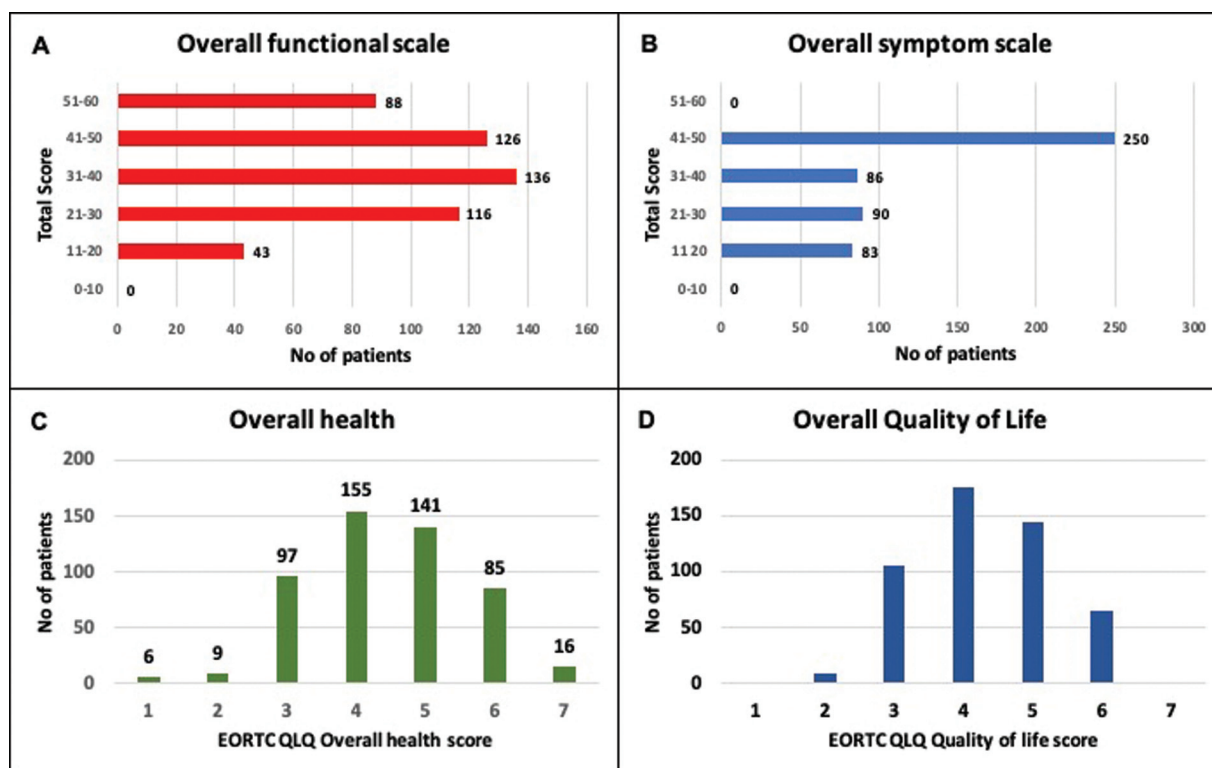


Fig. 3 Distribution of cases with European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30) response. (A) Overall functional scale. (B) Overall symptom scale. (C) Overall health score. (D) Overall quality of life score.

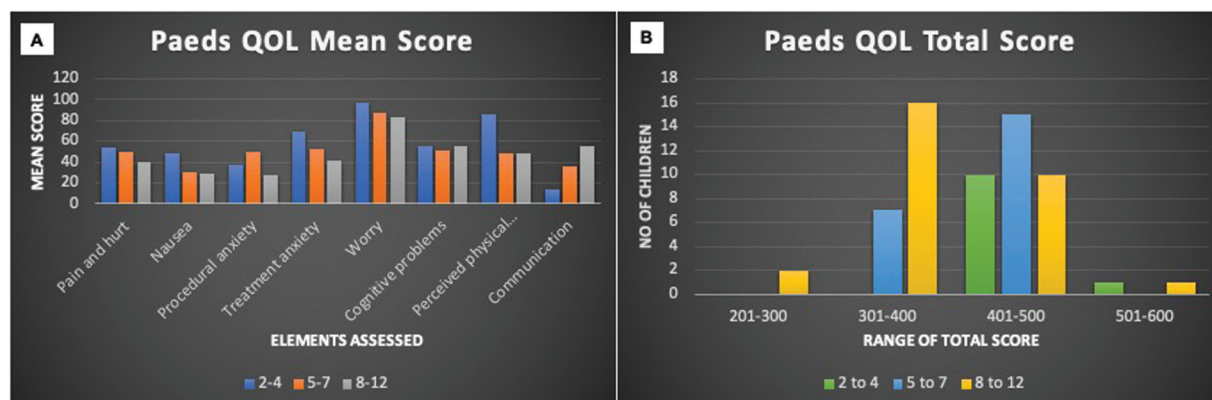


Fig. 4 Distribution of cases using Pediatric Quality of Life Inventory (Peds QOL version 3) questionnaire response. (A) Peds QOL mean score of different age groups in each dimension assessed. (B) Distribution of cases according to the Peds QOL total score in the three age subgroups.

histomorphological distribution with special emphasis on the psychological morbidity and HRQOL of this subgroup. This study is a first of its kind to use three different questionnaires for assessment of QOL in such patients. The results of our study are compared with the available literature from India¹⁸⁻²¹ and also with the international reported data.^{12,22-24}

Epidemiological Characteristics

The prevalence of 11.8% in our tertiary care referral center is higher than that in the urban population-based cancer registry of India (5.8%) as well as England (1.2%).²⁵ Other Indian studies have also reported prevalence ranging from 3.8¹⁹ to 5.71%.¹⁸ Other international series had reported the

incidence as 2.3% in Korea²⁴ and 2% in National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Monograph.²⁶ The contrast can be attributed to referral bias as the patient population of this hospital are young serving personnel from various peripheral armed forces hospitals predominantly in the AYA age group. Also, the reasons for higher percentage of Indian AYA patients with cancer as compared with the West would include the population pyramid of India with higher number of patients of this age group in our population.

Among the AYAs, incidence of cancer has been highest in the 31 to 39 years age group. In our study too, the incidence was highest in the 31 to 39 years age group being 47.80%.

Similar results were seen in Dutch study by Aben et al with 30 and 52% patients in the 20 to 24 and 25 to 29 years age groups, respectively.²³ Also, studies from the United States²⁷ as well as Australia²⁸ have found similar trends. The age-related trends were no different in Indian studies too, where an incidence of 45 to 55% was seen in the cancers of AYAs in the age group of 30 to 39 years.²⁹

While assessing the histomorphology, we found carcinoma breast to be the most common among females (29.3%), while NHL was the most common among males (12.6%). Our findings are comparable to other North Indian studies^{18,19} as well as with the results from the SEER data.²⁷ However, the predominant carcinoma type from another Indian study of Delhi region was the head and neck squamous cell carcinoma.¹⁸ Also, a study from Central India revealed hematolymphoid malignancies to be the most common cancer.²⁹ On comparing with other international studies, our findings were similar to that observed in the workshop summary of the National Cancer Policy Forum of the United States³⁰ and the Birch classification study from the United Kingdom.¹²

Further, while segregating the various cancer subtypes into different age subgroups, embryonal/undifferentiated tumors formed the predominant subtypes in the 1 to 10 and 11 to 20 whereas carcinomas dominated the 21 to 30 and the 31 to 40 age subgroups. Similar result was seen in a population-based study where data of GLOBOCAN 2012 was analyzed.³¹ They had a heterogeneous mix of cancers which changed with change in 5-year age intervals with a decreasing trend of hematolymphoid malignancies and thyroid carcinomas and increase in epithelial cancers with increasing age. We found a similar pattern of distribution of our cases with change in age subgroups (→ Table 1).

Quality of Life Assessment

It has been estimated that 30 to 40% of patients with cancer have high levels of distress which significantly affect the QOL.³² The NCCN distress thermometer with a visual analogue scale was first used by Roth et al in patients of prostatic carcinoma and a score of 5+ was considered eligible for a psychiatric referral.¹³ Since then few other studies have used this scale to assess level of distress among their patients and have come out with varying cutoffs^{33,34} ranging from 3¹⁴ to 7.³³ The NCCN guidelines have suggested a score of ≥ 4 for consideration for referral.³⁵ Our study showed maximum patients rendering a score of 5 or 6 thereby indicating a susceptibility for psychiatric morbidity. While assessing the individual characteristics of the stress thermometer, we found maximum problem faced by them was taking care of children and dealing with them as compared with the study by Van-Hoose et al³⁴ where these problems were faced by a smaller subset. The reason for this difference can be the age of the study population wherein they had a median age of 55 years whereas ours was an AYA population who would have younger children. Further, 65 to 75% of our cohort had emotional problems whereas theirs ranged from 35 to 50%.

Also, the spiritual and religious problems were higher among our cohort as compared with theirs. Similarly, most of the physical problems were also found in greater frequency in our study in comparison. The reason for a higher percentage of people facing distress-related issues among our cohort can be attributed to a younger generation facing a grave disease as compared with a more mature and experienced population of the above study. Also, the authors have attributed a lower distress score in their study to the timing of application of this thermometer where they have applied it within 6 months of diagnosis. We applied it only after completion of treatment of our patients. There have been studies which have refuted the use of this thermometer especially as a standalone measure of assessing distress as they did not find it reliable enough to identify survivors with psychiatric problems.³⁶ Keeping in mind such findings, we utilized other questionnaires too to evaluate our study subjects.

The EORTC QLQ C-30 questionnaire was introduced by the European Organization for Research and Treatment of Cancer¹⁵ with an objective to develop an integrated system for subjectively evaluating the QOL of patients joining international clinical trials. This questionnaire is cancer-specific and is a second generation product after modifications of its parent version which was introduced in 1987. Using this, we found majority (> 70%) of the patients with high scores in both functional and symptom scales. The median score was 40 in each of these scales thereby indicating a below average/poor QOL. The same has also been observed in a previous Indian study using the similar questionnaire wherein a significant correlation of poorer QOL was seen with those undergoing chemotherapy as compared with radiotherapy.³⁷ Overall physical health score as well as overall QOL score had shown around 50% of the patients with scores 4 or 5. Calculation of functional, symptomatic, and overall QOL scores have been validated to provide useful information to the clinicians in understanding the QOL.^{8,38}

Both the above questionnaires evaluated the cases more than 12 years in age. Those < 12 years were evaluated using Peds QL version 3.0 which was filled up by the parents/guardians of the child undergoing treatment. The pediatric cancer QOL was developed by Varni et al in 1998 keeping in mind the additional features such as cognitive and academic assessment which needs assessment in this age group.¹⁶ A modified version of this questionnaire, the Peds QL Measurement Model version 3.0 encompasses the essential core elements required for assessment of pediatric population including physical, emotional, social, and school functioning.³⁹ The overall mean score was > 40 in each of the three age subgroups of children thereby indicating an average QOL in the pediatric population. A similar score of 46 was observed in another study using this questionnaire in pediatric patients with cancer.⁴⁰ The DISABKIDS Chronic Generic Module (DCGM-37) and a study-specific questionnaire have assessed school attendance in children and have found significant increase in school attendance 5 months after start of treatment.⁴¹

Conclusion

This study describes the epidemiological profile of cancers in children and AYAs along with an inclusive assessment of psychosocial morbidity and HRQOL. The uniqueness of the study lies in the use of three different methods to assess the QOL. Our study revealed that this subset of patients is significantly vulnerable for distress since the time of diagnosis of cancer till completion of treatment affecting all aspects of their daily routine. We therefore recommend integral use of such well-established tools in cancer patients for diagnosis so that referral can be made for effective psychiatric management thereby enhancing their overall QOL.

Authors' Contributions

Conception and design: B.G., S.V., D.S.

Acquisition, analysis, and interpretation of data: B.G., P.G., S.S.M.S.

Drafting the article and revising it critically: B.G., P.G., S.V., R.K., M.K., A.P.

Final approval of the version to be published: S.V., D.S.

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The authors declare no financial implications during the conduct of this study.

Conflict of Interest

The authors declare no conflict of interest.

The study has the approval of the institutional ethics and review board/ committee.

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