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Original Article

Assessment of Psychological Distress Among Indian Adolescents and Young Adults with Solid Cancer Using the National Comprehensive Cancer Network Distress Thermometer

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Abstract

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Purpose The incidence of cancer has increased in India with a visible impact on the young population (aged 15–39 years). The present study aims to evaluate psychological distress among Indian adolescents and young adults (AYAs) with solid cancer using the National Comprehensive Cancer Network (NCCN) distress thermometer.

Methods The demographic and clinical characteristics of AYAs patients (age 15–39 years) with cancer were recorded. Assessment of psychological distress of patients using the NCCN distress thermometer was performed at three time points over a period of 3 months. Distress thermometer scale and a self-administered questionnaire in English and Hindi languages was handed over to participants at three time points: at treatment commencement (T1), at 1 month, and 3 months (T2 and T3, respectively) into therapy.

Results Of the 259 patients, 63% were women and 37% men; the median age was 34 years. In total, 71 (27%) were $\leq$ 24 years old and 188 (73%) were $>$ 24 years old. Bone sarcoma (39%) was common cancer in AYA patients aged $\leq$ 24 years and breast cancer (21%) in $>$24 years of age. The distress scores in both the groups were the highest at diagnosis (T1) followed by that measured at 1 (T2) and 3 months (T3) after diagnosis. The distress score in the age $\leq$ 24 years was the highest (6.7) at T1, followed by those measured at T2 (2.6) and T3 (1.1) and among age $>$ 24 years was the highest (6.6) at T1, followed by those measured at T2 (2.6) and T3 (1.2). Among AYA patients $>$ 24 years old, worry, nervousness, sadness, transportation, and sleep were the top five identified problems and in $\leq$ 24 years old, the top identified problems were worry, financial support, sleep, nervousness, and sadness.

Keywords

- adolescent and young adults
- AYAs
- Indian
- NCCN distress thermometer
- psychological distress

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Conclusion Adolescents and young adults experience some level of distress associated with the cancer diagnosis, effects of the disease, treatment regardless of the stage and various transitions throughout the trajectory of the disease. The distress thermometer is an easy and useful tool for the assessment of psychological distress in AYA cancers. Early identification of distress burden with the distress thermometer leads to effective interventions in patients with cancer which could improve outcomes including survival in AYAs with cancer in India.

Introduction

The annual burden of cancer cases in India has increased with a significant impact on the young population. Adolescent and young adults (AYAs) have been considered as a different group since mid-1990s considering their different needs.[1] As per recent reports from India, the incidence of cancer is increasing in younger age groups.[2,3]

As per the Global Burden of Diseases 2019 AYA Cancer Collaborators Report, there were ~1.19 million new cancer cases and 396,000 cancer deaths among AYAs aged 15 to 39 years.[4] Cancer is a common cause of mortality in the AYAs.[5]

The most commonly diagnosed cancers in AYAs are breast cancer, germ cell tumor, sarcomas, lymphoma, brain tumor, cervical carcinoma, colorectal and thyroid cancer.[6]

Cancer in early adult life is associated with infertility, sexual dysfunction, cardiovascular disease and a second cancer.[7,8,9,10]

AYA cancer patients of 15 to 39 years encounter more anxiety, depression, psychological distress, and face difficulty in getting knowledge of cancer, treatment, and stress related to this as compared with contemporaries living without cancer.[11] The psychological distress due to treatment and toxicities can result in loss of school, altered social profile, distorted relationships, high expenses, poor sexual life, and poor survival.[12] Studies reported that most of the adult patients diagnosed with cancer suffer from disease- or treatment-related adverse effects. The cancer-related distress was defined as an unpleasant experience of a psychological, social, spiritual, and physical symptoms that may interfere with the ability to cope effectively with cancer treatment.[13]

Routine distress screening was recommended by the National Comprehensive Cancer Network (NCCN) in 2007, with the development of a screening tool to assess distress in adult cancer patients; the NCCN distress thermometer (DT) and problem checklist (PCL).[14]

The psychosocial morbidity can be measured using tools to monitor the health-related quality of life (HRQOL). Interventions can be planned after factoring in the poor psychological outcomes.[15]

A few epidemiological studies have utilized a standardized screening tool to evaluate psychological distress changes among AYAs with cancer.[16,17] This study aims to assess psychological distress across three time points over a 3-month period after the diagnosis.

Materials and Methods

Study Design

A prospective, cross-sectional study on AYA cancer patients was conducted between September 2020 and August 2021 at Sri Aurobindo Institute Medical Sciences (SAIMS) Indore, India. International Conference on Harmonization-Good Clinical Practices (ICH-GCP) and the applicable legislation on non-interventional studies were followed in this study. Distress Thermometer scale and a self-administered questionnaire in English and Hindi languages were handed over to participants at the time of diagnosis or treatment commencement (T1), at 1 month (T2) and 3 months (T3) during the period of treatment. Patients were explained and asked to mark the number on a scale of 0 to 10 to show their distress level. If the patient's distress level is 4 or higher, oncology team member will look at the NCCN DT problem list. The study protocol was approved by the Institutional Ethics Committee (IEC No. SAIMS/IEC/2021/21). Informed consent before study participation was obtained. Patients younger than 18 years were ascent-consented by their legal guardians.

Inclusion and Exclusion Criteria

Patients and Methods

The demographic and clinical characteristics of AYAs patients with cancer including age, sex, education status, marital status, social history including smoking status, alcohol use, and financial support, were recorded. Assessment of psychological distress of patients using the NCCN DT was performed at the three time points over a period of 3 months.

The NCCN Distress Thermometer (DT)

The DT was developed by the National Comprehensive Cancer Network (NCCN) to measure cancer patients' distress. The DT is a single-item, which has a scale from 0 to 10 for patients to rate their distress level.[18] Patients rate their distress level, on a scale from 0 to 10, with 0 being the lowest and 10 being the highest. In addition, it included a list of problems that were categorized into five domains for selection by patients: (1) practical, (2) family, (3) emotional, (4) spiritual or religious, and (5) physical. The DT was chosen due

to its ease and specificity. A score of ≥ 4 corresponds to clinically significant distress in cancer patients.

Statistical Analysis

Data were analyzed using the Statistical Package for The Social Sciences (SPSS) software, version 23.0. The normal distribution of quantitative data was determined by the Shapiro–Wilk test. Independent sample *t*-test was used for comparison of two independent groups. Chi-square test was used to analyze differences between categorical variables from two independent groups. A p-value < 0.05 was considered statistically significant.

Results

Demographic Characteristics

In total, 259 patients (188 women and 71 men) were recruited into the study. The median age of the patients was 34 years. Seventy-one (27.4%) were ≤ 24 years old and 188 (72.6%) were > 24 years old. The proportion of patients with stage II, III, and IV disease was 19.3%, 63.3%, and 17.4%, respectively (►Table 1). The majority of patients had breast cancer (30.9%), followed by germ cell cancer (14.3%), ovarian cancer (9.7%), colon cancer (8.9%), Ewing sarcoma (7.7%), osteosarcoma (6.2%), lung cancer (5.8%), and cervical cancer (5.0%) (►Fig. 1).

Cancer Incidence by Age

Among AYA patients aged ≤ 24 years, germ cell tumor (40.8%), Ewing sarcoma (25.4%), and osteosarcoma (22.5%) were the most common types of cancer. In AYA patients aged >24 years, breast cancer (42.6%) was the most common cancer (►Table 2).

Trajectory of Distress Level Over Three Time Points

The average distress score at the age ≤ 24 years was the highest (6.7) at T1, followed by those measured at T2 (2.6) and T3 (1.1). The average distress score at the age > 24 years was the highest (6.6) at T1, followed by those measured at T2 (2.6) and T3 (1.2). The distress score decreased through the treatment period in both the age groups. Distress levels at all time points did not differ among patients with different disease status. The average difference in distress score between T1 and T2, T1 and T3, and T2 and T3 was 0.048 ($p = 0.875$), 0.029 ($p = 0.905$), and 0.036 ($p = 0.763$), respectively (►Table 3).

Analysis of the Distress Thermometer Problems List across the Three Time Points

At each time point, most problems belonged to the practical and emotional domains. At T1, theses were worry (100%), nervousness (93.1%), sadness (93.1%), transportation (88.8%), sleep (88.4%), depression (86.5%), financial support (86.5%), loss of interest in daily activity (78.4%), pain (71.4%), appearance (49.8%), and loss of sexual interest (49.4%).

At T2, major problems included nausea (82.2%), transportation (77.6%), fatigue (70.7%), depression (58.7%), sleep (55.6%), indigestion (53.7%), sadness (52.9%), worry (52.1%), loss of interest in daily activity (50.2%), and diarrhea (50.6%).

At T3, major problems identified, included worry (81.5%), transportation (81.1%), fatigue (78.0%), nervousness (74.5%), sadness (61.0%), nausea (51.7%), and financial support (52.1%).

Among AYA patients >24 years old, worry (100.0%), nervousness (94.1%), sadness (94.1%), transportation (89.4%), and sleep (87.2%) were the top five causes of distress.

Among AYAs ≤ 24 years old, the top five causes were worry (100.0%), financial support (91.5%), sleep (91.5%), nervousness (90.1%), and sadness (90.1%).

The distress significantly changes with time included childcare, work/school, dressing, indigestion, loss of sexual

Table 1 Demographic characteristics

Parameters	Number of patients ($N = 259$)
Age (y), Median (SD); Range	31.0 (7.1); 34.0 (15.0–39.0)
Age groups (y)	
≤24	71 (27.4)
>24	188 (72.6)
Sex	
Women	162 (62.5)
Men	97 (37.5)
Living circumstance	
Rural	93 (35.9)
Urban	166 (64.1)
Education status	
Secondary school	19 (7.3)
Undergraduate	170 (65.6)
Postgraduate	70 (27.0)
Marital status	
Married	194 (74.9)
Unmarried	65 (25.1)
Addiction	
Non-alcoholic	163 (62.9)
Tobacco	57 (22.0)
Tobacco and alcohol	27 (10.4)
Alcohol	12 (4.6)
Financial support	230 (88.8)
Income per annum	
<10,000	80 (30.9)
10,000–25,000	80 (30.9)
>25,000	99 (38.3)
Disease stage	
II	50 (19.3)
III	164 (63.3)
IV	45 (17.4)

Note: Data shown as *n* (%) unless otherwise specified

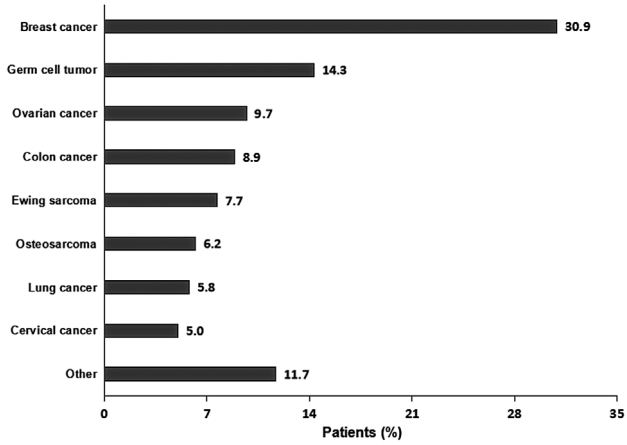

Fig. 1 Types of cancer.

interest, dry skin, and tingling hands/feet ($p < 0.001$, each), change in urination ($p = 0.008$), eating ($p = 0.041$), and swelling ($p = 0.030$) (►**Table 4**).

Table 2 Cancer incidence by age

Type of cancer	≤24 years ($n = 71$)	>24 years ($n = 188$)
Bone sarcoma	16 (22.5)	-
Brain tumor	2 (2.8)	2 (1.1)
Ewing sarcoma	18 (25.4)	2 (1.1)
Germ cell tumor	29 (40.8)	8 (4.3)
Ovarian cancer	6 (8.5)	19 (10.1)
Breast cancer	-	80 (42.6)
Cervical cancer	-	13 (6.9)
Colon cancer	-	23 (12.2)
Gallbladder cancer	-	3 (1.6)
Hepatocellular carcinoma	-	3 (1.6)
Head and neck cancer	-	8 (4.3)
Lung cancer	-	15 (8.0)
Stomach cancer	-	9 (4.8)
Urinary bladder cancer	-	3 (1.6)

Note: Data shown as *n* (%).

Discussion

The present study evaluated psychological distress among Indian AYA cancer patients. Distress scores in both groups (≤ 24 and > 24 years) were higher at T1 than at T2 and T3. Most of the reported problems among AYA patients were practical and emotional in nature. Among AYAs older than 24 years, worry, nervousness, sadness, transportation, and sleep were the top five problems, while in the age group of ≤ 24 years, worry, financial support, sleep, nervousness, and sadness predominated. The most prevalent problem across time-points for patients was worry (emotional problem). Several psychological problems included childcare, work/school, appearance, indigestion, loss of sexual interest, dry skin, and tingling hands/feet ($p < 0.001$, each) were significantly associated with higher distress scores.

A population-based study on a large population ($n = 3,199$) reported higher prevalence of psychological disorders in patients of the younger age groups.[19] Massetti et al reported that mental disorders are more common in AYA cancer patients aged 18 to 29 years.[20] The American AYA HOPE study collaborative group concluded that AYAs with cancer survivors exhibited significantly higher risk for developing poor psychosocial outcomes compared with the general population.[21] The present study also indicates a high prevalence of distress among AYA cancer patients.

In the present study, the distress scores were the highest at the commencement of treatment (T1) and tended to decrease thereafter (at T2 and T3). Other studies have shown that distress was high at diagnosis and reduced after diagnosis.[22,23]

Many studies have been previously reported that distress is fairly high at diagnosis and during treatment in AYAs.[24,25] A longitudinal study evaluated that about half of the AYAs experienced significant distress at diagnosis and nature of illness, difficulty, and uncertainty in treatment create a wide range of psychological concerns in AYAs with cancer.[26]

A meta-analysis reported that depression is associated with a high incidence of cancer incidence and mortality.[27] Therefore, interventions in the psychological management of cancer treatment, early after diagnosis can prevent escalation of distress and improve treatment outcomes.

In the present study, the emotional problem was found in most of the patients. At the time of diagnosis, almost all patients reported being worried, and more than a quarter of patients reported depression, nervousness, sadness, and loss of interest in daily activity Untreated anxiety and depression

Table 3 Trajectory of distress level over three time points

Parameters	T1	T2	T3	*P*-value	Between T1 and T2		Between T1 and T3		Between T2 and T3	
					Mean (SD)	*P*-value	Mean (SD)	*P*-value	Mean (SD)	*P*-value
Distress score										
Age ≤24 years	6.7 (2.1)	2.6 (1.7)	1.1 (0.9)	0.336	0.048 (0.3)	0.875	0.029 (0.2)	0.905	0.036 (0.1)	0.763
Age >24 years	6.6 (2.2)	2.6 (1.8)	1.2 (0.9)	0.641						

Note: Data shown as mean (SD).
T1: at diagnosis; T2: 1 month after diagnosis; T3: 3 months after diagnosis.

Table 4 Analysis of the distress thermometer problems list across the three time points

Parameter	All patients ($N=259$)				≤24 years ($n=71$)			>24 years ($n=188$)		
	T1	T2	T3	P value	T1	T2	T3	T1	T2	T3
Practical problems										
Childcare	104 (40.2)	81 (31.3)	75 (29.0)	$<0.001^{a,b,c}$	10 (14.1)	7 (9.9)	5 (7.0)	94 (50.0)	74 (39.4)	70 (37.2)
Financial support	224 (86.5)	123 (47.5)	135 (52.1)	0.143^{a}, 0.721^{b}, 0.404^{c}	65 (91.5)	35 (49.3)	40 (56.3)	159 (84.6)	88 (46.8)	95 (50.5)
Transportation	230 (88.8)	201 (77.6)	210 (81.1)	0.643^{a}, 0.300^{b}, 0.577^{c}	62 (87.3)	52 (73.2)	56 (78.9)	168 (89.4)	149 (79.3)	154 (81.9)
Work/school	118 (45.6)	116 (44.8)	116 (44.8)	$<0.001^{a,b,c}$	50 (70.4)	48 (67.6)	48 (67.6)	68 (36.2)	68 (36.2)	68 (36.2)
Emotional problems										
Depression	224 (86.5)	152 (58.7)	110 (42.5)	0.869^{a}, 0.637^{b}, 0.278^{c}	61 (85.9)	40 (56.3)	34 (47.9)	163 (86.7)	112 (59.6)	76 (40.4)
Nervousness	241 (93.1)	107 (41.3)	193 (74.5)	0.258^{a}, 0.925^{b}, 0.542^{c}	64 (90.1)	29 (40.8)	51 (71.8)	177 (94.1)	78 (41.5)	142 (75.5)
Sadness	241 (93.1)	137 (52.9)	158 (61.0)	0.258^{a}, 0.215^{b}, 0.129^{c}	64 (90.1)	42 (59.2)	38 (53.5)	177 (94.1)	95 (50.5)	120 (63.8)
Worry	259 (100.0)	135 (52.1)	211 (81.5)	0.998^{b}, 0.763^{c}	71 (100.0)	37 (52.1)	57 (80.3)	188 (100.0)	98 (52.1)	154 (81.9)
Loss of interest in daily activity	203 (78.4)	130 (50.2)	55 (21.2)	0.905^{a}, 0.116^{b}, 0.295^{c}	56 (78.9)	30 (42.3)	12 (16.9)	147 (78.2)	100 (53.2)	43 (22.9)
Physical problems										
Appearance	129 (49.8)	126 (48.6)	124 (47.9)	0.859^{a}, 0.898^{b}, 0.779^{c}	36 (50.7)	35 (49.3)	35 (49.3)	93 (49.5)	91 (48.4)	89 (47.3)
Change in urination	41 (15.8)	30 (11.6)	17 (6.9)	0.046^{a}, 0.066^{b}, 0.008^{c}	6 (8.5)	4 (5.6)	2 (2.8)	35 (18.6)	26 (13.8)	15 (8.0)
Diarrhea	51 (19.7)	131 (50.6)	28 (10.8)	0.005^{a}, 0.028^{b}, 0.552^{c}	6 (8.5)	28 (39.4)	9 (12.7)	45 (23.9)	103 (54.8)	19 (10.1)
Eating	69 (26.6)	122 (47.1)	99 (38.2)	0.001^{a}, 0.018^{b}, 0.041^{c}	8 (11.3)	25 (35.2)	20 (28.2)	61 (32.4)	97 (51.6)	79 (42.0)
Fatigue	108 (41.7)	183 (70.7)	202 (78.0)	0.462^{a}, 0.202^{b}, 0.071^{c}	27 (38.0)	46 (64.8)	50 (70.4)	81 (43.1)	137 (72.9)	152 (80.9)
Feeling Swollen	51 (19.7)	32 (12.4)	18 (7.4)	0.036^{a}, 0.043^{b}, 0.030^{c}	8 (11.3)	4 (5.6)	1 (1.5)	43 (22.9)	28 (14.9)	17 (9.7)
Indigestion	79 (30.5)	139 (53.7)	56 (21.6)	$<0.001^{a,b,c}$	6 (8.5)	25 (35.2)	4 (5.6)	73 (38.8)	114 (60.6)	52 (27.7)
Nausea	12 (4.6)	213 (82.2)	134 (51.7)	0.848^{a}, 0.557^{b}, 0.187^{c}	3 (4.2)	60 (84.5)	32 (45.1)	9 (4.8)	153 (81.4)	102 (54.3)
Pain	185 (71.4)	124 (47.9)	46 (17.8)	0.597^{a}, 0.404^{b}, 0.887^{c}	49 (69.0)	31 (43.7)	13 (18.3)	136 (72.3)	93 (49.5)	33 (17.6)
Loss of sexual interest	128 (49.4)	78 (30.1)	53 (20.5)	$<0.001^{a,b,c}$	6 (8.5)	6 (8.5)	4 (5.6)	122 (64.9)	72 (38.3)	49 (26.1)
Dry skin	66 (25.5)	53 (20.5)	43 (16.6)	$<0.001^{a,b,c}$	37 (52.1)	28 (39.4)	24 (33.8)	29 (15.4)	25 (13.3)	19 (10.1)
Sleep	229 (88.4)	144 (55.6)	59 (22.8)	0.333^{a}, 0.669^{b}, 0.204^{c}	65 (91.5)	41 (57.7)	20 (28.2)	164 (87.2)	103 (54.8)	39 (20.7)
Tingling hands/feet	40 (15.4)	107 (41.3)	107 (41.3)	$<0.001^{a,b,c}$	36 (50.7)	48 (67.6)	48 (67.6)	4 (2.1)	59 (31.4)	59 (31.4)

Note: Data shown as n (%).
T1: at diagnosis; T2: 1 month after diagnosis; T3: 3 months after diagnosis.

can have a negative impact on life with lasting consequences including reduced survival. Trained nurses, counselors, and navigators in communication and assessment skills to recognize anxiety and depression in cancer patients will be helpful in identifying different types of distress.[28]

Financial problems are generally due to low family income and lack of insurance coverage are consistent with other studies.[29] The majority of the patients reported problems such as a lack of financial support and lack of health insurance. Poor availability of transport services posed a difficulty in reaching hospital for treatment from rural areas.

Among AYAs of different age groups (≤ 24 and > 24 years old), worry, nervousness, sadness, and sleep were the common. Moreno-Smith et al reported fatigue, nervousness, and sleep difficulties were associated with poor disease outcomes.[30] The early recognition of these emotional problems may be helpful in diagnosing depression in cancer patients.

The concept of symptom burden is commonly used in medical and psychological literature. It denotes symptoms experienced by patients as a result of the chronic or terminal illnesses or associated treatments.[31] Patients with advanced cancer experienced poor psychological and physical outcomes, which was associated with poorer HRQoL.[32] It is a recommended metric of psychological and physical status among patients affected by severe and chronic diseases, including cancer.[32,33]

Chan et al evaluated the symptom burden and HRQoL using the DT. In this study, an association between DT score and problem list items was statistically significant. Several psychological and physical problems such as worry, decreased sexual interest, and constipation were significantly associated with distress scores. Chan et al[20] demonstrated a significant relationship between several RSCL symptoms including worry, depressed mood, and nervousness, and DT.[34]

Other studies provide evidence supporting an association of anxiety/depressive symptoms and fatigue with the cognitive function observed in patients with cancer.[35] Various screening tools were designed to measure stress levels in patients with cancer. The use of DT will help clinicians design future management strategies for cancer in adolescent and young adult population.

Conclusion

Distress is a psychological entity hitherto unquantified in the management of cancer patients,. We have made the first assessment of distress among the vulnerable and dynamic demography of AYA cancer. AYAs experience some level of distress associated with the cancer diagnosis, effects of the disease, treatment regardless of the stage and various transitions throughout the trajectory of the disease. Distress can be a reason for non-adherence to cancer treatment. Common types of distress that were identified in Indian AYAs with cancer were worry, nervousness, sadness, and sleep disturbance. Patient should be assessed to ascertain their level of distress at the initial visit and at appropriate intervals. Clinicians should recognize, monitor, document, and treat distress level at all stages of disease. The DT is an easy and useful tool for the assessment of psychological distress in AYA cancers. Early identification of distress burden with the DT leads to effective interventions in patients with cancer which could improve outcomes including survival in AYAs with cancer in India.

Conflicts of Interest

None declared.

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