

Beyond Numbers – Recent Understanding of Emotional Needs of Persons Diagnosed with Cancer 2007–2018

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Abstract

Epidemiology is a vital tool of public health. The usefulness of epidemiology is not only about numbers of persons' ill in the community but also to understand the associations, the presentation, identification of new syndromes, to map the historical trends, and calculate morbid risk. The emotional impact of the diagnosis of cancer is well-recognized. Indian cancer research relating to the psychosocial aspects has been largely limited to counting the numbers with psychiatric syndromes. The review covers 12 years of the Indian research in psycho-oncology to understand the different aspects of epidemiology. During the review period, there are growing number of epidemiological studies (29); psychiatric morbidity ranges from 41.7% to 46%; and prevalence rate ranges from 4.4% to 97.8% for anxiety and 1.2%–89.9% for depression; majority of the studies have used one-stage screening for assessment, which is not the ideal method of identifying mental disorders. The severity of the disorders is presented only in nine studies. Quality of life is the most common associated dimension of the studies. There is the absence of studies of posttraumatic growth, resilience, and spirituality. This review calls for greater rigor in the planning of studies of emotional impact, especially the use of two-stage method, longitudinal studies, studies of different types of cancer and in different stages, include additional measures such as disease burden, coping, resilience, spirituality, and the family/social factors to understand the emotional aspects of living with cancer. There is a need for describing the emotional aspects of living with cancer (lived-in experiences) beyond the clinical syndromes.

Keywords: Epidemiology, prevalence, psycho-oncology India, two-stage study

INTRODUCTION

Psycho-oncology, as part of the care of persons diagnosed with cancer, is about 40 years old. Jimmie Holland was the founder of this field.^[1] The psycho-oncology has become a subspecialty in the field of oncology, studying the cancer experiences beyond medical treatment.^[2] The emotional impact of the diagnosis of cancer is universal. It is this recognition that is reflected in considering 'distress' as the sixth vital component of care. There is high recognition of this aspect of the diagnosis and treatment of cancer in Western settings, where psycho-social support is provided as an essential part of the total care programs, like providing distress management, support to minimize caregiving burden and survivor workshops through the nurses, medical social workers, rehabilitation workers, psychiatrists, and psychologists.^[1] However, in India, psycho-oncology is still in the beginning stages. In most of the centers, emotional support occurs more by chance rather than by design.

Epidemiology is a vital tool in public health. The best example of the value of epidemiology in cancer is the establishment of linkage of tobacco use and cancer. This linkage has resulted in massive changes in public policy such as curbs on advertising, restricting the use of tobacco in public places, and taxes on tobacco products, with associated decreased rates of use of tobacco. Similarly, a study found in low cervical cancer risks in different religious groups as Catholic nuns, the Amish, Mormons, and Jews, probably because of a smaller number of sexual partners and lowered infection risk.^[3] Conventionally,

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the purpose of epidemiology is to address seven aspects of understanding health and illness conditions.

Morris described the seven uses of epidemiology. These are: (i) understanding the magnitude of the mental disorders; (ii) the etiological factors; (iii) the morbid risk; (iv) historical study; (v) completion of syndrome picture; (vi) identification of new syndromes; and (vii) treatment utilization.^[4]

Studies from the Western countries have demonstrated that the prevalence of emotional distress and psychiatric disorders are different in different cancers, in different stages, in association with different treatments, among the two sexes, depending on the literacy, socioeconomic status, and spirituality.^[1,5,6] In order for the science and service of psycho-oncology to grow in India, there is a need for an understanding of the prevalence, pattern, and associations of emotional distress in the different groups of the Indian patients. Only such understanding of the Indian patients can lead to routine emotional health support to all persons diagnosed with cancer and their caregivers, as pointed out by Mehrotra “there are ample data on the prevalence of psychiatric morbidity but unclear whether it has had a visible impact on actual screening for significant distress in Indian oncology settings.”^[7]

The aim of the review paper is to explore the empirical literature pertaining to all aspects of the epidemiology of emotional problems in persons diagnosed with cancer. The literature spreads over 12 years since 2007–2018 from India, to understand what is known and what areas need future research focus.

METHODS

The investigators used various data base includes PubMed, Google Scholar, ProQuest, EBSCO, and Sage Journals. The terms used were psychosocial oncology, psycho-oncology, psychology, cancer, malignancy, carcinoma, India, intervention, anxiety, depression, distress, quality of life, well-being, pain, and palliative. We also recognize that the associated areas such as coping, suffering, spiritual, reactions to illnesses such as denial, survivors, caregivers, and staff stress would give a holistic picture to understand the emotional needs of cancer diagnoses.

Additional limits included publication between 2007 and 2018 and all adults (above 18 years). The year 2007 was chosen as there was a review from Mehrotra about psycho-oncology research in India covering publications till 2006.^[7] It would be interesting to see the progress from 2007 onward in India. Studies were selected for initial review if they met the following predetermined inclusion criteria: original articles, published in English, adult cancer patients and/or partners or caregivers who resided in India, availability of full-length article, and studies needed to have a psychological component as the principal focus. We manually searched from the references of the relevant articles and also contacted the experts, by correspondence, in the field to access all the articles. Studies published in conference

proceedings, commentaries, case studies, discussions, books, book chapters, or research not published in the English language were not included.

Study selection

Titles and abstracts were initially assessed for eligibility. If it was possible to confirm that an article met the inclusion criteria from the abstract alone, the full-text article was retrieved.^[8] If it was clear from the abstract that an article was not eligible, it was excluded [Figure 1].

Data extraction

The following specific information relating to data collection and results was extracted individually from each identified article and entered into a predesigned Excel spreadsheet: first author, year, journal, aims, study design, sample size, disease stage, settings, mean age, cancer type, percentage of women, assessment tool, follow-up assessment, intervention description, depression prevalence and anxiety prevalence, sociodemographic observation, limitation, implication, and conclusion.^[9]

RESULTS

The electronic database searches initially yielded the following results. An approximate of 521 abstracts were then retrieved and critically appraised for the inclusion criteria. Of these, 112 studies met the inclusion criteria. In that, 29 studies were included for the systematic review on the prevalence of psychiatric problems.

The majority of these studies have utilized descriptive methods (85), as contrasting to assessment (8) or intervention (19) research. Despite some variation, the number of descriptive studies per year has increased from 2007 to 2018, especially in 2016 and 2017 with 16 and 21 studies, respectively. While the number of intervention and assessment studies has remained low [Figure 2].

Prevalence of anxiety and depression

Of these 112 studies, 29^[10-38] studies examining the prevalence of anxiety and depression in cancer [Table 1] were identified.

The sample size of studies varied widely from 30 to 768 patients. The total sample size of across all 29 studies was 6595 patients. Data on participants age were reported by 18^[10-12,14-17,20,21,23,27,29-32,34,35,37,39] of the 29 studies. The mean age across the studies varied from 45.8 to 59.05 years. Twenty-five of the 29 studies mentioned the setting which is oncology clinic/hospital, tertiary care hospital, and palliative care. However, most of them did not mention the recruitment place such as inpatient, outpatient, and daycare. 13^[10,13,14,16,17,24,25,27-29,31,34,36-38] out of 29 studies had no information on the cancer stage. Eight^[12,20,21,23,30,32,33,35] studies had all the stages included, 4^[11,18,19,22] studies had advanced stage/palliative, and one^[15] study had I–III stages. 19^[11-13,16-20,23-33,35-38] studies included more than one cancer type in the sample. The remaining studies focused on organ-specific, including breast, gynecological, lung,

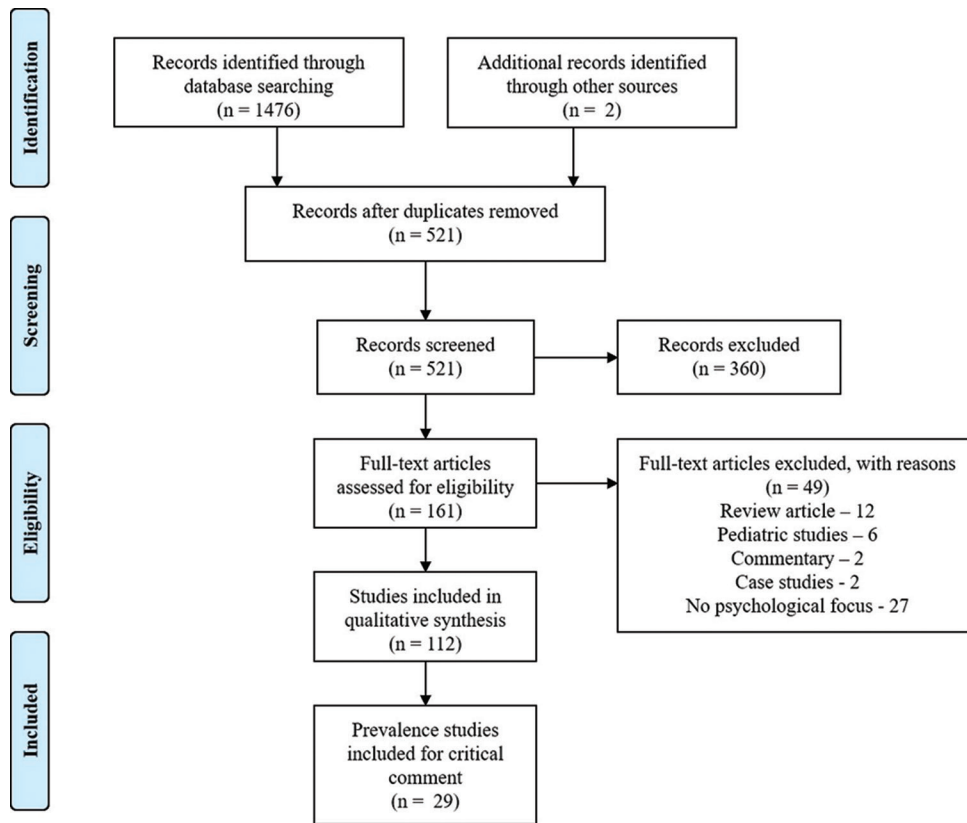


Figure 1: Overview of the search strategy used to conduct the literature review

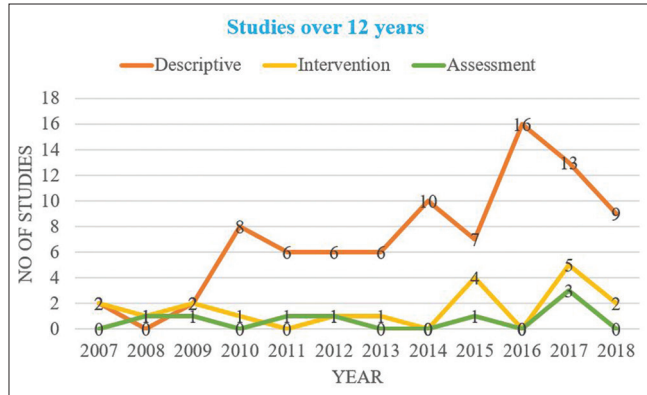


Figure 2: Number of descriptive, measurement, and intervention studies per year over 12 years

and head-and-neck cancer. Overall, on an average, 57% of women were in all 29 studies as in most of the studies breast cancer was included.

A most common tool used for assessment was Hospital Anxiety and Depression Scale in 11 studies. Other tools used to assessing the psychiatric disorder were Patient Health Questionnaire,^[12,14,30] Hamilton depression rating scale,^[34] General Health Questionnaire 28,^[32] Depression Anxiety and Stress Scale,^[37] Sinha's Anxiety Scale and Depression Scale,^[38] Brief Edinburgh Depression Scale,^[13] Death Anxiety Scale,^[19] Generalized Anxiety Disorder,^[12,30] Distress Inventory for Cancer version 2,^[21] PRIME-MD PHQ,^[10] Patient Health

Questionnaire-15 Plus,^[30] Edmonton symptom assessment scaleregular questionnaire,^[29] Brief fatigue inventory,^[31] and Delirium Rating Scale.^[24]

Psychiatric morbidity ranged from 41.7% to 46%.^[12,24] The most common disorders were anxiety and depression. In 20^[10,12-14,17-24,28-30,33-37] studies, depression rates ranged from 4.4% to 89.9% and in anxiety ranging from 1.2% to 97.8% of prevalence. Among 29 studies, 13^[10,12,17,20,21,23,24,28-30,33,35,37] studies reported the prevalence of both anxiety and depression, 5^[13,14,18,22,34] studies on depression, 2^[19,36] studies on anxiety, and one^[31] study reported on the prevalence of fatigue. Most studies reported wide range of prevalence with 20% to 40% in depression^[10,20,24,34,35] and anxiety.^[20,23,24] Bhatnagar *et al.* stated 4.4% depression and 1.2% anxiety, in contrast, Ghoshal *et al.* with 89.9% depression, and 97.8% with anxiety.^[29,33] Chintamani *et al.* reported the range of depression with the responders (22%) and nonresponders (70%) of the treatment.^[22] Shankar *et al.* stated depression was in most cases moderate severity (34%), and there were very few with severe depression (3.4%).^[12]

Diagnosable, psychiatric morbidity was the most prevalent among genitourinary malignancy (55.6%), and depression was the most common among endocrine malignancies.^[12] Whereas Bhattacharyya *et al.* reported depression was found high in blood cancer.^[13] Santre *et al.* reported gastrointestinal cancer showed higher anxiety and depression.^[35] Brahmabhath *et al.*, Gopalan *et al.*, and Singh *et al.* stated that female

Table 1: The prevalence in psychiatric morbidity from 2007 to 2018 in India

Reference, year and setting	n	Tool	Prevalence of anxiety and depression
Pandey <i>et al.</i> , 2007 ^[21]	123	DIS-2 HADS	12% anxiety, 10% depression. Distress positively correlated with anxiety and depression
Mendonsa and Appaya ^[10] 2010 and Tertiary care hospital - outpatients	101	PRIME-MD PHQ	44% had at least one PRIME-MD PHQ diagnosis. MDD, panic disorder, and other anxiety disorders in 37% of the women. 7% had sub-threshold diagnoses only. MDD in 25.7%, other depressive disorder 16.8%, other anxiety disorder 10.9%, panic disorder 5.9%, 72% had stress score of 2 or more. Women with psychiatric morbidity did have significantly higher psychosocial stressors. 57% of those with psychiatric morbidity reported socio-occupational dysfunction, 20% reported mild dysfunction (Reported "somewhat difficult" to do the daily chores), 14% reported moderate dysfunction and 23% reported severe dysfunction
Kandasamy <i>et al.</i> ^[11] 2011 and Hospice and Palliative care	50	VASP MDASI HADS FACT-G FACIT-SP	Depression and anxiety correlated negatively with spiritual well-being
Chintamani <i>et al.</i> ^[22] 2011	84	HADS	70.5% nonresponders compared with 22.0% of the responders had depression. 51.5% of the patients who received more than three neoadjuvant chemotherapy cycles showed depression, while 64.7% of patients who had received less than three cycles did not suffer from depression
Brahmbhatt <i>et al.</i> ^[32] 2012 and Cancer hospital	100	HADS GHQ	Anxiety and depression levels increased after surgical treatment in breast, colorectal, and HNC cancer patients from the HAD and GHQ scale
Chittem <i>et al.</i> ^[20] 2012 and Oncology hospital	329	RSC HADS BIPQ	Awareness of cancer diagnosis had lower levels of both anxiety and depression. Unaware of cancer diagnosis had moderate-to-severe anxiety and depression with 26.97% and 30.34%, respectively
Karthikeyan <i>et al.</i> ^[31] 2012 and Oncology hospital	121	BFI FACT-G	Patient received radiotherapy, 10% had mild fatigue, 45% with moderate, and 45% with severe fatigue. Among patients who received chemotherapy only 1.69% reported moderate fatigue, while majority reported severe fatigue 98.30%. Among patients who received concurrent chemoradiation, 9.52% with mild fatigue and moderate fatigue (11.90%) and 78.57% had severe fatigue
Bhatnagar <i>et al.</i> ^[33] 2013 and Palliative care	686	Pain assessment forms	Depression (4.4%) and anxiety (1.2%) were rarely reported
Abhishekh <i>et al.</i> ^[34] 2014 and Tertiary care hospital - outpatients	100	HDRS	The prevalence of depression was 28% (mild=26%, moderate=2%)
Santre <i>et al.</i> ^[35] 2014 and Tertiary care hospital	100	HADS	47% anxiety and 39% depression. 23% of cancer patients moderate to severe category. 42% emotional distress on HADS score
Mohite <i>et al.</i> ^[36] 2014 and Cancer hospital	50	30 Structured questionnaires on anxiety	74% moderate level of anxiety and 24% severe level of anxiety
Shukla and Rishi ^[19] 2014 and Cancer hospital	80	FACT-G, FACIT-SP DAS	18.8% high death anxiety spiritual well-being and QOL reduces the death anxiety
Singh <i>et al.</i> ^[37] 2015 and Tertiary care hospital - outpatients	300	DASS-21	Prevalence of depression, anxiety, and stress was 90%, 56%, and 28%. Anxiety mean scoring in initial cycle of chemotherapy cycles and duration of diagnosis has shown lower level of anxiety compared to later stages
Nayak <i>et al.</i> ^[28] 2015	768	Structured validated questionnaire	60.7% had anxiety and 57.6% had depression
Ghoshal <i>et al.</i> ^[29] 2016 and Regional cancer centre	89	ESAS-r	Anxiety in 97.8% and depression in 89.9% of the patients. Anxiety and loss of sense of wellbeing had severe symptoms (50%). Moderate-to-severe depression was present in 50% of the patients
Bhattacharjee and Banerjee ^[26] 2016 and Regional cancer centre	200	STAI	The state and trait anxiety of the cancer patients and their normal counterparts <i>t</i> value was 4.55, it is significant. For the trait anxiety of the cancer patients and normal individuals the <i>t</i> value (3.78) is significant
Bhuroo <i>et al.</i> ^[38] 2016 and Cancer hospital	40	SASDS	Mean score of cancer patients in respect to anxiety and depression higher than the mean scores of noncancer patients
Padmaja <i>et al.</i> ^[25] 2016 and Oncology hospital	200	4DSQ	Significant correlations were found between cancer patients' depression and anxiety, and caregivers' depression, anxiety, distress, and somatization; patients' distress and somatization, and caregivers' anxiety and age, respectively ($P < 0.5$)

Contd...

Table 1: Contd...

Reference, year and setting	n	Tool	Prevalence of anxiety and depression
Gopalan <i>et al.</i> ^[24] 2016 and Tertiary care hospital: Inpatient	384	DRS MINI	41.7% had a psychiatric disorder. Adjustment disorder was in 22.6%. Of these, adjustment disorder with depressed mood was 19.5% and adjustment disorder with anxious mood was 3.1%. 10.9% had major depressive disorder. Thus, a total of 33.5% of patients had either anxiety or depressive disorder. The proportion of patients having delirium was 6.5%. Hypomania was seen in small (1.6%) of patients
Chaitanya <i>et al.</i> ^[23] 2016 and Oncology hospital	455	HADS	39.78% participants had borderline anxiety, followed by 32.75% abnormal anxiety. 51.43% participants had abnormal depression, 30.77% participants were in borderline stage
Shankar <i>et al.</i> ^[12] 2016 and Tertiary care hospital: Outpatients	543	PHQ-9 GAD	46.4% psychiatric morbidity, depression was 37.5% and anxiety was 35.8%. In most cases, depression was of moderate severity (34.1%) and very few patients had severe depression (3.4%)
Bhattacharyya <i>et al.</i> ^[13] 2017 and Chemotherapy Day Care Centre	174	BEDS	55.7% identified with depression
Purkayastha <i>et al.</i> ^[14] 2017 and Tertiary care hospital	370	PHQ-9 WHOQOLBREF Scale	21.5% depression. (6% mild depression, 7% moderate depression, 4% moderately severe depression, and 4% severe depression). QOL was lower in patients with depression
Tripathi <i>et al.</i> ^[15] 2017 and Oncology hospital	134	HADS BIABCQ	High levels of stigma were associated with higher anxiety and higher depression
Tandon and Mehrotra ^[16] 2017 and Oncology hospital	30	PTGI MMIS MCMQ RBSM GSES EP ASS FACT-G HADS	Posttraumatic growth was negatively correlated with anxiety whereas there was a trend of positive correlation with QOL and negative correlation with depression
Nayak <i>et al.</i> ^[18] 2017 and Oncology hospital	768	QOL Vidhubala	Psychological well-being was associated with depressive symptoms in 54.4%
Palat <i>et al.</i> ^[17] 2018 and Oncology hospital	76	PCOS HADS DT	In 79% and 61%, HADS score of 11 or above indicating clinically significant depression and anxiety in caregivers
Mukherjee <i>et al.</i> ^[27] 2018	100	HADS WHOQOL BREF Scale	There was a significant effect of educational level, residential status, income level on anxiety, depression, and QOL among the patients. There was no significant effect of duration of treatment and family type on anxiety, depression, and QOL
Prakash Saxena <i>et al.</i> ^[30] 2018 and Oncology hospital	100	PHQ-9 GAD PHQ-15	34% had mild anxiety, 10% had moderate, and 5% had severe anxiety. 28% had mild somatic disorder, 7% was moderate, and 1% had severe somatic disorder. 32% had mild depression, 31% was moderate, and 8% had severe depression

4DSQ: The Four-Dimensional Symptom Questionnaire, ASS: Assessment of Social Support, BEDS: Brief Edinburgh Depression Scale, BFI: Brief fatigue inventory, BIABCQ: Body Image After Breast Cancer Questionnaire, BIPQ: Brief Illness Perceptions Questionnaire, DAS: Death Anxiety Scale, DASS-21: Depression Anxiety and Stress scale, DIC2: Distress Inventory for Cancer version 2, DRS: Delirium Rating Scale, DT: Distress Thermometer, EP: Emotional Processing, ESAS-r: Edmonton symptom assessment scaleregular questionnaire, FACIT-SP: Functional assessment of chronic illness therapy-spiritual well-being, FACT-G: Functional assessment of cancer therapy general, GAD: Generalized Anxiety Disorder, GHQ - General Health Questionnaire, GSES: Generalized Self Efficacy Scale, HADS - Hospital Anxiety and Depression Scale, HDRS: Hamilton Depression Rating Scale, MCMQ: Medical Coping Modes Questionnaire, MDASI: M.D. Anderson symptom inventory, MINI: Mini-International Neuropsychiatric Interview, MMIS: Meaning Making Interview Schedule, PCOS: Palliative Care Outcome Scale, PHQ-9: Patient Health Questionnaire, PHQ-15: Patient Health Questionnaire - plus, PTGI: Posttraumatic Growth Inventory, QOL: Quality of life, QOL Vidhubala: QOL questionnaire version II - Vidhubala, et, RBSM: Religious belief salience measure, RSC: Rotterdam Symptom Checklist, SASDS: Sinha's anxiety scale and depression scale, STAI: State-Trait Anxiety Inventory, VASP: Visual analog scale for pain, MDD: Major depressive disorder

experience higher psychiatric morbidity^[24,32,37] specifically with high anxiety,^[26] and Bhattacharyya *et al.* reported that male has higher depression.^[13] Whereas, Santre *et al.* reported no difference in gender.^[35] Early-stage disease has higher anxiety and depression.^[35] However, another study by Shankar *et al.* reported psychiatric morbidity was higher with an increase in the stage of the disease.^[12] Similarly, Prakash Saxena *et al.* stated 61.8% of IV stage patients had anxiety.^[30]

Patients receiving chemotherapy had higher depression and anxiety.^[13,30] However, Karthikeyan *et al.* reported that among patient receiving chemotherapy had severe fatigue.^[31] Three studies support that lower socioeconomic status has a higher rate of psychiatric morbidity.^[10,12,14] Four studies^[12,35-37] reported that there is no difference in age, type of cancer, education, occupation, whereas Bhattacharyya *et al.*^[13] and Chintamani *et al.*^[22] reported that more than 50 years old,

higher education, employed, and monthly income of >5000 rupees have depression. The sociodemographic details have an inconstancy in all the aspects.

DISCUSSION AND FUTURE DIRECTIONS

In the current review, there is wide variation in the prevalence rates, for example, depression rates ranged from 4.4% to 89.9% and anxiety ranged from 1.2% to 97.8% of prevalence. This wide range could be due to the heterogeneity in sociodemographic factors in the sample and different tools used for assessment. There are wide variations in the tools used for the study of additional dimensions of emotional distress. The common tool used for assessment was the Hospital Anxiety and Depression Scale in cancer settings. There were variations of the prevalence rates across different types of cancers. Similar is the finding of differing rates in the different stages of cancer and therapies. All of these observations bring to focus, the complexity of emotional reactions to living with cancer.

Epidemiology is an important public health tool to understand the prevalence, patterns, associated factors, and the morbid risk. The examples of linkage of smoking to lung cancer and the role of infection to cervical cancer are good examples of such an approach. As the prevalence, pattern and associations are different in different communities, it is important that Indian studies focus on understanding of the epidemiology of the Indian patients. Two studies illustrate the importance of such studies. In the study by Purkayastha *et al.* (2017), the introduction of the degree of disability modified the numbers of those identified as having depression from 21.5% to 4%.^[14] Similarly, the study by Tandon *et al.* using a specific tool-like card shorting task for the study of coping methods led to the identification of a new set of coping measures in the Indian population.^[40] It is important that epidemiological studies are designed to bring out all of the dimensions of epidemiology. There is a need to identify the sample size, tools for the assessment and evaluation of associated features adequately to get meaningful results.

The relevance and importance of Indian studies is clear from the following reports. Indian studies, by Mehrotra and Chaturvedi *et al.*, have shown that Indian patients with a diagnosis of cancer express distress differently and also utilize different types of supports to cope.^[7,41,42]

Mehrotra noted “there are also a few challenges that are rather unique to India and need to be extensively addressed by future researchers”.^[7] Chaturvedi mentioned that “India does not have an active society or a group of psychiatrists of mental health professionals who could form an association.”^[42] Similarly, Barthakur *et al.* reported “few survivors reported having received counseling before surgery and during treatment. It was of benefit to them.... However, general concern was that such services are by far and large unavailable and much in need to address softer issues.”^[43] Chaturvedi “.... family plays a significant role in each stage of diagnosis and management of chronic illness

such as cancer... consideration of Indian cultural beliefs and practices provides a salient example of differences that may impact communication in cancer care.”^[41]

India is a plural society in terms of religion, social class, literacy, place of stay, family structure, and all of these have implications for the occurrence of emotional distress following the diagnosis of cancer.^[44] It is for this reason, there is a need for Indian studies involving persons from a wide range of backgrounds and from different parts of the country. Recognition of universal nature of the occurrence of emotional distress, in different forms, in all groups of persons diagnosed with cancer and surviving cancer calls for greater attention to both the identification, classification, intervention, and study of association with survival.

There is a positive trend for an increasing number of studies in the past few years. Our review found an increase of publication relating to psycho-oncology from India 2007 to 2018 [Figure 2]. An overall conclusion that can be drawn from the 29 studies is that cancer patients’ emotional health is compromised as compared to the normal population. Singh *et al.* and Bhuroo *et al.* showed a statistically significant difference between cancer patients and noncancer patients in mental health.^[37,38]

In contrast to the studies from Western centers, the amount of studies from India is limited and has many limitations. The limitations of the studies conducted in India, to date are:

1. Almost all of the studies have used a screening tool to identify “psychiatric patients.” This is not adequate as screening tools; generally, identify the “at-risk” population and not the diagnosable patients. For diagnosis, there is a need for two-stage study, with the second stage examining the “positive” group to make a clinical diagnosis. In general, the positivity following screening is around 60%, depending on the tool and the cutoff point.^[45] In India, the paucity of psychiatrists for second stage diagnosis requires that at least for each center, the sensitivity and specificity of the screening tool should be established. In the presentation, the results should be presented as possible psychiatric cases and not diagnostic groups. Similarly, Fatiregun *et al.* conducted a two-stage study on breast cancer patients with anxiety disorder found that the cases dropped in two-stage assessment. Initial diagnosable patients were 26.5% after the two-stage it was 18.5% anxiety cases.^[46]
2. Common emotional problems: The most common categories of symptoms reported are anxiety and depression ranging from 4.4%–97.8% to 1.2%–89.9%, respectively. It is significant that none of the studies have identified new psychological symptoms/syndromes specify to a specific group of persons diagnosed with cancer or the differing way both anxiety and depression are presented. A study by Karthikeyan *et al.* investigated the prevalence of fatigue during different treatment phase in cancer. The results shows severe fatigue was seen higher among the patients receiving chemotherapy.^[31] This

study shows the value of thinking beyond the diagnostic syndromes in emotional health. The other common symptoms/complaints such as sleeplessness, cognitive disturbances, sexual difficulties, and spiritual challenges are lost in exploring only the diagnostic syndromes.

- a. Missing to state proportion: Eight of 28 studies have stated the mean score as the results of anxiety and depression, there was no proportion mentioned. This does not give a complete picture of the number of people or proportion having the disorder
- b. Nature of psychiatric disorder: The most common psychiatric disorder in cancer is adjustment disorder. Whereas, current studies have focused on anxiety, depression, panic disorder, delirium, somatoform disorder, and eating disorders. In general, the diagnosis of cancer brings the patients to address alternative decisions about life and experience crisis. It is an existential crisis where patients start thinking on immediate death. Mohandoss and Thavarajah found 0.61% of suicides in cancer patients over 14 years in India.^[47] Most of this situation arises because of the myth and stigma which is built around this disease and due to the lack of the right information about the disease
- c. Severity of Symptoms: Mental health assessment is always presented with the degree of severity of the disorder. In the current review, only nine studies have stated the results with the degree of the psychiatric disorder. Purkayastha *et al.* states that in breast cancer patients 4% of them had severe depression.^[14] Similarly, other studies shows 3.4% and 8% severe depression in cancer patients.^[12,30] Abhishekh *et al.* examined with the lung cancer on depression where 2% of them had moderate depression.^[34] However, Chittem *et al.* (2012) examined with the patient's awareness of the cancer diagnoses, a patient with unaware of the diagnoses had 26.97% and 30.34% of moderate-to-severe anxiety and depression.^[20] However, the patient was aware of the diagnoses showed a lesser degree of anxiety and depression, i.e., 11.26% and 18.54%, respectively.^[20] Ghoshal *et al.* found newly diagnosed cancer patients having higher anxiety and loss of sense of well-being, with 50% severe symptoms and 50% with moderate-to-severe depression.^[29] Whereas, Prakash Saxena *et al.* reported 5% with severe anxiety and Mohite *et al.* stated 24% had a severe level of anxiety.^[30,36] Similarly, a study on advanced cancer patient reported 18.8% had high death anxiety,^[19] and a study reported 23% of them having score moderate-to-severe in HADS.^[35] Through these data, we can understand only a small percentage people show a severe degree of distress
- d. In the studies under review, the most common tool was used on quality of life. Additional tools such as coping scale, resilience scale, posttraumatic growth scale, spirituality scale, burden scale, standardized

disability scale, which could have given a greater understanding of the dimensions and relationships of psychological distress have not been utilized. Future studies should include these dimensions of epidemiology

- e. Sociodemographic features: The common features reported are age, stage, type, gender, and socioeconomic information in many studies, but there is inconsistency. Most of them did not mention on which time point of the disease they conducted the study. This is the major limitations in the studies because it does not allow us to understand at which point it is most challenging to cope with the illness. Three studies have given details of the time point of the study; anxiety in initial cycle of chemotherapy cycle and duration of diagnosis has shown lower level of anxiety compared to later stage,^[37] neo-adjuvant chemotherapy receiving patients showing higher depression in nonresponder^[22] and finally, anxiety and depression in women with breast cancer undergoing surgical treatment were not significantly associated with stigma^[15]
- f. The other striking aspects of the studies are the lack of a standardized way of categorizing the sociodemographic and other risk factors. Like using the Kuppaswamy scale to assess the socioeconomic status.^[48] It is also to be noted that the numbers are too small in most of the studies to group them across the various sociodemographic groups.

It is significant that only one of the seven purposes of an epidemiological survey have been fulfilled by the majority of the studies reviewed in this paper. The identification of etiological factors has occurred to a very limited level. No reports are there identifying new syndromes or differing presentation of the known clinical syndromes. This limitation of the studies is important as preventive, promotive efforts can only come from such an identification etiological associations and possible causation. All the studies have used the standard diagnostic criteria and the wider range of syndromal description and the identification of new syndromes or variations in the presentation has not occurred. This is especially relevant as the degree of distress, the manifestation of distress does not always follow the clinical diagnostic criteria. Purkayastha *et al.* overall depression in breast cancer patients was 21.5% while in the category of severe depression is 4%, there is a 20% variation in the degree of depression. Studies seems to have decided on what to find and found them (the much talked about "suitcase syndrome" – you find what you have put into the suitcase). Similarly, as most of the studies are one time studies, the historical trends and calculation of "morbidity risk" has not been possible.

CONCLUSION

Emotional health care is an important part of care of persons living with cancer. There is a need to understand the emotional

impact of the diagnosis of cancer in the persons and their caregivers. Increasing information can result in greater recognition and appropriate interventions by care providers. The recent increasing trend in the study of emotional health aspects of living with cancer is welcome. The wide prevalence of emotional distress calls for greater understanding of the factors predisposing the individual as well as factors that protect individuals. Such an attempt will allow for greater attention to the vulnerable groups for interventions as well as to develop population group-specific interventions. Future studies should use the two-stage design; quantification of the severity of the disorder; a collection of sociodemographic factors in a standardized manner; adequate sample size to bring out differences across subgroups; and use additional tools such as coping, posttraumatic growth, resilience, burden, and spirituality. This is both a challenge for future studies and an opportunity to advance knowledge and services in this field.

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Conflicts of interest

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