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Spectrum of psychosocial dimensions of cancer in Indian scenario: An analytic review

Mayank Pancholi

Department of Surgical Oncology, Sri Aurobindo Medical College & PG Institute, Indore (M.P.)

Himanshu Patidar

Department of Surgical Oncology, Sri Aurobindo Medical College & PG Institute, Indore (M.P.)

Corresponding author email: dr_himanshu1@yahoo.com

Sanjay Desai

Department of Surgical Oncology, Sri Aurobindo Medical College & PG Institute, Indore (M.P.)

Vinod Kumar Dhakad

Department of Surgical Oncology, Sri Aurobindo Medical College & PG Institute, Indore (M.P.)

Simran Behal

Department of Pharmacology⁵, Sri Aurobindo Medical College & PG Institute, Indore (M.P.)

Abstract---Objective: Psycho-oncology refers to psychological, social, behavioral issues related to cancer prevention, treatment and survivorship. The prevalence of cancer in India is around 2.25 million with 1.1 million new cases per year. This research analyzed psychosocial factors affecting the victims of cancer in India & identified various dynamics playing role in management. Method: A prospective, cross-sectional study was performed over one year period. A psychosocial questionnaire was designed for collecting information. Based on this questionnaire, responses were recorded, reflecting patient's feelings and experiences. This study was conducted at tertiary care centre RDGMC, Ujjain, India. The study group included 120 admitted patients. Results: Out of 120 patients (54%) were males and (46%) were females. The sample included (50%) patients newly diagnosed with cancer & Head & Neck cancer was the commonest cancer, affecting (37%) patients. (41%) patients were compliant, (31%) patients were partially compliant, (28%) patients were non compliant to the treatment. (63%) patients continued treatment. (28%) patients

abandoned the treatment & (9%) patients got deceased. Financial constraint was the commonest reason for abandonment accounting for 65 % of the patients. It was observed that (74%) patients experienced psychosocial stigma. Conclusion: This research highlights the factors like financial stressors & abandonment in a cancer patient in a rural Indian setup. Patients who were advised surgery experienced more fear & anxiety as compared to those who were advised chemotherapy and/or radiotherapy alone. It instigates us to make an in depth study of these parameters to improve the health care of cancer patients.

Keywords---psychosocial challenges, cancer, abandonment, compliance.

Introduction

Cancer is an abnormal growth of cells which proliferates in an uncontrolled manner and tends to metastasize (spread). Most cancers are named for the cell type or organ in which they start. If a cancer spreads (metastasizes), the new tumor bears the same name as the original (primary) tumor. Cancers with poor prognosis are Lung cancer, Colon and rectal cancer, Breast cancer, Pancreatic cancer, Prostate cancer, Leukemia, Non-Hodgkin lymphoma, Liver and bile duct cancer.^[1]

According to International Agency for Research on Cancer (IARC), estimated cancer burden have risen to 18.1 million new cases and 9.6 million deaths in the year 2018^[2]. One in 5 men and one in 6 women worldwide develop cancer during their lifetime and one in 8 men and one in 11 women die from the disease^[3]. The prevalence of cancer in India is around 2.25 million with 1.1 million new cases per year^[4].

The term Psycho-oncology refers to psychological, social, behavioral issues related to cancer prevention, treatment and survivorship^[5]. It concerns itself with emotional responses of patients their families & caretakers as well as factors that may influence cancer morbidity & mortality^[6]. It is now known that psychosocial issues affect patients in all stages of cancer^[7]. The psycho social ramifications are serious, long-lasting and broad.^[8]

Research shows that psycho social factors play a role in the rate at which cancer worsens leading to mortality^[9]. In studies of immune cell cancers, it is seen that negative affectivity and social stress activate the sympathetic nervous system, the hypothalamus-pituitary-adrenal axis, which affect immune system involved in inflammation^[10]. Inflammation is known to be involved in tumor growth as well as in promoting several distressing symptoms such as fatigue, depression, increased pain sensitivity, and social withdrawal^[11]. Social withdrawal restricts the patient from the benefits of treatment, counseling and followup care, ultimately affecting quality of life and survival rate^[12].

Psycho oncology is a dormant area in this sub continent with scanty research available in India. Increasing number of cases as well as the burden of illness instigated our team to understand the panorama of cancer disease and undertake this research project. This research analyzed psychological and social factors affecting the victims of cancer in rural India and identified various dynamics playing role in its management. Most of these factors being modifiable can result in a better outcome of the illness [13].

Settings and Design

This study was conducted at tertiary care center RDGMC, Ujjain, India. The study group included 120 admitted patients. An easy to use psychosocial questionnaire was designed in reference to the study group population based on PQD-BC and was used for collecting the information.

Material and Methods

A prospective, cross-sectional, non funded study was performed over a period of one year from January 2018 - December 2018. Inclusion criteria for this study was an admitted cancer patient who is more than >15 years of age, who has come for screening, diagnosis, treatment or follow up of the disease. Exclusion criteria was a patient <15 yrs old. The data was collected from the study group on the basis of psychosocial questionnaire covering most of the psychosocial aspects with translation in local language (*Hindi*). Informed consent was taken from all the participants and no incentives were provided to them. Responses were recorded using face to face interview & telephonic interviews. Results were interpreted after translation into English and content analysis among the three authors.

Results

Demographic Profile

Out of the 120 patients 65 (54%) were males and 55 (46%) were females with male > female ratio. Thus the prevalence of cancer found in this study is similar to data published by IARC. 87 (73%) patients belonged to rural and 33 (27%) patient's belonged to urban locality. Rural predominance could be attributed to large flow of patients coming from surrounding rural suburbs. (Figure 1, Figure 2)

Educational qualification

In this study 91 (76%) patients were literate and 29 (24%) were illiterate. Literacy was defined as person >7 years of age who could read and write one language. Farming was the most common occupation followed by manual labor work. Shop keeping, job workers, house wife, retired from previous services, unemployed were among other occupations found in this study group. (Figure 3)

Cancer Distribution Pattern

This study significantly denotes that 53% patients were unaware about their illness and were newly diagnosed with cancer. 26% patients were previously

diagnosed with cancer and now came for either treatment or follow up. 17% patients among the study group who came for screening purpose were diagnosed with cancer. 4% patients were already diagnosed with cancer previously (post diagnosis status) and were undergoing treatment. This data clearly indicates the rising trend of newly diagnosed cancer among the population. (Figure 4)

Cancer Types

Head and Neck cancer was the commonest cancer affecting (37%) of the patients^[14] who presented at various stages of cancer. 5 year survival rate in head and neck cancer in India is 42.4% - 45.1% which is far less than western population data. Patients in the study group belonging to rural setup who came in with advanced disease had grave prognosis^[15]. Second most common cancer in the study group was breast cancer accounting for 23%. It was exclusively found in female study group with 5 year survival rate in breast cancer ranged from 64.9% - 66.1%. It was followed by gastrointestinal tract and genitourinary tract cancer accounting for 12% each. Gastrointestinal tract cancer included colorectal cancer, carcinoma stomach, hepatic cholangiocarcinoma and pancreatic cancer amongst the common ones. Genitourinary cancer included prostate cancer and bladder cancer as the most common cancer among male study group and cervical cancer as most common cancer in female study group^[16,17]. It was followed by lung cancer contributing to 6% of the cancer and had poor prognosis. (Figure 5)

Compliance status

Compliance played a significant role in diagnosis, treatment and follow up of cancer patients affecting the survival rate. In all 49 (41%) patients were compliant with the treatment prescribed to them and ensured proper care and follow up leading to comparatively better prognosis. Out of all patients 37 (31%) patients were partially compliant with the treatment prescribed to them which grossly affected the outcome of the disease. Lastly 34 (28%) patients were non compliant to the treatment guidelines set. They were on and off in taking treatment, some of them refused surgery and were also irregular while taking chemotherapy cycles when prescribed to them which majorly affected their disease prognosis. (Figure 6)

Spectrum of affective symptoms

Among all the patients 89 (74%) patients experienced psychosocial stigma during the course of diagnosis and treatment of cancer in following manner. (Table 1). A significant finding is the increased rate of a motivation among other factors in the study group. It was followed by worry and sadness which accounted for 20 % of the cases. Constant thinking about the disease and the incurability factor lead to worry and ultimately sadness in these patients^[18]. It was also found out that worsening signs and symptoms lead to sociality which was found in 18% of the patients. These affective symptoms played a huge role in treatment and care of cancer patients.

Management

Patients who were screened for cancer and later if diagnosed with cancer were also included in this study. Treatment intervention depended upon the type, staging of cancer also on the age and general condition of the patient. 86 (72%) patients took treatment in the form of surgery, chemotherapy. Main aim of surgical intervention was to achieve tumor free margins, negative lymph node status and reconstruction. Chemotherapy in the form of neo adjuvant chemotherapy, concurrent chemotherapy, post operative chemotherapy was advised and successfully given to the patients^[19]. 34(28%) patients refused for any intervention despite of proper counseling and so their decision was respected.

Amongst the study group 79 (66%) of the patients were well aware about their disease and had a strong familial support. Interestingly 49 (41%) patients tried alternative treatment in the form of Ayurveda, Homeopathic, Unani, spiritual and other therapies for their cancer illness. In due course of time 76 (63%) patients continued treatment with regular follow up, 10 (9%) patients got deceased and 34 (28%) patients abandoned the treatment. Treatment abandonment was a significant factor considered in this study. Various causes of abandonment were studied^[20]. Financial constraint was the commonest reason accounting for 65 % of the patients who abandoned the treatment. Social factors like fear of losing job, social stigma, familial pressure, willing for treatment at nearby place, sudden familial emergency were other reasons for treatment abandonment. Personal reasons included feeling of well being, no current complains, not willing to continue further treatment lead to abandonment in the study population.

Challenges faced

Generally most of these patients belonged to rural low socioeconomic group who could minimally afford cancer treatment. Many patients and relatives sold land, economic goods, pawned valuable items to raise money for their cancer care^[21]. Financial challenge was faced by 54% patients. Long course of illness, prolong hospital stay forced patients to move out of their place for cancer care which was seen in 24% patients. Loosing job was one of the most crucial challenges faced by 22% patients. Social stigma due to body dysmorphism, difficulty to cope up with daily life activities were other challenges faced by the study group^[22].

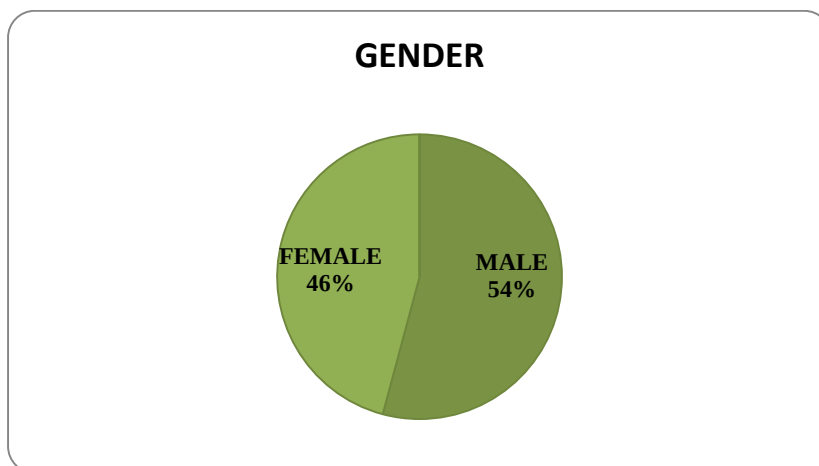


Figure 1: Demographic Profile

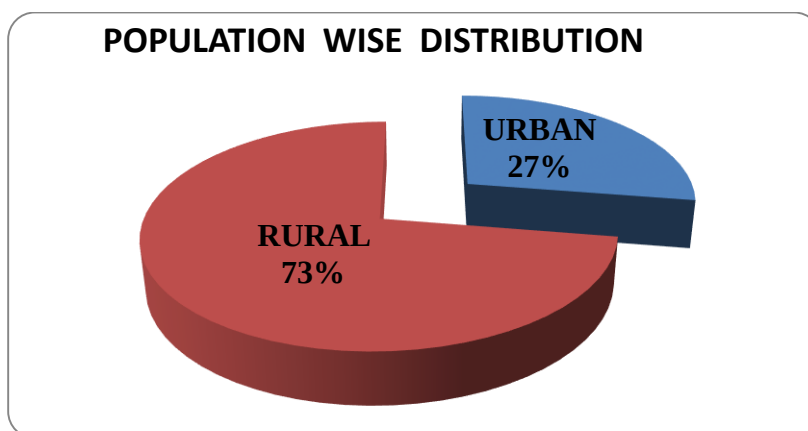


Figure 2: Population wise Distribution

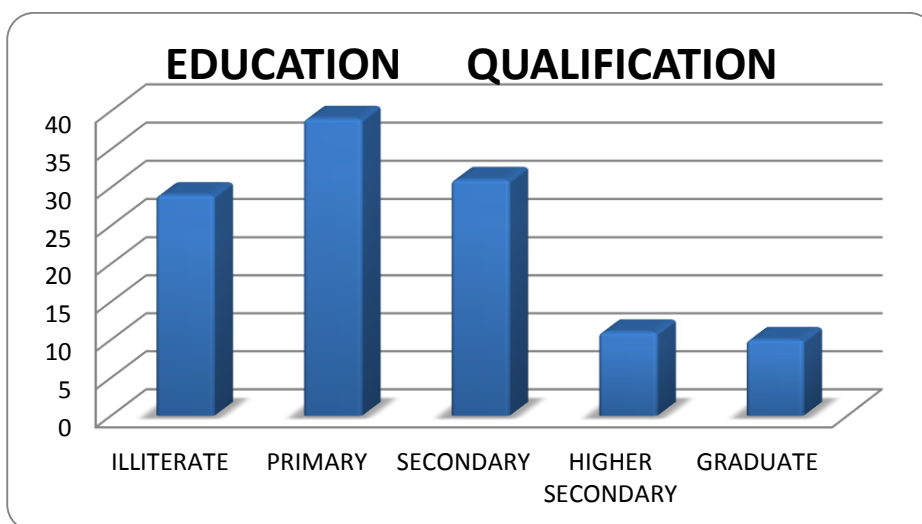


Figure 3: Distribution according to educational qualification

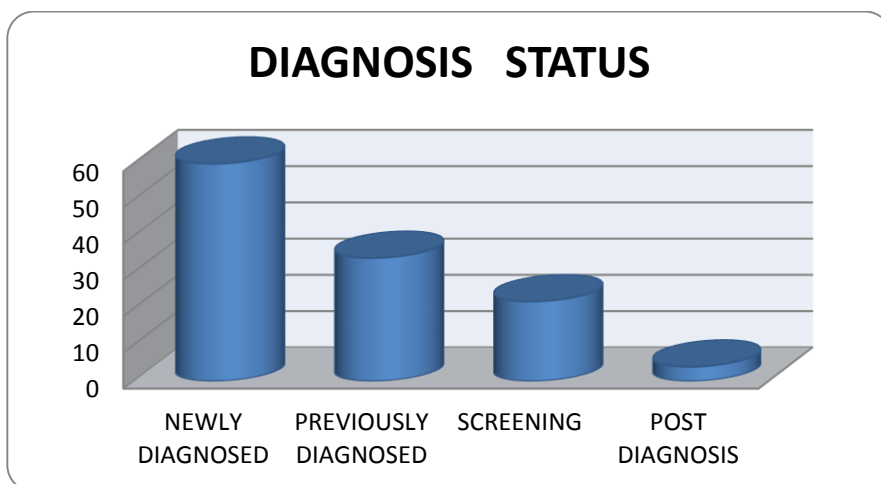


Figure 4: Diagnosis status

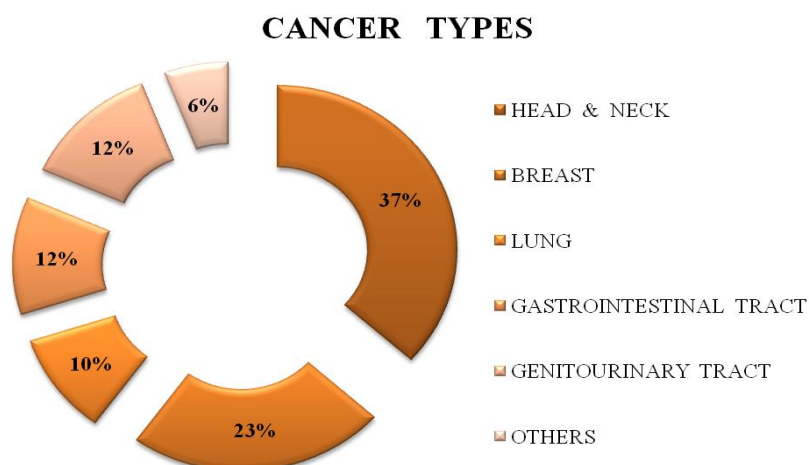


Figure 5: Distribution according to Cancer Pattern

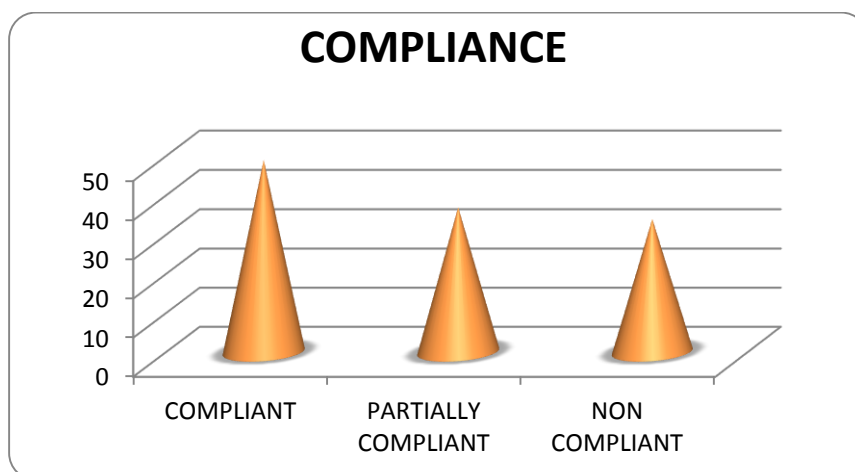


Figure 6: Compliance status

Table 1: Spectrum of affective symptoms

Amotivation	25%
Asociality	18%
Hopeless	13%
Helpless	17%
Others	7%
Worry & Sadness	20%

Discussion

Interestingly the research study concluded data in relation to various cancer types prevalent in India and their prognosis. Male preponderance and rising trend of cancer is seen in rural population which was also noted in this study [23]. Multiple psychological and social issues are observed in Indian patients^[2425] which are fairly more uncommon in the developed countries such as family problems, shyness and inability to understand the illness presented to them. This affects the treatment and survival rate significantly in Indian health care scenario compared to western world. Despite of these countless hurdles the study group reflects a high rate of compliance status attributable to the trust in treating doctor and dedicated responsible team effort by the department. This ultimately reflected significantly high survival rate in the study population as compared to current data available from Indian cancer registry^[26]. Unfortunately any public sector or community based services were unavailable to the study group in order to ease their burden.

The diagnosis of cancer puts a vast impact on patient and family members^[27]. Moreover, the findings of amotivation and other psychosocial stigmas need further evaluation to understand the impact of ignorance as well as financial difficulties in health care in India for cancer management. This study also showed that proper counseling, guidance, good patient care can immensely contribute to increase the compliance status of patient for cancer care thus improving survival rate and quality of life in these patients^[2829]. Study also highlighted various trends of alternative treatment among the study group which needs further evaluation as to whether it can be used as an adjuvant therapy with allopathic care for cancer patients.

Loosing job, failure to cope up with daily life activities, poor familial support, isolation and various physical and mental burden over the patients and their relatives at times forced the patient for abandonment of treatment effecting the quality of life in a cancer patient. This issue can be properly taken care of by good counseling, dedicated support staff and appropriate treatment care as seen in this study^[3031]. Our study showed amotivation to be among the most common psychosocial issues. However in the study published by Kodali et al worry and sadness was the most common psychosocial issue^[32]. This difference in findings could be because of multiple factors such as the rural background and family structure of the patients and demographic variations. Social issues detected were asociality, isolation and difficulty maintaining relationships with their friends and family members^[33].

Also patients expressing worry and sadness could be integrated into music therapy sessions^[34,35], group cancer awareness walks sessions presented by cancer survivors. All of these are an integral part of raising the spirit and building morale of cancer survivors^[36]. This may be associated with better outcomes and a longer event-free survival^[37]. However, lack of such scenario and logistic help led to failure of conducting any such follow up programming this study group.

Conclusion

This research highlights obstacles in the journey of a cancer patient in a rural Indian setup. Moreover, it brings to light common cancers occurring in the study population group and their compliance status playing a massive role in survival rate. More than half of the patients continued follow-up is note worthy in spite of little insurance or infrastructure support available for the cause till date. Psychosocial stigma also played a vital role in the course of cancer treatment and also noted various affective symptoms seen in cancer patients. It also sheds a light on alternative treatments opted by the patient for cancer care. This study instigates us to make an in depth study of these parameters to improve the health care of cancer patients in our country. After acknowledging the findings of this study it is recommended to take immediate steps for early and cost-effective screening for cancer in rural setting.

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