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Review Article

The unmet need of psycho-oncology services for integrated cancer care in India: a review

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ABSTRACT

Cancer has varied effects on mental health of the patients, their family and friends as well as the caregivers. The emotional, social, interpersonal, rehabilitative and psychological effects of cancer on all of them can contribute to psycho-social distress. Appropriately addressing psychological, social and behavioral issues through psycho-oncology services improves the physician-patient relationship, increase satisfaction to the ongoing treatment, create a positive attitude towards treatment and outcomes and improve the quality of life. It also has a role in preventive oncology as well as in cancer rehabilitation. Global recognition of the need of psycho-oncology services has led to establishment of a lot of international organizations and societies in the developed countries. On the other hand, there are no societies or standard guidelines for psychosocial care in India. Also, due to lack of awareness and cancer education, the stigma associated with this care compounded by the stigma associated with cancer is a major hindrance to availing mental health care in India. Identifying this unmet need, creating awareness about the need of distress management during key transitions in cancer care pathway and providing training and research opportunities in this field in India will pave the way to improve the outcomes of cancer treatment delivery and patient compliance as well as satisfaction to the provided care. Psycho-oncology services need to be integrated into the existing cancer care pathways in a structured manner so as to enable ease of availability of these services for the patients and their families when in need.

Keywords: Psycho-oncology, Cancer rehabilitation, Psycho-social response to cancer, Psycho-education

INTRODUCTION

Cancer is one of the most prevalent non-communicable diseases, responsible for a lot of suffering and deaths in the world. It affects the patient and his/her entire family as well as each and every person around the patient in one way or the other.[1] It can be debilitating for both patients and the caregivers – physically, as well as emotionally. There are social and interpersonal consequences related to cancer and its treatment for both the patient as well as the family members which can lead to an increase in psycho-social distress. If these needs go unrecognized and are not addressed, it can lead to considerable psychological morbidity in the patient and the family.[2]

With regards to cancer care, there are remarkable advances as far as the medical, surgical, and radiation oncology services and technology as well as availability of these facilities are concerned. There is also a noteworthy progress in the field of personalized cancer care or precision oncology.[3] However, the emotional,

interpersonal, social, rehabilitative and psychological components, though being recognized as essential to cancer care pathway, are not witnessing a similar progress, more so in developing countries like India.[4,5] With a definite prediction regarding the increase in incidence of cancer across the globe, this needs to be addressed so as to enable a holistic approach to cancer care. This is where the field of psycho-oncology and cancer rehabilitation comes into being.[6]

SCOPE OF PSYCHO-ONCOLOGY

Founded in 1970s by Dr. Jimmie Holland, Psycho-oncology mainly attempts to bring about a positive change in the attitude of cancer patients and caregivers. It is a sub-specialty of oncology with four key pillars or foundations – Psychological, behavioral, social and ethical.[7] It is a branch whose success relies on collaboration and cross-disciplinary interactions to understand the need, timely address the issues and apply the concepts in clinical context.[3,4,7]

It is an evolving field just like the other sub-specialties of cancer and attempts to explain the intricacies of relationship between the psyche and the cancer, the emotions involved, the adaptation and response of the patients' and caregivers to the evolving cancer and its ramifications.[8] Social, cultural and individual beliefs and perceptions all affect a patient or a caregiver's adaptation to cancer and facilitating a positive adaptation in these aspects also falls in the domain of psycho-oncology.[4,7,8] Its scope is vast as shown in Figure 1 and covers a lot of psychological, behavioral and often social factors that may play a role in cancer prevention, treatment choices, and prognosis. It also provides a valuable tool to teach how to properly approach the disease as a person, as family, as society and globally.[7-9]

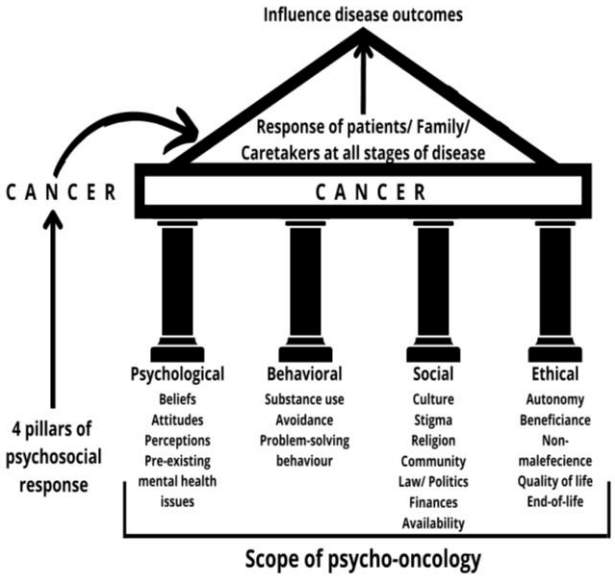

Figure 1: Four pillars of psycho-social response to cancer and scope of psycho-oncology.

ROLE OF PSYCHO-ONCOLOGY

The news that one has cancer has a varied effect on mental health of the patients and/ or the caregivers. Just as the cancer affects organ function based on the specific organs affected by cancer, bodily functions and homeostasis as well as the performance status of the patient, it also affects the mental health and well-being of the patient. The uncertainties associated with cancer diagnosis, treatment, survival and prognosis all add to fear, anxiety and depression in these patients.[10] Nearly 30-40% of cancer patients have impaired psychological health and a higher proportion of patients report unrecognised and/ or untreated psychosocial needs or disorders developing as a direct or indirect result of cancer and/ or its treatment.[11,12]

For patients, the news can make them lose their sense of self and their self-sufficiency, shatter their hope towards leading a long and healthy life, and may also lead them to withdraw or leave from relationships. Psychological distress is often a significant factor in these patients and needs to be addressed. Denial can be difficult to address without understanding the psychological, social and behavioural mindset of the patients and/ or caregivers.[10,11,13] Appropriately addressing psychological, social and behavioural issues would improve the physician-patient relationship, increase satisfaction to the ongoing treatment, create a positive attitude towards treatment and outcomes and improve the quality of life. Psycho-oncology approaches also focus on empowering patients to take decisions for their health so as to achieve the desired level of independence and a good quality of life.[14] It basically deals with maintaining the dignity of the patient throughout the treatment journey and beyond and this has been summarized in Figure 2.

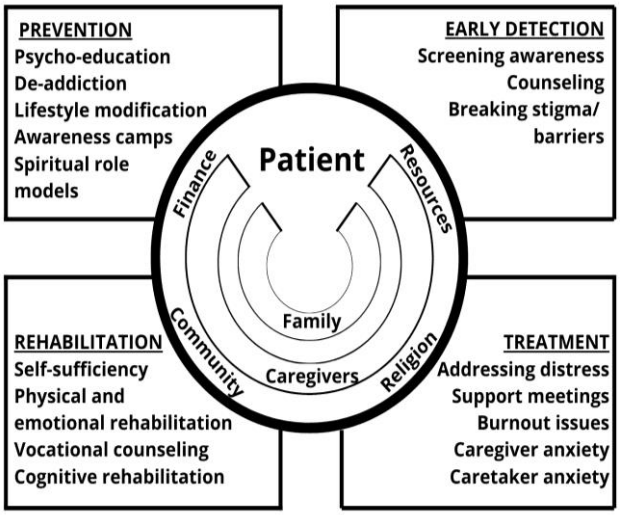

Figure 2: Inter-relationships between patient, caregivers, caretakers and community with regard to cancer care as well as various possible interventions to prevent, detect, treat or rehabilitate cancer patients in the society.

For caregivers such as family members of the patient, friends, multidisciplinary treating team, and other healthcare staff who deal with these patients, the predominant psychological effect is one of helplessness towards the situation, wherein, presence and outcome of cancer needs to be accepted with a compassionate attitude so as to support the patient in his/ her journey. Caregiver anxiety is a known issue in these families and begins with breaking the bad news to the patient. The significant queries of whether to disclose the news to the patient, whether the treating team is the best one for the patient, the uncertainty of outcome of treatment and often, awareness of disabling treatment or guarded prognosis are all sources of caregiver anxiety. Coping with this stressful situation can be improved by psycho-oncology approaches and therapies.[15,16] This is a very important aspect of managing cancer patients as a motivated and positive caregiver can provide better support to the patient during and after treatment.

For the hospital staff and the treating team, it is very commonly seen that burnout can occur due to caregiver burden of facing the situation daily in their career. Some patients may be hostile due to lack of sense of control and independence in their routine and these can be perceived as ungratefulness towards the treating team. This perception can also lead to caregiver anxiety and stress. Understanding the effects of cancer on the treating team and addressing them is also one of the key components of psycho-oncology.[17,18]

To summarize, psycho-oncology deals with a known but, an undertreated component of integrated and individualized cancer care pathway – The emotional response of each and every person dealing with cancer and the psychological, behavioural and social factors that can affect the disease treatment and outcomes.[11,14,16,18]

Apart from these commonly known applications of the field, it also plays a role in preventive oncology by interventions such as lifestyle and de-addiction counselling, cancer awareness and behavioural and psychosocial changes to remove the social taboos. This aids participation in cancer screening programs as well as increases the reach for genetic counselling to reduce cancer prevalence. Grief and bereavement counselling is also a significant part of psycho-oncology and this can be achieved with individual or group counselling. Cancer rehabilitation is also an important part of psycho-oncology. Thus, it has definite role in controlling cancer incidence and prevalence besides having a positive effect on treatment outcome, doctor-patient communication and trust. It also facilitates a better compliance to treatment and improves quality of life.[19,20]

PSYCHO-ONCOLOGY AS A FIELD – DEVELOPMENT AND PROGRESS IN WORLD

Institute of Medicine (IOM), which is the health arm of National academy of sciences in United States of America (USA) demands that psychosocial needs of the patients need to be integrated in to cancer care pathways. It very clearly states that it is not possible to deliver good-quality cancer care without addressing patient's psychosocial health needs.[21] Since 1970s, multiple national societies have come into existence in USA and these together have culminated into the formation of International psycho-oncology society (IPOS) in 1984.[22] Guidelines have also been developed in this field and National comprehensive cancer network (NCCN) also provides a framework for assessing and managing psychological distress in cancer patients. It also provides a patient guidance on managing mental health with the help of psycho-oncology integrated cancer care.[23] American college of surgeons' commission on cancer in their recommendation requires the institutions to include distress assessment and management as a part of cancer care for accreditation process.[24]

It is with the recommendation of IPOS that the term "distress" was chosen to address the psychological needs of these patients as it is less stigmatizing and more acceptable, less embarrassing, measurable with a tool like the distress thermometer or by self-evaluation. Distress in relation to cancer treatment means an unpleasant patient experience in psychosocial, existential, physical, mental or spiritual nature that interferes with patient coping mechanisms and decision making and makes the patient vulnerable to psychological crises. Distress has been labelled the sixth vital sign in oncology care by IPOS along with pain, pulse, temperature, respiratory rate and blood pressure. A simplified algorithm on how to utilize this simple screening parameter as a psychological fitness assessment tool is shown in the Figure 3.[25,26]

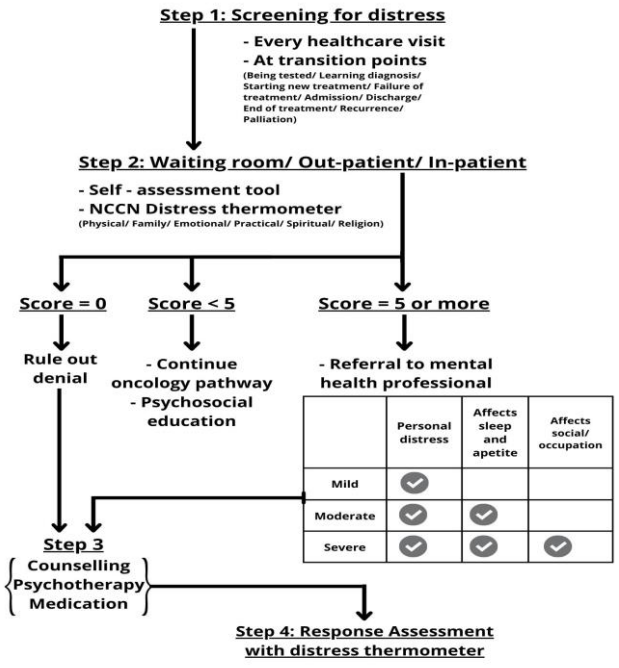

Figure 3: Step Wise Algorithm to incorporate psycho-oncology services into cancer care pathway.

Similar national recommendations and guidelines exist in United Kingdom (UK), Canada and Australia among other developed countries. The British Psychosocial oncology society (BPOS) was formed in 1983 and has been working in this field since last 3 decades. It integrated with IPOS in 2007 with a shared dream of promoting psychosocial support to all stakeholders dealing with cancer.[7] European cancer patient coalition in collaboration with European society of medical oncology and IPOS also provides a guide on cancer patient survivorship which is another effort globally to improve quality of life of patients with cancer. The Council of the European Union, 2008 have pointed out on the need for a focused, individualized comprehensive multi-disciplinary approach and optimal psycho-social care for routine cancer care, rehabilitation and post-treatment follow-up for all cancers to attain optimal outcomes.[27]

A structured integration of psycho-oncology exists in these developed countries where in they suggest key steps such as incorporation of psychological experts in multi-disciplinary team, getting a distress screening for all patients at specific time points, standardized protocol for screening using a validated screening tool and plan for further assessment and follow-up as well as research initiatives. Understanding of the key disease and life altering moments such as recurrence, change to palliative care plan as well as remission are all points where specific psycho-oncological interventions are designed based on the recommendations of these organizations.[23,25,27]

Multiple universities in developed countries offer degree, diploma and certificate courses in the field of psycho-oncology so as to fulfil the need of these professionals. Similarly, Canadian association of psychosocial oncology (CAPO) provides multiple teaching modules and certificate courses for health care professionals as well as psychological experts to learn and understand the concepts and practical application of psycho-oncology. They also provide steps to incorporate these professionals in cancer care pathways in these countries based on their research and experience. Specific distress screening tools, intervention algorithms, the role of different therapies as well as medications in these patients as well as the respect for the religious and spiritual needs of patients with help of chaplains and similar staff are all being developed and evolved to improve patient experience and satisfaction with cancer care pathways.[29-32]

PSYCHO-ONCOLOGY AS A FIELD – DEVELOPMENT AND PROGRESS IN INDIA

Even though psycho-oncology got recognition and structured development in nations across the world since 1970, with establishment of national and international societies as well as training opportunities as mentioned above, cancer patients in India are far from having access to mental health care that they so often need. There are no societies or no standard guidelines for psychosocial care in India. Also, due to lack of awareness and cancer education, the stigma associated with this care compounded by the stigma associated with cancer is a major hindrance to availing mental health care in India, even if deemed necessary. The developments and research in this field have not percolated in the Indian oncology community and its practice is not yet well known in the country.[33-35]

India has only three institutions that provide psycho-oncology degree courses - Cancer Institute (WIA), Adyar, Chennai; Center of Psycho-oncology for Education and Research (COPER), Bangalore, and Tata Medical Center, Kolkata. For a country with a large demography, with rising incidence of cancer, this is definitely not a sufficient number.[34] Hospitals in urban areas have started making attempts to incorporate psycho-oncology services in their cancer care program but, due to lack of a structured approach and in the absence of national data or guidelines, these isolated efforts will need significant leverage to cater to all cancer patients. Some private institutes are providing training in the field as well as some interested professionals are training from the international institutes and societies to serve these patients but, the recognition and opportunities that these professionals need are not yet available.[33,34,36]

The existing fraternity of counselors, social workers and chaplains are not educated and trained in this field. A recent analysis of the limited Indian data pointed out that most Indian scientific studies are cross-sectional and that there is a significant lack of scientific evidence based on coping, resilience, spirituality, and distress management as well as rehabilitation of cancer patients in the country.[35] The literature worldwide has pointed towards a negative referral bias towards these professionals with a near disregard of the psychological symptoms of the patients by the oncology multi-disciplinary teams. The primary oncologist is a vital stakeholder in the psycho-oncology algorithm as the patient usually develops a very trusting relation with this doctor. Western data supports the point that referral by this primary oncologist is a key factor in the patient getting the psychological support when needed. Global data shows that less than half the patients currently get a sound solution to their psychological problems even when they have expressed the need for the same.[37] Similar data from India is lacking. However, this needs to be addressed in our country as well by increasing the awareness in the caregivers and caretakers on one hand and by increasing the availability and accessibility on the other.

THE ROAD AHEAD

The demand or the need for psycho-oncology services is definitely going to increase as there is a growing awareness of mental health issues in our community for other diseases as well, after the corona virus associated pandemic. To cater to this demand, there needs to be a focus on developing a multi-pronged approach where in,

united efforts are necessary at individual level to look into the mental health of each and every patient for caregivers, and to vocalize mental health issues for the patient and family, at community level by working in the direction of psycho-education, de-addiction and lifestyle improvement and at socio-political level, by bringing in more institutes for training of the professionals, developing regional and national networks/ registries for this field to facilitate international collaborations for training opportunities as well as for sharing experiences, creating research and development opportunities to develop Indian data. Acquiring demography specific national and regional data and understanding our oncology population is the pressing need of the hour.[34,35,38-40] An algorithmic approach to integrate psycho-oncology care into the treatment pathway in a stepwise fashion is shown in Figure 3.[24,40]

Workshops, seminars and publications on Indian data need to increase in this field as this also gives the professionals from our country a chance to interact with international experts. Also, this gives them the much needed recognition, motivation and stimulus to continue developing the field. These trained professionals can then provide a structured training platform for future psycho-oncologists and help build a pool of dedicated, trained and motivated professionals to be a part of the oncology multi-disciplinary team.[39,40] Longitudinal data, collaborative studies and demography specific psychometric tools with standardization based on our psycho-social and cultural values will be very helpful in taking care of all the stakeholders involved in cancer care pathway.[35,36]

Social stigmas, myths and taboos associated with cancer as well as with psychological disorders need to be addressed and eliminated by increasing awareness and psycho-education. The labels associated with psychological diagnosis in community needs to be discarded and this can be achieved only by enabling community participation and social/ political commitments.[34,35] For development of the field and for providing a comprehensive, individualized cancer care in India, government officials, community leaders, legal authorities, educational institutions, medical fraternity and religious/ spiritual groups all need to come together to address this unmet need so as to provide these patients the dignity in care pathway that they deserve.[39,40]

CONCLUSION

Psycho-oncology services need to be integrated into the existing cancer care pathways in a structured manner so as to enable ease of availability of these services for the patients and their families when in need. Identifying this unmet need, creating awareness about the need of distress management during key transitions in cancer care pathway and providing training and research opportunities in this field in India will pave the way to improve the outcomes of cancer treatment delivery and patient compliance as well as satisfaction to the provided care.

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